KCE REPORT 361

KCE
Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d’Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

HOW TO IMPROVE ACCESS TO HEALTH CARE FOR PEOPLE WITH INTELLECTUAL DISABILITIES?

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HEALTH SERVICES RESEARCH

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HOW TO IMPROVE ACCESS TO HEALTH CARE FOR PEOPLE WITH INTELLECTUAL DISABILITIES?

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COLOPHON

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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
ADL	*Activities of daily living*
ARAPH	*Association de Recherche-Action en faveur des Personnes Handicapées* (Research-Action Association in favour of People with Disabilities)
ATC2	Anatomical Therapeutic Chemical classification system, level 2 (therapeutic subgroup)
AVIQ	*Agence pour une Vie de Qualité* (Walloon agency for family, handicap and health matters)
BAP	Budget d'Assistance Personnelle (personal assistance budget)
BDF	Belgian Disability Forum
BRaP	*Brussels Aanmeldingspunt voor Personen met een Handicap* (Brussels contact for people with disabilities)
CDC	Centre for Disease Control and Prevention, United States of America
CSNPH – NHRPH	*Conseil Supérieur National des Personnes Handicapées – Nationale Hoge Raad voor Personen met een Handicap* (Belgian Superior Council of People with Disabilities)
ED	Emergency Department
EDF	European Disability Forum
EPS	*Échantillon Permanent – Permanente Steekproef* (Permanent Sample)
EZL	*Eerstelijn zones* (primary care zones, Flanders)
FALC	Facile à lire et à comprendre : Easy Read
FPS Public Health	Federal Public Service Public Health
FPS Social Security	Federal Public Service Social Security (ministry of social security)
GDPR	General Data Protection Regulation
GMD – DMG	*Globaal Medisch Dossier – Dossier Médical Global*
GP	General practitioner(s)
HAP	Healthy Athletes Program
HC	Health Care
HCP	Health Care Professional(s)

HIS	National Health Interview Survey
ICD	International Classification of Disease
ID	Intellectual Disabilities
IMA – AIM	*Intermutualistisch Agentschap – Agence Intermutualiste* (Intermutualistic agency)
IQ	Intellectual Quotient
IQR	Interquartile range
IRDES	*Institut de Recherche et Documentation en Economie de la Santé* (Institute of Research and Documentation in Health Economics, France)
LOK – GLEM	*Lokale Kwaliteitsgroep – Groupe Local d'Evaluation Médicale* (peer exchange group on quality of care)
LUSS	*Ligue des Usagers des Services de Santé* (French-speaking patient platform)
NHI	National Health Insurance
RIZIV – INAMI	National Institute for Health and Disability Insurance
PAB	*Persoonlijk assistentiebudget* (personal assistance budget)
People with ID	People with Intellectual Disabilities
PPS Social Integration	Public Planning Service for Social Integration (Ministry of Social Integration)
PREM	Patient Reported Experience Measures
PROM	Patient Reported Outcome Measures
PRT	*Patienten Rat und Treff* (German speaking patient platform)
PVB	*Persoonsvolgend budget* (personalised assistance budget)
SCR – DVC	*Diensten van het Verenigd College - Services du Collège Réuni* (Brussels French and Flemish public services)
Service PHARe	*Service Personnes Handicapées Autonomie Recherchée* (Brussels service for persons with handicap)
HGR – CSS	Superior Health Council (*Hoge Gezondheidsraad - Conseil Supérieur de la Santé*)
SISD	*Services intégrés de soins à domicile* (integrated care services)
SMOG	*Spreken Met Ondersteuning van Gebaren* (speaking with the aid of gestures)
SO	Special Olympics
SSMG	Société Scientifique de Médecine Générale (Scientific Society of General Practice)

UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
VAPH	*Vlaamse Agentschap voor Personen met een Handicap* (Flemish Agency for People with Handicap)
VPP	*Vlaamse PatiëntenPlatform* (Dutch-speaking patient platform)
WHO	World Health Organisation

■ SCIENTIFIC REPORT

1 CHAPTER 1: INTRODUCTION

1.1 Context

Adopted by the United Nations in 2006 and ratified in 2009 by Belgium, the Convention on the Rights of Persons with Disabilities (UNCRPD) promotes, protects, and ensures the full enjoyment of human rights by people with disabilities and ensures that people with disabilities enjoy full equality under the law. Consequently, Belgium considers that people with disabilities should be treated as full and equal citizens and commits to provide the necessary support to achieve and protect the Rights as described in the Convention (see Box 1). In particular, Art. 25 specifies that "*persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability"*[1].

Box 1 – Guiding principles of the Convention on the Rights of Persons with Disabilities

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
- Non-discrimination
- Full and effective participation and inclusion in society
- Respect for difference and acceptance of people with disabilities as part of human diversity and humanity
- Equality of opportunity
- Accessibility – “Universal design”
- Equality between men and women
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

In such context, Special Olympics Belgium (SO Belgium) submitted a research proposal to the KCE on the following research topic: "*How can the health status of people with an intellectual disability be measured and improved?*" SO Belgium is the national branch of the American association SO, dedicated to the organisation of sport competitions for people with intellectual disability (ID) and the improvement of the health and well-being of their athletes via "The Special Olympics Healthy Athletes Program (HAP)". The HAP provides free and non-binding health screenings in welcoming settings. In Belgium it includes 7 areas: general fitness, podiatry, hearing, vision, dental hygiene, healthy lifestyle choices, and an osteopathic screening. Health care professionals (HCP) and students perform these screenings, detect health problems, provide health advice and organise referrals to specialists if necessary.

Based on their experiences, SO staff in Belgium reports that health problems remain frequently undiagnosed or untreated in people with ID and are hardly recognised by the persons themselves or their supporters[a]. Sometimes, the health problem can be incorrectly linked to the ID.

Based on internal data collected during HAP, SO Belgium noticed a high prevalence of health problems among athletes: 21.6% had untreated tooth decay, 30.4% were obese, 49% did not pass the hearing test and a stunning 56% of the athletes is wearing an incorrect shoe size[b]. Moreover according to SO, addressing the health needs of people with ID is crucial to the success of reducing health costs. Eliminating the health disparities in people with ID can save the health system a lot of money, but will, more importantly, improve their quality of life.[2]

Another non-profit Belgian association advocating for the quality of life and the participation of people with ID in the society, *Inclusion asbl,* highlighted difficult access to health care for people with ID. *"The findings are clear. Accessibility of health care remains a major difficulty for people with intellectual disabilities: fear of consultation, feeling of not being listened to, complexity of information transmitted, impression of being infantilised, examinations that are too quick, lack of accessibility of places…"* (translated from Inclusion asbl (2018). In their memorandum, they notably recommend the improvement of the training of health care professionals and the improvement of the reimbursement of speech therapy for children.[3]

1.2 Research questions and general methodology

After a scoping phase including preparatory interviews with key informants, the following research questions were set up for the KCE study:

- What is the extent of health disparities between people with and without intellectual disabilities in their access to selected health care professionals and services? This question was mostly addressed by a quantitative approach. See chapter 2: Belgian landscape of health care for people with ID and Chapter 3: Quantitative analysis of health care use.
- What are the barriers and the solutions to access health care for people with intellectual disabilities? This question was adressed by a qualitative approach and a literature scan. In this study, access to health care concerns the health care provided as part of routine care and not the specialised care aiming at caring the health condition underlying the ID in itself: access to ID diagnosis and ID rehabilitation care is out-of-the scope of this study. See Chapter 4: International Literature scan on barriers and facilitators , Chapter 5: Barriers to health care access in Belgium for people with intellectual disability and chapter 4.
- What are the acceptable and feasible solutions to improve access to health care for people with ID in the Belgian context? This question was adressed by a consultation of Belgian experts, stakeholders and decision-makers. See Chapter 5. The different steps followed during the research are summarised in the Figure 1:

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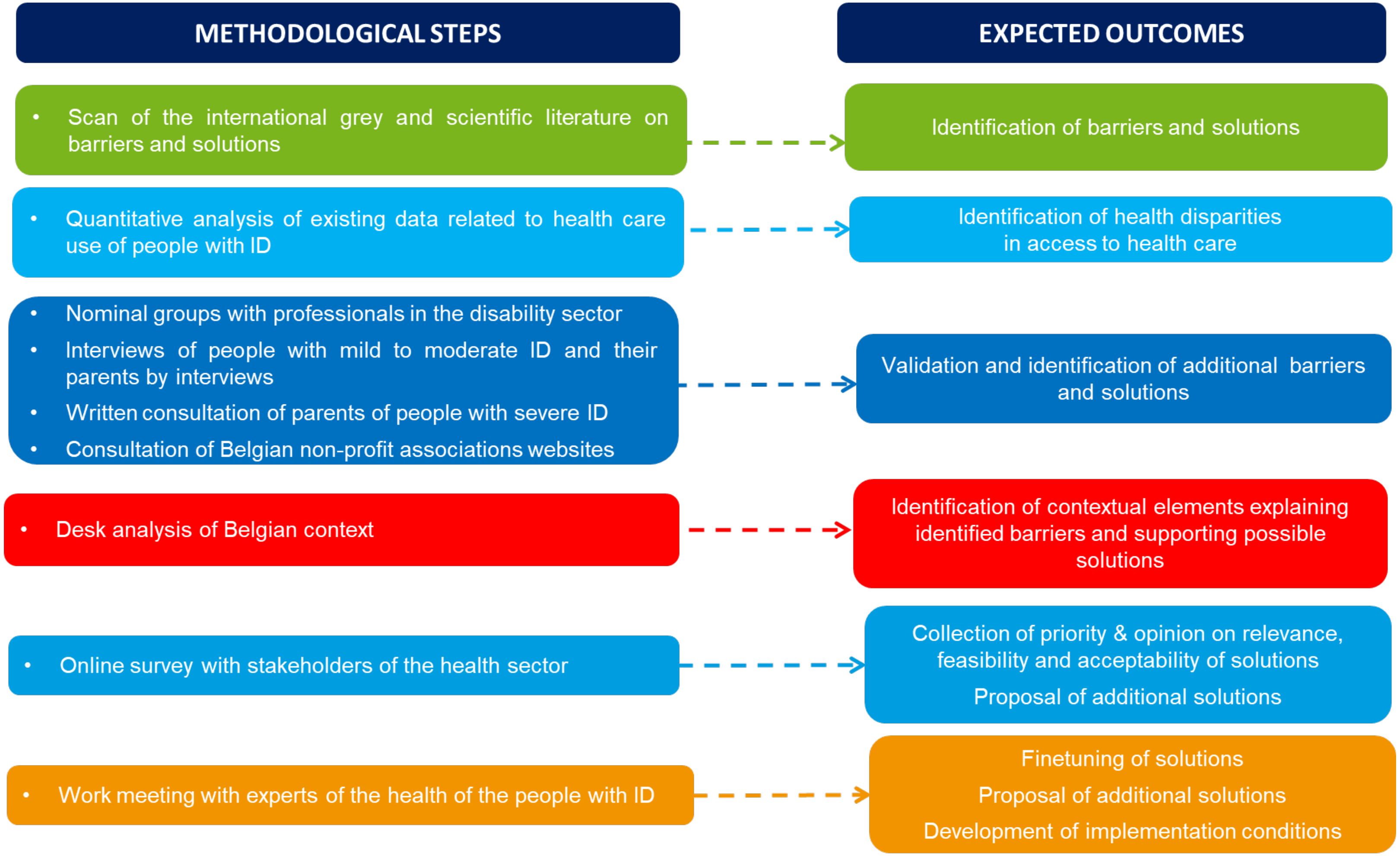
[a] In this report, supporters refer to people who help, care and support a person with ID. They can be informal caregivers like families and friends or professionals like educators or social workers (see 1.4).

[b] Internal data of HAP received after personal communication with Special Olympics.

- Step 1: Scan of the international scientific and grey literature on barriers and solutions
- Step 2: Comparative analysis of the existing data related to health care use between people with ID and people without ID based on the data of the *Intermutualistisch Agentschap – Agence Intermutualiste* (IMA – AIM)
- Step 3: Validation of previously identified barriers and solutions and identification of additional barriers or solutions as experienced in Belgium through individual interviews and nominal groups with professionals of the disability sector and people with ID, consultation of relatives of people with severe ID and identification of existing Belgian projects around health of people with ID.
- Step 4: Description of the Belgian context aiming at understanding the role of contextual elements on some barriers and at defining proposals of solutions tailored to the national context.
- Step 5: Consultation of stakeholders and experts, via an online survey and a work meeting, to identify the relevance, the feasibility and the priority of solutions

The details of each methodology will be given in each concerned chapter.

Figure 1 – Methodological steps and expected outcomes of the study on access to health care for people with ID, 2020-2022



METHODOLOGICAL STEPS

EXPECTED OUTCOMES

- Scan of the international grey and scientific literature on barriers and solutions

Identification of barriers and solutions

- Quantitative analysis of existing data related to health care use of people with ID

Identification of health disparities in access to health care

- Nominal groups with professionals in the disability sector
- Interviews of people with mild to moderate ID and their parents by interviews
- Written consultation of parents of people with severe ID
- Consultation of Belgian non-profit associations websites

Validation and identification of additional barriers and solutions

- Desk analysis of Belgian context

Identification of contextual elements explaining identified barriers and supporting possible solutions

- Online survey with stakeholders of the health sector

Collection of priority & opinion on relevance, feasibility and acceptability of solutions

Proposal of additional solutions

- Work meeting with experts of the health of the people with ID

Finetuning of solutions

Proposal of additional solutions

Development of implementation conditions

1.3 Concepts and definitions

1.3.1 Impairment and disability

A disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions) (see Box 2).[4] Although the appellation "*people with disabilities*" is sometimes used to refer to a single population, this represents actually a much diversified group of people with a wide range of needs. Two individuals with the same type of disability can be affected in very different ways. Some disabilities may be hidden or not easy to see.

Box 2 – Illustrations of impairment and disability

- Examples of **impairment** include loss of a limb, loss of vision or memory loss
- Examples of **activity limitation** are difficulty in seeing, hearing, walking, or problem solving.
- Examples of **participation restriction** are restriction in working, engaging in social and recreational activities, or in obtaining health care and preventive services.
- Examples of **disability** are intellectual disability, physical disability, sensory disability and mental/psychological disability.

Based on websites of Centre of Disease Control and Prevention (CDC) and World Health Organisation (WHO)[4, 5]

Since the 60's, two different approaches to describe the disability concept were co-existing: the medical approach and the social approach. **The medical model** focuses on the issue of the person's health condition - illness or injury - which directly results in their disability. **The social model** focuses on the barriers created by the society itself. Disability is no longer based on the notion of impairment alone but considers the environmental conditions and social disadvantages caused by that impairment. In order to integrate the medical and social models, the WHO established the International Classification of Functioning, Disability and Health (ICF) in 2001. This classification creates a common vocabulary and descriptive framework around the term "functioning".

The recent integration of the social approach with the medical view of disability is supported by the results of the 2007-2008 Australian National Health Survey in which 40% of the included people with severe or profound disability rated their health as good, very good, or excellent.[6]

As pointed out in a report commanded by *Unia*, the Belgian Centre for Equal Opportunities, "*the recognition of universal legal capacity for all people with disabilities is of great importance for the realisation of the right to health care based on free and informed consent. The danger of stereotypes leading to indirect or direct discrimination in the field of health care is particularly great because the medical (and disablist) model of disability is the most prevalent: that people with disabilities lack decision-making capacity, have a reduced quality of life, etc.*" (translated from Hardonk et al. (2015).

Based on a mixed medical and social vision, the World Health Organisation (WHO) defines a **disability** as "*an umbrella term for impairments, activity limitations and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual (environmental and personal) factors.*"[7] Defining disability as an interaction means that "*disability*" is not anymore an attribute of the person.[8] This statement is illustrated by the different terminologies currently used in Belgium to designate people with intellectual disability: '*personne en situation de handicap intellectuel*' in French and *'persoon met een verstandelijke handicap*' in Dutch. In the same frame of mind, the Art. 1 of the UNCRPD defines the **persons with disabilities** as those who have "*long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*"[1] Otherwise, each country has its own official definition of a person with disability, or even sometimes no official definition (Box 3).

Box 3 – Examples of definitions of disability

In the **United States of America (USA)**, the Centre of Disease Control and Prevention[c] (CDC) defines impairment as an absence of or significant difference in a person's body structure or function or mental functioning. For example, problems in the structure of the brain can result in difficulty with mental functions, or problems with the structure of the eyes or ears can result in difficulty with the functions of vision or hearing [4]. The American With Disabilities Act (1990) defines a disability "*as a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. This Act does not specifically name all of the impairments that are covered.*"[9]

In **Germany**, disability is defined as follows: *"a limitation of physical, psychological or mental ability that lasts longer than six months and prevents the person from living a life typical of their age. Disabilities include not only physical and mental conditions but also chronic illnesses (such as rheumatism, multiple sclerosis, cancer) and mental illness."*[10]

In **France**, the Law of February 11, 2005 on *« Egalité des droits et des chances, la participation et la citoyenneté des personnes handicapées » defines handicap as "any limitation of activity or restriction of participation in society suffered by a person in his or her environment due to a substantial, lasting or permanent impairment of one or more physical, sensory, mental, cognitive or psychological functions, a multiple disability or a disabling health disorder."* (translated from Loi française n° 2005-102, 2005)

In Belgium, the definition of people with a disability chosen in the (inter)Federal Strategy for Handicap and in the Federal Action Plan for Handicap 2021[d], is the same as in the Art. 1 UNCRPD (see 1.3.1). Those strategy and plan provide recommendations to adapt the society to the needs of people rather than the other way round (see Appendix 1 for a selection of measures related to the access and quality of care for persons with disabilities).

People with disabilities are among the most marginalised groups in the world, having poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than people without disabilities.[11] In Belgium, more than ten years after the ratification of the UNCRPD, people with disabilities still face great challenges as shown by statistics on poverty risk, social exclusion and labour market participation. For example, according to Eurostat data[ef], 30.1% of the people with disability are at risk of poverty and social exclusion compared to 14.5% for people without disability in Belgium.[12]

Moreover, vulnerability of people with ID could be triggered by their likelihood to be exposed to social determinants of poorer health and by the cumulative effects of additional vulnerability factors such as gender or ethnic origin[13-15].

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[c] The Centre of Disease Control and Prevention (CDC) is the American's leading science-based, data-driven, service organisation that protects the public's health: https://www.cdc.gov/about/index.html

[d] The Federal Action Plan for Handicap in French and in Dutch is available here: https://socialsecurity.belgium.be/fr/publications/plan-daction-federal-handicap-2021-2024,https://socialsecurity.belgium.be/nl/publicaties/federaal-actieplan-handicap-2021-2024

[e] Data retrieved from the graph *People with disability at higher risk of poverty or social exclusion* (year of reference: 2019): https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Disability_statistics_-_poverty_and_income_inequalities#In-work_poverty:_people_with_activity_limitation_more_exposed_than_people_with_no_limitation

[f] Belgian data : https://ec.europa.eu/eurostat/statistics-explained/index.php?title=File:Tab_1_at-risk-of-poverty_or_social_exclusion_AROPE_by_level_of_activity_limitation,_2019_v3.png (14/07/2022)

1.3.2 *Intellectual impairment and disability*

Intellectual impairment is a state of incomplete development of mind, which means that the person can have difficulties understanding, learning, and remembering, and in applying learning to new situations. However, people with ID can learn. They just need more time or learn differently than others.[8]

Also known as intellectual disabilities, learning disabilities[g], learning difficulties, and formerly as mental retardation or mental handicap, **intellectual disability** can be caused by injury, disease, genetic conditions (Down syndrome, Fragile X syndrome, phenylketonuria), complications during pregnancy (foetal alcohol syndrome, prenatal infection), complications during labour and birth, disease exposure during childhood (measles, meningitis), extreme malnutrition, and toxic exposure during childhood (lead or mercury exposure), etc. Sometimes, the cause of the intellectual disability is unknown.[16] ID is a lifelong condition.

Intellectual functioning, also called intelligence, refers to general mental capacity such as learning, reasoning, problem solving, etc. Normal intellectual functioning is defined by an intelligence quotient (IQ) ≥ 70.[17, 18]

Adaptive behaviour is the collection of conceptual, social, and practical skills that were learned and performed by people in their everyday life.

- *Conceptual skills* include language and literacy; money, time and numbers of concepts; and self-direction.
- *Social skills* include interpersonal skills, social responsibility, self-esteem, goal ability, social problem solving, the ability to follow rules and to obey laws, and to avoid being victimised.
- *Practical skills* include activities of daily living (or personal care), occupational skills, health care, travel and transportation, schedule a routine, safety, use of money and use of the telephone.[17, 18]

An **intellectual disability** is characterised by limitations in intellectual functioning and adaptive behaviour, in a varying degree of severity. Four levels of intellectual disability are identified: mild (IQ 55-70), moderate (IQ 35-54), severe (IQ 20-34) and profound (IQ<20).[19]

The main difficulties of people with ID concern concentration, orientation in space, asking for external help when faced with a problem, managing unexpected situations, accepting the gaze of others, learning and memorising information, communicating, expressing oneself, understanding general and abstract concepts, representing oneself in time, the notion of the value of money, making choices and decisions, as well as carrying out certain daily life activities (shopping, eating, cleaning, administrative management, etc.).[20]

According to the 2001 WHO Health Report and Maulik et al. (2021), the overall prevalence of intellectual and developmental disability is between 1 and 3% of the population.[5, 21] In the USA, in 2010, the life of approximately 6.5 million people were impacted by ID, meaning 3% of the population.[18] A review made by the Inserm (France) in 2016 shows a prevalence of 1 to 2% of the population living with an ID.[22] In Belgium, there is currently no administrative data to identify all people with an intellectual disability.[23]

Sometimes, people with ID also have other co-occurring disabilities, including physical disabilities, psychiatric conditions, blindness, or may be deaf or hard of hearing.[24] While some health conditions associated with disability result in poor health and extensive health care needs, others do not. However, all people with disability have the same general health care needs as everyone else, and therefore need access to mainstream health care services (see 1.4). Like everyone, people with intellectual disability want to live a healthy and meaningful community life.[18]

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[g] In the UK, learning disabilities is the accepted term to designate people with intellectual disabilities and is not only targeting people with specific learning problems without low IQ.

1.3.3 Health disparities, health inequities

The Centres for Disease Control and Prevention defines **health disparities** as "*preventable differences in disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations"*.[25]

An interesting insight is provided by Ruth Northway, Professor of Learning Disability Nursing and Head of Research in the Faculty of Life Sciences and Education at University of South Wales in one of her review articles published online: *"The need to treat people equally can be interpreted as the need to treat everyone in an identical manner. However, if people have different needs, then simply providing the same intervention will inevitably result in some needs not being met, thus treating people equally does not always mean treating them the same. Not all differences in health access are inequities but where differences are unnecessary, avoidable, unfair and unjust then inequity exists. A failure to make the necessary adjustments to promote equality of access to health care results in inequity. It requires that barriers to health are identified, removed or modified since doing so is a fair and just response to historical disparities" (*Michael et al.(2008), Whitehead (1992) and Braveman et al.(2017) cited by Northway, 2017).

Increasing evidence suggests that, as a group, people with ID experience poorer levels of health than the general population. Although they are exposed to the same health issues as every person, people with ID face higher rates of obesity, diabetes, chronic pain, osteoporosis, thyroid disorders and asthma.[24, 26, 27] Respiratory and circulatory diseases (with greater congenital and lesser ischaemic diseases compared with the general population) were the main causes of death.[28]

People with ID die on average 16 years earlier than people without ID. The biggest cause is not the medical condition inducing the disability, but rather an inactive and unhealthy lifestyle and poor detection and diagnosis in health care.[29] *Inclusion asbl* also highlighted a lower life expectancy of 66.1 years based on data from Inserm.[22] In 2019, 85% of people in the UK population died aged 65 and over. The corresponding proportion of people with ID was 38%.[30] Almost half of adults had 7 to 10 long-term health conditions when they died. An explanation given by Northway is that the lower life expectancy of people with ID is related to restricted *"access to appropriate and timely health care and the quality of the health care received".*[31] In a study undertaken by Hosking et al. (2016) and commented by Northway, *"37% of the deaths of people with intellectual disabilities were classified as being amenable to health care intervention compared with 22.5% of deaths amongst the general population. Access to health care would thus appear to be a significant factor that leads to inequalities and inequities in health and one which is amenable to change*."[31] Recent data from the report on the learning disabilities mortality review programme (2020) shows that, compared to the general population, people with ID were more than 3 times as likely to die from an avoidable medical cause of death. Most of the excess was due to treatable medical causes of death.[30] Alicia Bazzano, SO Chief Health Officer explains that "*People with intellectual disabilities receive fewer diabetes exams and less diabetes care than those without disabilities although the prevalence of diabetes among people with ID is 1.5 times the rate of the general population. Type 2 diabetes is preventable and this is one reason for which disparities for people with ID must be addressed*." (Balogh et al. (2015) cited by Centers for Disease Control and Prevention, 2020).

As reported on the WHO website, a disabled person is three times more likely to be denied health care and four times more likely to be treated badly in the health care system. The reality is that few countries provide adequate quality services for people with disability.[32] People with disability face barriers, stigmatisation and discrimination when accessing health and health-related services and strategies.[11] People who feel harassed because of their disability sometimes avoid going to places, changing their routines, or even moving from their home. For instance, people with ID are more likely to have difficulty receiving preventive check-ups such as cancer screenings or may not be offered certain treatments.[31, 33-35]

Box 4 – International examples of health disparities related to intellectual disability

In **Switzerland**, Wieland et al. (2016) indicate, regarding the hospitalisation of patients with intellectual and developmental disabilities in Swiss hospitals, that between 1997 and 2008, only 0.2% of them were hospitalised every year, while 1% of the general population was hospitalised per year. Statistically, they should have the same ratio of hospitalisation as the general population. This shows that 0.8% of the people with ID have either not been identified as being disabled or worse, might not have the same access to health care as the general population in Switzerland (Wieland (2016) cited by Lalive d'Epinay Raemy, 2019).

In **the USA**, according to the National Council on Disability, people with ID face a *"constellation of health and health care disparities, including inadequate health and wellness promotion and inconsistent access to high quality health care services."*[36] This is confirmed by the reviews of Krahn and colleagues which document that, in the USA, people with ID experience poorer access to quality health care and have poorer health outcomes than people without ID, and by the experts of Special Olympics which highlight that people with ID have less access to health promotion programmes, inducing that people with ID experience dramatically higher rates of preventable health issues than peers without ID.[24, 34, 35]

In **the United Kingdom**, it is more and more recognised that people with ID experience greater difficulties in accessing health care appropriate to their needs although measures have been put in place to address this problem as explained by Northway who insists that "*differences remain and continued efforts are required if we want that real change is to be achieved*".[31] Glover et al. (2019) report that, in the UK, "*Overall people identified by their GP as having ID had higher rates of admitted-patient care episodes and longer durations of stay than those without. Differences varied considerably between clinical specialties with rates more elevated in medical and paediatric than surgical specialties.*

Admitted-patient care rates for women with ID in obstetrics and gynaecology were lower than for other women, while rates for admitted-patient dental care were much higher for both men and women with ID".[37]

In **the Netherlands**, a national study on the access to primary care for people with ID, revealed that, as a consequence of the socialisation of care for people with ID towards ambulatory and home care settings, an increasing number of GPs come into contact with these subgroup of patients. Also people with ID visit more frequently their GP, encouter other health problems (compared to people without ID) and need more chronic follow-up. This results in an increased workload for the GPs and more specific training is required.[38]

People with ID continue to face barriers to health as the public health and health care systems have been slow to keep pace with the social changes. People with ID remain one of the most medically underserved groups in the world and still face significant health disparities not directly caused by their disability.[24] Very often, public authorities do not perceive the lack of care to people with disability as a public health issue and action is not taken towards disability inclusion in the health sector. Their needs are also often overlooked in national disability strategies and action plans to implement and monitor the UNCRPD. Thus, disability inclusion in the health sector remains a breach in state's health policies agendas.[32]

Belgium has the duty to give to people with ID the opportunity to access health care of a quality comparable to the rest of the population. "*It is important both to enhance the capacity of people with intellectual disabilities (and those who support them) to access the health care system and also to ensure that the system is able to respond in an appropriate and timely manner to their needs.*"[31]

1.3.4 Reasonable adjustments

According to Unia, "***a reasonable adjustment** is an action that modifies an environment to make it accessible to a person with a disability*".[39] Such a measure compensates for the effect of the unsuitable environment that a person with a disability faces. Reasonable adjustment allows people with disabilities to work, go to school, play sports, access health care services, etc., like everyone else. Reasonableness is assessed on the basis of cost, frequency and duration of use, impact on the organisation, on the person with a disability and on the environment, lack of equivalent alternatives, etc.[40] Reasonable adjustment does not aim to give people with disabilities an advantage over others. On the contrary, they compensate for the disadvantages they suffer because of an unsuitable environment.

Providing reasonable adjustment is an obligation under Belgian anti-discrimination legislation and the UNCRPD. The law states that the failure to provide reasonable adjustment for people with disabilities constitutes discrimination.[41] Moreover, since 11 March 2021, the Belgian Constitution has been extended by the Art. 22ter: "*Every person with a disability has the right to full inclusion in society, including the right to reasonable adjustment*."[h]

Reasonable adjustments can take different forms: adaptations of buildings, equipment, services and/or procedures. They address an individual problem, which distinguishes it from accessibility but sometimes a reasonable adjustment can benefit several people with disabilities.[39, 41] Accessibility is related to the notion of universal design. It refers to a design (of space, equipment, etc.) that can be used by all without adaptations and therefore de facto adapted to the needs of people with intellectual disabilities. An example of universal design proposed by *Inclusion asbl*: waiting rooms set up in a space separated from the main circulation areas with enough seats and toilets nearby.

Unapei[i], a French non-profit association, has published a practical guide to accessibility, listing a series of tips to assist professionals and services in their approach to accessibility for people with ID, including suggestions for reasonable adjustments for the health sector:[42]

- Improving accessibility and organising a quality reception
- Training professionals
- Providing a specific approach and adapted support
- Specific pain management
- Coordinating care and ensuring continuity of care
- Improving prevention and medical follow-up
- Organising palliative care

Alongside this advice, Unapei created in 1999 the S3A pictogram (see Figure 2) as the symbol for 'Welcome, Accompaniment and Accessibility' for people with ID. When structures, products, services and benefits of all kinds are made accessible to people with ID through the implementation of technical and human means, this pictogram can be affixed to counters, places of passage, products or documents. It aims to reassure people with ID and encourage them to venture into the establishment and thus to access professionals who are aware of their needs.[23] *Inclusion asbl* recommends the introduction of an accessibility declaration for each health professional in which he or she could indicate the level of accessibility (e.g., compliance with people with reduced mobility standards; use of Easy Read; implementation of and compliance with the "specifications" for the S3A logo, etc.). Each professional would have to update this information regularly[j].

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[h] Personal translation of the Belgian Constitution. Original text is available here: https://www.senate.be/doc/const_fr.html#t1

[i] The French association Unapei is an associative movement of families, friends, disabled people, professionals, carers, volunteers, etc. working for a supportive and inclusive society, respecting the differences and free will of people with ID, autism, multiple disabilities and mental disabilities.

[j] *Inclusion asbl*, personal communication on 03/11/2022.

Figure 2 – S3A Pictogram

Other associations like *Inclusion asbl* or SO have compiled a series of reasonable adjustment tips for HCP. *Inclusion asbl* focuses its suggestions of reasonable adjustments rather on the quality of reception and accessible communication of people with ID within the health sector (adapted from the original text of Inclusion asbl (2019)):

- Give special attention to the reception: adopt a caring and reassuring attitude
- Don't infantilise the person: prefer to be addressed in a formal manner
- Take your time, be "patient": present things step by step
- Use language that is easy to understand: use words from everyday language
- Use pictures to illustrate what you are saying: have a binder of pictures available
- Pay attention to the person's understanding: rephrase if necessary
- Make sure the place and information are accessible: set up an escort service
- Ensure coordination and continuity of care: support the establishment of multidisciplinary consultations

Special Olympics rather focus on inclusion in health care services to ensure that space or programmes are in compliance with the law on disabled people.[24] For example, they advise to ask people with ID if there is a particular adjustment that might help them better use or benefit from the services (see more on accommodations in Table 41 available in Appendix 2). A practical development of adjustments adapted to a specific setting, i.e., a university hospital, is illustrated by Figure 21 available in Appendix 2.

1.4 Lexicon

The lexicon displayed in Table 1 presents the definition of the key terms as used in this report.

Table 1 – Lexicon of key terms

Term in English	Definition in the framework of the KCE project	Term in French	Term in Dutch
Easy Read	As recommended by United Nations, in this report, we use the term Easy Read to refer to adapted communication with people with ID.[43] Easy to read format and plain language aim to improve adult people with intellectual disability's ability to understand and to have access to information. The rules to be followed are not a lot and apparently simple: Arial 14 font, wide line spacing, one sentence per line, easy language and if possible, a pictogram or an image to explain each phrase. Easy Read could be applied in various ways: media (as blog, sites, magazines, leaflets, radio, etc.), direct and written communication with people with ID, educational and social activities, learning/teaching materials…[44]	*Langage facile à lire et à comprendre (langage FALC)*	*Eenvoudige taal*
Supporters	Professional and informal carers around the person with ID who do not belong to health care (educators, social workers, family, friends, etc.)	*Entourage*	*Entourage*
Health care professional	A person who practises, in Belgium, one of the following professions: doctors, dentists, pharmacists, nurses, physiotherapists, midwives, health care assistants or paramedics (dieticians, occupational therapists, orthoptists/optometrists, prosthetists, bandagers/orthoptists, medical laboratory technicians, chiropodists, medical imaging technologists, patient transport (non-emergency), oral hygienists, speech therapists, pharmacy assistants, and audiologists), clinical psychologist and clinical orthopaedagogist, and 112 crew.[k]	*Professionnel de santé*	*Zorgverlener*
Informal carer	Non-professional carer of a person with an intellectual disability (parents, siblings, friends, neighbours, etc.)	*Aidant proche*	*Mantelzorger*
Institutions	Full-time residential services in the disability sector for people with ID	*Services résidentiels*	*Woonvoorzieningen*
Mainstream care	Health care not directly aiming at diagnosing disabilities and providing specialised care for people with ID	*Soins courants*	*Dagdagelijkse medische zorg*
Person with disability	A person who has "*long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder his/her full and effective participation in society on an equal basis with others*".[45]	*Personne en situation de handicap*	*Een persoon met een handicap*
Professional carer	Education and social care staff from the (intellectual) disability sector	*Personnel socio-éducatif*	*Socio-educatief personeel*

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[k] http://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=nl&la=N&cn=2015051006&table_name=wet

2 CHAPTER 2: BELGIAN LANDSCAPE OF HEALTH CARE FOR PEOPLE WITH ID

This section aims at providing contextual information in order to better apprehend the barriers and solutions when it comes to access to health care for people with ID. It briefly depicts: 1) an overview of the public authorities involved in the disability field in Belgium; 2) the procedure for handicap recognition; 3) a description of the people and services caring for people with ID; 4) the current organisation of health care for people with ID according to the 7B model of access to health care.

In this chapter, there is no distinction according to the regional or community level: differences between the different institutions and services for people with ID mostly lay upon the missions and the target groups rather than the geographic area or the languages spoken inside the service.

2.1 Authorities and representatives

Although the federal government is competent to regulate the rights of patients in the context of the practice of medicine, the federated entities can also grant rights to the same patients when they do not concern medical activity.[46] In that context, the limits of the competences of the federal level and the federated entities are often blurred and therefore not easy to draw.

The federated entities define the legal framework as well as norms for staff and infrastructure, but the institutions have the freedom to choose the resources and activities that will help them to achieve their social project.

It is beyond the scope of this report to provide a detailed description of the distribution of the competences across disability and health sectors. Consequently, Figure 3 only displays a general overview of the major entities involved in the disability sector, including 3 national advisory boards[l]. Up-to-date and detailed information on the respective missions and organisation of the federal and federated entities are available on their official websites. A detailed presentation of the Belgian health care system can be found in the report of the European Observatory on Health Systems and Policies.[47]

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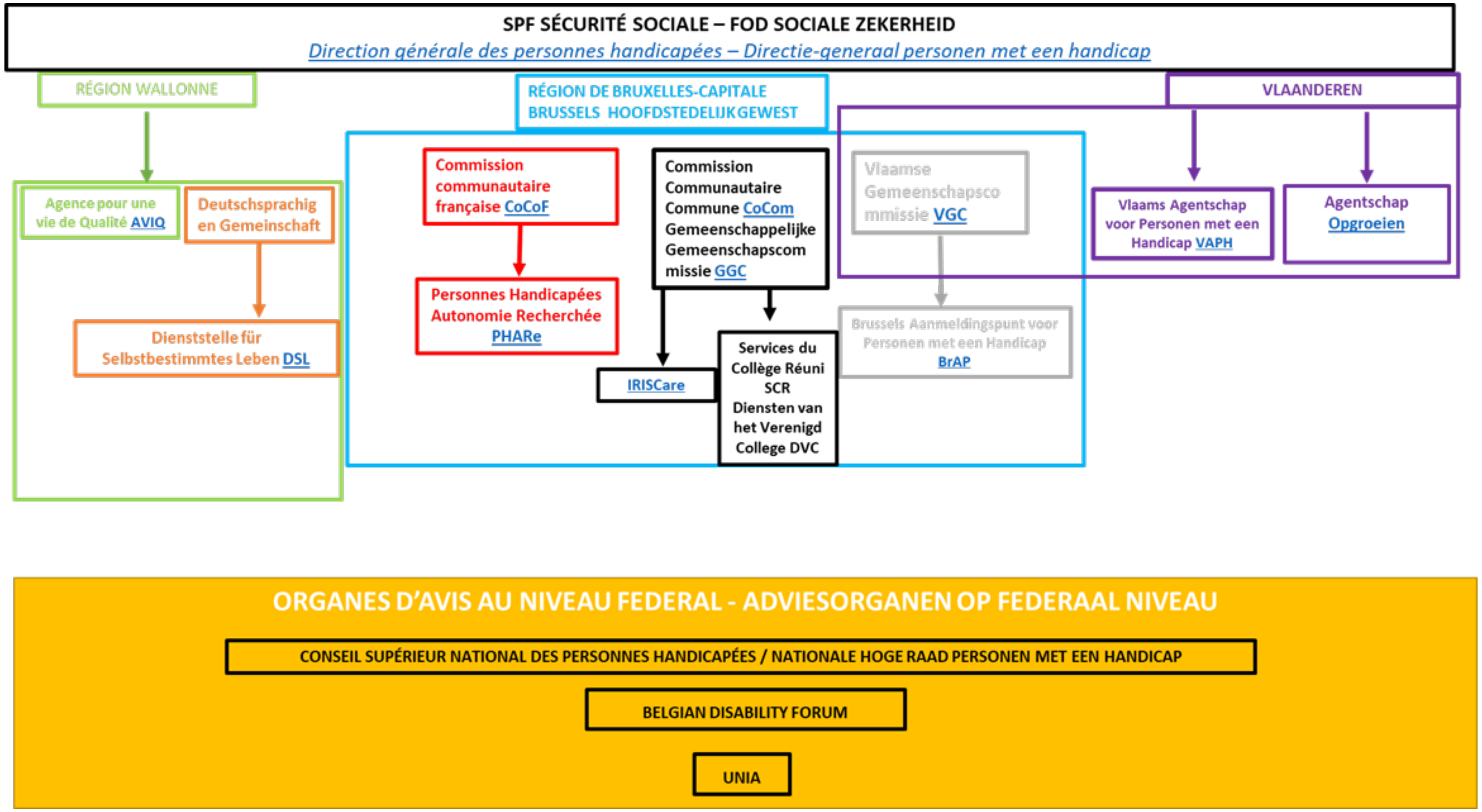
[l] There are additional regional and local advisory boards, acting on initiative or on request of their governing authority but these are not detailed in this report.

Figure 3 – Overview of Belgian entities involved in the disability sector (2022)



2.1.1 National Superior Council for Disabled People

The *Conseil Supérieur National des Personnes Handicapées – Nationale Hoge Raad Personen met een Handicap* (CSNPH – NHRPH), established in 1967, is responsible for examining all matters at federal level that may affect the life of people with ID and regularly publishes advice on various topics: allowances for people with disabilities, employment, accessibility of public buildings, mobility, etc.[m]

The consultative mission of the CSNPH – NHRPH consists in the regular consultation of people with ID and experts active in the disability sector on legislation concerning people with disabilities. The CSNPH – NHRPH may either provide advice upon request of Ministers or Secretaries of State or on its own initiative. The advice of the CSNPH – NHRPH are not binding.

The CSNPH – NHRPH also participates in various working groups to improve the quality of life for people with disabilities. It ensures a structured collaboration with the other disability advisory councils, the Belgian Disability Forum and Unia.

The CSNPH – NHRPH collaborates with other consultative organs at the regional level: NOOZO (*Vlaamse Adviesraad Handicap for Flanders*)[n], *Conseil de stratégie et de prospective*[o] (Walloon region), *Conseil consultatif bruxellois francophone des personnes handicapées*[p] (Brussels region) and the Belgian Disability Forum (BDF) at European and international level.

2.1.2 Belgian Disability Forum

Launched in 2001, the Belgian Disability Forum (BDF) aims to promote the rights of people with disabilities to the European institutions by bringing together 18 Belgian organisations representing people with disabilities, with a mission of exchange of information, experiences, knowledge and ideas. The BDF is the unique independent contact point at the European Union level, able to relay the expectations of people with disabilities and to disseminate at national level the achievements and projects of the European Union.

The aim of the BDF is representing Belgian people with disabilities in the European Disability Forum (EDF), informing Belgian people with disabilities about the major European and international issues, lobbying at Belgian and European level to improve the rights of people with disabilities and participating in the European decision-making process in all areas that have an impact about people with disabilities[q].

2.1.3 Unia

Since 2016, Unia is the independent interfederal[r] public institution that fights discrimination and promotes equal opportunities. Its independence and engagement in favour of human rights is recognised by the Global Alliance of National Human Rights Institutions.

Unia is competent for addressing discrimination on various grounds, such as: race, faith or beliefs, disability, age and sexual orientation. Unia provides individual support but also organises campaigns for raising awareness and informing the public, provides training on antidiscrimination laws, advice for diversity in the workplace, offers customised training and provides tools for

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[m] The *Conseil Supérieur National des Personnes Handicapées – Nationale Hoge Raad Personen met een Handicap* is the National High Council for the Disabled People. See more here (in French & Dutch): http://ph.belgium.be/

[n] Flemish Council of persons with disability: https://www.noozo.be/nl/

[o] Walloon Council of strategy and prospective: https://www.aviq.be/fr/conseil-de-strategie-et-de-prospective

[p] Brussels French speaking Council of People with Disabilities: https://phare.irisnet.be/service-phare/a-propos-de-nous/conseil-consultatif/

[q] Additional information can be found on the website of the Belgian Disability Forum: http://bdf.belgium.be/fr/

[r] Interfederal competence means that, in Belgium, the centre is active at the federal level as well as the level of the regions and communities. See more on the website of Unia: https://www.unia.be/en/about-unia

fighting for equal opportunities and against discrimination, as well as formulates targeted advice and recommendations for organisations and government authorities. Unia is also a knowledge and expertise centre and plays a role in the promotion and the protection of human rights in Belgium[s].

2.2 Disability recognition

This section briefly presents how the status of people with disability is granted.[48]

For people under 21 years old, the acknowledgement of the disability to benefit from additional familial allowances is under the responsibility of the federated entities. To benefit from the additional familial allowances, the disability of the child has (i) to have physical or mental consequences (pillar 1); (ii) to impact on the daily activities (e.g., mobility, hygiene, or learning capacities) when compared to a child of the same age (pillar 2); and (iii) to impact the household (medical treatment, extra transportations, adaptation of the housing, etc.) (pillar 3). The assessment is performed by a medical doctor. Since January 2019, *Kind&Gezin*[t] has the authority for the evaluation of the disability of children living in Flanders, where the additional familial allowances have been integrated in the *Groiepakket*[u]. Since 2022, in Brussels, the evaluation is managed by IRIScare[v] and by the *Dienststelle für Selbstbestimmtes Leben*[w] for the German speaking community. In the Walloon region, the *Agence pour une Vie de Qualité*[x] (AVIQ) is the competent authority. When having a score of at least 4 points in the pillar 1 or at least 6 points in total, the additional familial allowances is automatically granted as well as a majored intervention for health insurance[y] (see 2.4.3 Affordability).

For people aged 18 years and over, when applying for an integration allowance or the acknowledgement of the disability, the evaluation is based on 6 domains: mobility, cooking and eating, washing and dressing, maintain the home and perform household chores, assessing and avoiding danger and maintaining contact with other people. The assessment is performed by the medical doctors of the *Directie Generaal Personen met een handicap − Direction Générale des Personnes handicapées* of the Federal Public Service Social Security (FPS Social Security). For each domain, a maximum of 3 points is allocated: 0 points = no difficulties, 1 point = small difficulties, 2 points = severe difficulties, 3 points = impossible without help from another person[z]. A minimum of 7 points is required to obtain the integration allowance. The integration allowance (*integratietegemoetkoming − allocation d'intégration*) aims at compensating the extra costs endured as a person with ID in order to participate in social life.

The income replacement allowance (*inkomensvervangende tegemoetkoming − allocation de remplacement de revenus*) can be granted to people with ID when aged between 18 and 65 years old if they are not able to work because of their disability or if when working, they earn only a third or less of what a healthy person can earn on the labour market. The assessment focus then on the earning capacity (*capacité de gain –*

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[s] Information retrieved and translated from the website of Unia: https://www.unia.be/en/about-unia

[t] Health services for children and mothers in Flanders, see more here (in Dutch): https://www.kindengezin.be/nl

[u] Literally “growth package” Every child in Flanders is entitled to a *Groeipakket*: a package of financial benefits tailored to each child in each family. The *Groeipakket* varies from child to child, see more here: https://www.groeipakket.be/en

[v] Regional public agency for all matters relating to social protection in the Brussels Region: https://www.iriscare.brussels/fr/

[w] Public agency for people with disability of the German community: https://selbstbestimmt.be/

[x] Walloon agency in charge of health, family and handicap care: http:///www.aviq.be/

[y] Details of measures directly attributed to children (in French): https://handicap.belgium.be/docs/fr/annexe-mesures-automatiquement-octroyees-enfants.pdf

[z] People can assess their disability by using the simulation tool of the *Direction Générale des Personnes handicapées – Directie Generaal Personen met een handicap* *https://handicap.belgium.be/docs/fr/module-autonomie.xls (FR)* *https://handicap.belgium.be/docs/nl/simulatietool-zelfredzaamheid.xls (NL)*

verdienvermogen). The assessment is also performed by the *Direction Générale des Personnes handicapées – Directie Generaal Personen met een handicap.*

Box 5 – Key data on people with disability in Belgium (2020)

In 2020:

- A total of 598 241 individuals benefited from an acknowledgement as a person with a disability (all causes of disability).
- 206 259 individuals received a monthly income replacement allowance / integration allowance
- Chromosomic anomalies represented 1.4% of the pathologies leading to a income replacement allowance / integration allowance

Source: Annual report of the General Directorate Handicap of the Federal Public Service Social Security (2020)

Once acknowledged as adult or child with disability, several social measures[aa] are automatically granted, including regarding health care. Measures related to health care will be detailed in the section 2.4.

2.3 Places of residence

People with ID may take up residence in different places: they can live on their own – with or without support from their supporters; with their family; in a collective (private or licensed) structure. The type of residence depends, among other factors, on the personal choice, the age, the degree of incapacity, or the financial resources of the person; this choice is likely to impact the access to health care.

This section aims at briefly presenting the different forms of collective structures offered to people with ID, focusing on the structures that may influence access to health care services. It should be noted that a collective structure can be accredited for different types of services provided at the same place with the same staff and resources. Among other examples, some structures have simultaneously a day-care offer and a full-time residential offer with a rotation of the educative staff between the different poles of activities. Collective structures can be private or public, with or without accreditation, with or without subsidies[bb]. Besides these collective structures, other forms of support also exist such as outreaching services.

In Flanders, the current organisation is based on a continuum from support to residence. At each level, two systems coexist: the directly accessible assistance (*rechtstreeks toegankelijke hulp* RTH) and the intensive one for which people must pass by the Intersectoral gateway for children (*Intersectorale toegangspoort*) or the VAPH for adults.

In the absence of more precise data, there is currently no official information regarding the proportion of people living on their own, living with relatives or in a collective structure.[49]

[aa] Details on additional measures are available here (in French): https://handicap.belgium.be/docs/fr/annexe-mesures-automatiquement-octroyees-adultes.pdf

[bb] See, for example, the question discussed at the *Parlement de Wallonie* on the “maisons pirates” (litt. pirate houses) for more details: https://www.parlement-wallonie.be/pwpages?p=interp-questions-voir&type=28&iddoc=100133

2.3.1 *Services for children and youths*

These services usually welcome children and youths until 18-21 years. The financial contribution to the cost of reception and accommodation is defined by law and vary according to the type of services and the regions. In general, for young people in residential services, this amount is equivalent to 2/3 of the family allowance. For access to other types of services, the contribution is generally set at a daily cost.

- **Day-care services for disabled youths** aim at supporting the health, development and integration of the youths, in a partnership with them, their families and, where appropriate, with other relevant actors. An individual project, specifying objectives, means and evaluation procedures, gives concrete form to this partnership. Depending on the type of service and the person's needs, the youth will have access to support in the following areas: medical follow-up, nursing care, functional rehabilitation, educational, creative and recreational activities, psychological follow-up or therapy, and activities aimed at independence. Day-care services have no agreement for overnight stays.

- **Residential services for youths** usually welcome youths aged between 0 and 21 for permanent day and night care in an adapted environment when the family can no longer provide this support (age range varies depending on the institutions). In these services, youths benefit from medical follow-up, nursing care, functional rehabilitation, educational, creative and recreational activities, psychological follow-up or therapy, activities aimed at autonomy as well as support for the families. The teams are made up of educators, social workers, speech therapists, physiotherapists, nurses, psychologists, doctors, administrative staff, etc.[50]

- **Specialised reception services for youths** usually welcome youths who are not in school (temporarily or for a longer period) and who, because of the seriousness of their disability, do not attend an ordinary or special educational establishment. They usually provide day care during the week, with varying degrees of intensity depending on the needs of the youths at any given time. These services provide individual, educational, medical, therapeutic, psychological and social care, adapted to their needs.

While this section presents the activities as separated, they can be integrated in the same service. For example, the multifunctional centre (*multifunctioneel centrum* MFC) in Flanders is aimed at people with disabilities up to 21 years of age (exceptionally extendable to 25 years) who need specific support. A multifunctional centre provides counselling, day care, accommodation[cc].

2.3.2 *Services for adults*

Adults with ID have access to 4 different services: adult day-care services, overnight residential services for adults, adult residential services and supportive housing services.

- **Day-care services for adults** welcome people with ID from the age of 18 during the day with a focus on educational support achieved through different activities but also psychological, social and therapeutic support.

- **Adult Night Residential Services** only provide overnight accomodations to people with ID who have activities during the day (work, volunteering, day-care centre, etc.). Night-time support takes place both during the week and at weekends.

- **Adult residential services** are 24h/24 living facilities aimed at people with ID with severe limitations. They benefit from therapeutic and educational supervision that enables them to live as "normally" as possible. Learning about food and hygiene, emotional and sexual life awareness, psychological support are all part of the support provided.

- **Supervised Housing Services** are for people with ID of any age. The educational staff of the Supervised Housing Services constantly look after the physical, psychological and social comfort of the beneficiaries,

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[cc] https://www.vaph.be/zorg-ondersteuning/dagopvang-verblijf-ondersteuning

which may include help with budgeting, hygiene, food, etc. In Flanders the VAPH recognises the so-called ‘vergunde zorgaanbieders’, which are licensed care settings and/or providers offering collective day care or residential support in addition to individual counselling. There are also outpatient counselling services.

2.4 Access to health care and organisation of care

This section presents the current access and organisation of care for people with ID in Belgium. There is no separate health care trajectory for people with ID: the offer of health care takes place in the mainstream health care system, following the same legal framework, governance, funding and regulations than for the rest of the population covered by the national health insurance.[47]

Consequently, this section opts for a description of access based on the 7B framework developed by Roose & De Bie.[51] Articulated around 7 key dimensions related to access to health and/or social care, the 7B framework has been developed in Flanders in order to identify in which dimensions access to social care services could be improved.

Box 6 – The 7B model adapted from Roose & De Bie, 2008

- Availability (Beschikbaarheid) refers to the existence of a supply of (social) services which can be called upon even for matters that do not relate directly to the assessed problem.
- Affordability (Betaalbaarheid) refers to the extent to which the patient has the resources to cover the indirect and direct costs related to the care.
- Trustworthiness (Betrouwbaarheid) refers to the extent to which the patient can trust the services provided and the professionals that will treat him or her in a respectful way, without fearing for his/her physical and mental integrity.
- Familiarity (Bekendheid) refers to the extent to which the patient is aware of the existence of the services but also has access to appropriate information related to health, health care services, patient rights and other aspects related to health and wellbeing.
- Reachability (Bereikbaarheid) refers to the (lack of) thresholds when care is needed: these can be physical thresholds (e.g. transportation) or immaterial ones, as in the gatekeeping system.
- Functionality (Bruikbaarheid) refers to the extent to which the care provided are experienced as supportive and meeting the needs.
- Comprehensibility (Begrijpelijkheid) refers to the extent to which the patients are aware of the reason for the intervention and the way in which the problem should be approached.

2.4.1 Overview of the 7B model of access applied to people with ID

For each dimension of the 7B framework, indicators were identified in the Belgian health care system, with a focus on the federal level. These indicators are all related to the provision of mainstream care (*gewone geneeskundige hulp – soins courants*) and do not concern the delivery of health care for the disability. For example, this table does not describe the rehabilitation centres under the authorities of the federated entities. As stated in the section 2.3, differences in access and organisation mostly lay upon the place of residence. Table 2 presents a general overview of the access and organisation of health care for people with ID according to their place of residence.

Table 2 – General overview of the access and organisation of health care for people with intellectual disability according to place of residence

	Place of residence of the people with intellectual disability			
	Living in autonomy – with or without supporters and outreach services	Supervised Housing Services[dd]	Collective structures[ee]	
			Day care only or night care only	Full residential service
	Availability			
Health care staff on site 24/7	None	None	Depends on institutional project & missions	Depends on institutional project & missions
Availability of health care coordinators	Personal choice	Depends on institutional project & missions	Depends on institutional project & missions	Depends on institutional project & missions
Type 2 diabetes care trajectory	Same conditions as people covered by the national health insurance (NHI)	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI
Renal failure care trajectory	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI
	Affordability			
Specific insurability status	Yes	Yes	Yes	Yes
Increased reimbursement *(Intervention majorée – Verhoogde tegemoetkoming)*	Under specific conditions	Under specific conditions	Under specific conditions	Under specific conditions
Third-party payment scheme (*Tiers payant – derdebetalersregeling)*	Under specific conditions	Under specific conditions	Under specific conditions	Under specific conditions
Copayment *(Ticket modérateur – remgeld)*	Under specific conditions	Under specific conditions	Under specific conditions	Under specific conditions
Maximum billing *(Maximum à facturer – maximumfactuur)*	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI

[dd] People living in Supervised Housing services are supported by educators.

[ee] People living in collective structures are supported by socio-educative staff, that may include health care professionals depending on the project and accreditations of the structure.

Chronic illness status *(Statut affection chronique – statuut van persoon met een chronische aandoening)*	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI
Chronic disease fix-payment *(Intervention forfaitaire pour maladies chroniques – Forfait voor chronisch zieken)*	At least 12 points of disability + Co-payments	At least 12 points of disability + Co-payments	At least 12 points of disability + Co-payments	At least 12 points of disability + Co-payments
Additional financial measures for health care	Private insurance / specific budget of federated entities	Private insurance / specific budget of federated entities	Private insurance / specific budget of federated entities	Private insurance / specific budget of federated entities
Financial coverage for the costs of transportation	Only if severe mobility problems	Only if severe mobility problems	Only if severe mobility problems	Only if severe mobility problems
Trustworthiness				
Guarantee of having a trained health care staff in primary care	None	None	Depends on institutional project & missions	Depend on the partnership with the local primary care services
Guarantee of having a trained educator staff for providing health care	None	None	Depends on institutional project & missions	Depends on institutional project & missions
Guarantee of having a trained health care staff in hospitals	None	None	None	Depend on the partnership with the local hospitals
Compulsory training for generalist practitioners (GP)	None required	None required	None required	None required
Compulsory training for educators on health-related issues	None required	None required	Depends on institutional project & missions	Depends on institutional project & missions
Global medical record *(Dossier médical global – globaal medisch dossier)*	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI
Familiarity[ff]				
Existence of adapted information on health and disability	None	None	None	None
Existence of adapted information on health services and hospitals	None	None	None	None

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[ff] This section refers to official information provided by public authorities.

Existence of adapted health prevention information & interventions	None	None	None	None
Existence of adapted information on patient rights	None	None	None	None
Reachability				
Obligation of consulting a medical doctor for accessing some health care (=clinical gatekeeping)	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Similar than nursing homes
Obligation of providing specific documents to access (some) health care (=administrative gatekeeping)	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Similar than nursing homes
Place of care by a generalist practitioner (GP)	At the GP practice or home visit	At the GP practice or home visit	At the GP practice or home visit	Similar than nursing homes
Place of delivery of nursing care	Home visit or at the nursing practice	Home visit or at the nursing practice	Depends on institutional project & missions	Depends on institutional project & missions
Place of delivery of physiotherapy care	At the physio practice or home visit	At the physio practice or home visit	Depends on institutional project & missions	Similar than nursing homes
Place of delivery of specialty care	At the specialist practice or home visit	At the specialist practice or home visit	Depends on institutional project & missions	Similar than nursing homes
Functionality				
Coverage in GP care	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Adapted benefit codes for health care provided in collective structures
Coverage in specialised care	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Adapted benefit codes for health care provided in collective structures
Coverage in dental and oral care	Extra benefits in nomenclature	Extra benefits in nomenclature	Extra benefits in nomenclature	Extra benefits in nomenclature
Coverage in nursing care	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Adapted benefit codes for health care provided in collective structures. Exclusion of benefits for palliative patient, supplementary fees for

				palliative care, diabetes management and nursing consultations.
Coverage in physiotherapy care	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Same conditions as people covered by NHI	Adapted benefit codes for health care provided in collective structures.
Coverage in speech therapy	Limitation of benefits	Limitation of benefits	Limitation of benefits	Limitation of benefits
Comprehensibility				
Intercultural mediators	Same conditions of access	Same conditions of access	Same conditions of access	Same conditions of access
Experts by experience	No specific to ID	No specific to ID	No specific to ID	No specific to ID

2.4.2 *Availability*

A wide range of health care services and professionals is available for those covered by the national health insurance, including people with ID.[47]

As stated above, availability of health staff in collective structures for people with ID is left to the discretion of the institution. It depends, among others, on the profile and number of the beneficiaries as well as the missions and educational projects of the institutions. Standards are defined and controlled by the federated entities.

Care coordinators are available for people with ID, living in autonomy with or without supporters, upon request of the people with ID and/or their supporters. For those living in a supervised Housing Service or in collective structures, the presence of a health care coordinator depends on the type of services.

As any Belgian citizen, people with ID could be integrated in a health care trajectory for type 2 diabetes or chronic renal failure. Health care trajectories aim at organising and coordinating health care, treatment and follow-up of a patient with a chronic disease. The health care pathway is based on a formal collaboration between the patient, the general practitioner and the specialist.

2.4.3 *Affordability*

Affordability or financial accessibility of health care is the same for people with ID as for the people covered by the National Health Insurance (NHI) (*ziekte- en Invaliditeitsverzekering – assurance maladie-invalidité*). People with ID are covered by the system of Maximum Billing (*maximumfactuur – maximum à facturer*), can benefit from the status chronic disease patients (*statuut chronische aandoening – statut affections chroniques)* and the fixed payments for chronically ill patients *(forfait voor chronisch zieken – intervention forfaitaire pour malades chroniques).*

Regardless of where they live, disabled people who receive an allowance granted to a disabled person pursuant to the Law of 27 February 1987 on allowances for disabled people are automatically entitled to the increased reimbursement for themselves and their household (spouse by marriage or cohabiting life partner, as well as their dependants). The same applies to a disabled child whose physical or mental incapacity of at least 66% is certified by a doctor from the Directorate-General for Disabled People of the Federal Public Service Social Security. For those who do not fall into one of these categories, they can benefit from the increased intervention based on an enquiry into their income, which must be below a certain ceiling.

The fixed payments for chronically ill patients (*forfait voor chronisch zieken – intervention forfaitaire pour malades chroniques)* is an individual entitlement linked to co-payments paid by the beneficiary (having to reach a certain ceiling two years in a row) and to a dependency criterion. The fact that the person lives in a community residence has no impact on this measure.

The status chronic disease patients (*statuut chronische aandoening – statut affection chronique)* is an individual recognition linked to the beneficiary's health expenses (intervention of the compulsory insurance + co-payments having to reach a certain ceiling) or to the benefit of fixed payments for chronically ill patients. It is also granted, for a longer period, to people suffering from a rare or orphan disease, the health expenditure criterion having to be met for entitlement. The fact that the person lives in a community residence for the disabled has no impact on this measure either.

2.4.3.1 Increased reimbursement

The increased reimbursement (*verhoogde tegemoetkoming – intervention majorée*) is automatically granted to people with ID benefiting from allowances from the FPS Social Security (legal basis: Law of February 27, 1987). Children with a disability of minimum 66% also automatically benefit from the increased reimbursement. If people with ID are acknowledged as people with ID but without benefiting from allowances, they may directly apply to their sickness funds. The granting of the increased reimbursement depends then on the total income of the household, similarly to the rules for persons covered by the national health insurance.

People with ID granted with disability allowances benefit from a reduced co-payment (*remgeld – ticket modérateur*) when consulting a GP, a medical specialist, a physiotherapist, a nurse and other categories of paramedical professions (e.g., speech therapists).

The application of the third-party payment (*derdebetalersregeling – tiers payant*) is compulsory to a limited extent for patients benefiting from the increased reimbursement (see the Royal Decree of September 8, 2015, related to third-party payment).

2.4.3.2 Specific measures at regional level

In Flanders, people with ID benefit from a *Persoonlijke-assistentiebudget* (PAB)[gg] or a *Persoonsvolgend budget* (PVB)[hh]. The PAB is a budget that the *Vlaamse Agentschap voor Personen met een Handicap* (VAPH) gives to (the parents of) children with ID to organise and finance the assistance for the child at home or at school. The PVB is a tailor-made budget with which adult with ID can “buy” care and support, in their own network, from voluntary organisations, from individual supervisors, and from healthcare professionals licensed by the VAPH.

In Brussels, the *Budget d'Assistance Personnelle* (BAP) is piloted by AccessAndGo. Similarly to the Flemish PVB, this is a budget allocated to the disabled person or their representative so that they can organise help and support according to their needs and expectations. People can decide for themselves what help they need and how they want to organise it. The BAP pays for an assistant or assistants to help the disabled person with activities of daily living such as getting up, washing, preparing meals, cleaning, etc. at home, at work or at the place of leisure activities. Assistants can also help people with ID in their own daily life or provide support to their family[ii].

[gg] Personal assistance budget, more on the PAB (in Dutch): https://www.vaph.be/persoonlijke-budgetten/pab/algemeen

[hh] Personal assistance budget, more on the PVB (in Dutch): https://www.vaph.be/persoonlijke-budgetten/pvb/algemeen

[ii] More on the Brussels budget (in French): https://accessandgo.be/service/budget-d-assistance-personnelle-bap-bruxelles

In Wallonia, the AVIQ grants a *Budget d'Assistance Personnelle* (BAP) to people with disabilities with significant functional limitations[jj]. The objective of the BAP is to help maintain and/or increase the quality of life, in the natural environment, of people with disabilities and to allow families to have access to the necessary support to be able to assume their responsibilities towards their disabled relatives. Based on a personalised intervention project, the beneficiary of the BAP budget can call on a service provider to help in the following areas: assistance with activities of daily living; assistance with activities of domestic life; assistance with social and leisure activities; assistance with work activities; assistance with travel related to activities of daily living. The provider is paid by the AVIQ based on an agreement.

2.4.4 Trustworthiness

Trustworthiness lays, among others, on the competences, knowledge and skills of the supporters and the professionals. It also includes the legal context.

Concerning competences and knowledge of health care professionals (HCP), physicians can follow continuing education courses and participate to peer review activities (*Lokale Kwaliteitsgroep LOK – Groupe Local d'Evaluation Médicale GLEM)* in order to be accredited. In some specialties, the accreditation is conditioned by a minimum activity threshold per year (e.g., dentists should attest at least 300 patient contacts per year) and/or by the attendance of specific training sessions (e.g., mandatory retraining to keep a professional title for emergency nurses). To date, training and education of health care professionals regarding health care for people with ID are let at the discretion of the health care institutions and the educational system.

When it comes to the supporters, the current situation cannot be considered as fulfilling the trustworthiness.

The Art. 124 of the Law of 10 May 2015 related to the exercise of the health care professions allows the delivery of nursing care as defined by the Art. 46 §1 2° of the same Law by a family member under specific conditions.[52] This exception is limited to members of the patient's family who act as close carers. It requires a training delivered by the medical doctor or the nurse, but the content and the magnitude of such training are let at the discretion of the professionals. There is also no requirement for the training of the professionals delivering the training to the supporters.

[jj] More on the BAP (in French): https://wikiwiph.aviq.be/Pages/Budget-d%27assistance-personnelle-(BAP).aspx

Box 7 – Article 124 of the Law of 10 May 2015, related to health care professions

Artikel 124	**Article 124**
Onverminderd de in het Strafwetboek gestelde straffen alsook, desgevallend, de toepassing van tuchtmaatregelen wordt gestraft met een gevangenisstraf van acht dagen tot drie maanden en met een geldboete van zesentwintig tot tweeduizend euro of met een van deze straffen alleen:	Sans préjudice de l'application des peines prévues par le Code pénal ainsi que, s'il échet, de l'application de sanctions disciplinaires, est puni d'un emprisonnement de huit jours à trois mois et d'une amende de vingt-six à deux mille euros ou d'une de ces peines seulement :
1° hij die zonder in het bezit te zijn van de vereiste erkenning of zonder te voldoen aan de voorwaarden gesteld in artikel 45, § 1, één of meer activiteiten van de verpleegkunde zoals bedoeld in artikel 46, § 1, 1°, uitoefent met de bedoeling er financieel voordeel uit te halen of gewoonlijk één of meer activiteiten zoals bedoeld in artikel 46, § 1, 2° en 3°, uitoefent.	1° celui qui, ne disposant pas de l'agrément nécessaire ou ne réunissant pas les conditions fixées par l'article 45, § 1er, exerce une ou plusieurs activités relevant de l'art infirmier telles que prévues à l'article 46, § 1er, 1° , avec l'intention d'en tirer un bénéfice financier ou exerce habituellement une ou plusieurs activités visées à l'article 46, § 1er, 2° et 3°.
Die bepaling is niet van toepassing op de personen die gemachtigd zijn de geneeskunde uit te oefenen en op de vroedvrouwen, de zorgkundigen, de hulpverleners-ambulanciers en de beoefenaars van de kinesitherapie en de paramedische beroepen, voor wat de reglementaire uitoefening van hun beroep betreft. Ze is evenmin van toepassing op de student in de geneeskunde, de student in de kinesitherapie, de student vroedvrouw en de personen in opleiding voor een paramedisch beroep of voor hulpverlener-ambulancier die de vermelde activiteiten verrichten in het kader van hun opleiding of op de student die de vermelde activiteit verricht in het kader van een erkende opleiding voor het behalen van een in artikel 45, § 1, of in artikel 56, bedoelde erkenning;	Cette disposition n'est pas d'application aux personnes habilitées à exercer la médecine, ni aux accoucheuses, aux aides-soignants, aux secouristes-ambulanciers et aux praticiens de la kinésithérapie ou d'une profession paramédicale pour ce qui est de l'exercice réglementaire de leur profession. Elle n'est pas davantage d'application à l'étudiant en médecine, à l'étudiant en kinésithérapie, à l'étudiante accoucheuse et à la personne suivant une formation paramédicale ou de secouriste-ambulancier exerçant les activités susmentionnées dans le cadre de sa formation, ni à l'étudiant exerçant les activités susmentionnées dans le cadre d'une formation reconnue permettant d'obtenir l'agrément visé à l'article 45, § 1er, ou à l'article 56.
Deze is ook niet van toepassing op personen die deel uitmaken van de omgeving van de patiënt en die, buiten de uitoefening van een beroep, na een door een arts of een verpleegkundige gegeven opleiding, en in het kader van een door deze opgestelde procedure of een verpleegplan, van deze laatsten de toelating krijgen om bij deze welbepaalde patiënt één of meer in artikel 46, § 1, 2°, bedoelde technische verstrekkingen. Een door de arts of het verpleegkundige opgesteld document vermeldt de identiteit van de patiënt en van de persoon die de toelating heeft gekregen. Dit document wijst eveneens de toegelaten technische verstrekkingen, de duur van de toelating evenals de eventuele bijkomende voorwaarden aan die door de arts of de	[Cette disposition] n'est pas non plus d'application pour la personne qui fait partie de l'entourage du patient et qui, en-dehors de l'exercice d'une profession, au terme d'une formation délivrée par un médecin ou un infirmier, selon une procédure ou un plan de soins établi par celui-ci, reçoit l'autorisation de ce dernier d'effectuer auprès de ce patient déterminé une ou plusieurs prestations techniques visées à l'article 46, § 1er, 2°. Un document délivré par le médecin ou l'infirmier indique l'identité du patient et de la personne ayant reçu l'autorisation. Ce document indique également la ou les prestations techniques autorisées, la durée de l'autorisation ainsi que les éventuelles conditions supplémentaires posées par le médecin ou l'infirmier pour exécuter la ou les prestations techniques.

verpleegkundige gesteld worden voor het uitoefenen van de technische verstrekkingen;	
[1 Deze bepaling is evenmin van toepassing op personen die bij derden diagnostische oriëntatietests afnemen, na een opleiding gegeven door een arts of een verpleegkundige en nadat ze van die laatsten de toelating hebben gekregen om bij derden een of meerdere technische prestaties te verrichten zoals bedoeld in artikel 46, § 1, 2°, en die noodzakelijk zijn om bovengenoemde oriëntatietests te kunnen afnemen. Het document dat de arts of de verpleegkundige aflevert, vermeldt de identiteit van de persoon die de nodige toestemming krijgt om de toegelaten technische prestaties te verrichten alsook de duur van die toestemming en de eventuele bijkomende voorwaarden die de arts of de verpleegkundige oplegt om de technische prestaties te verrichten. De Koning legt de lijst van de betrokken diagnostische oriëntatietests en de finaliteiten van die tests, de voorwaarden voor het verrichten van die tests vast alsook de voorwaarden waaraan de opleiding en de toestemming die aan het eind daarvan verleend wordt, moeten voldoen.]1	Cette disposition n'est pas non plus d'application aux personnes qui font passer à des tiers des tests d'orientation diagnostique, et ce au terme d'une formation délivrée par un médecin ou un infirmier et après avoir reçu l'autorisation de ces derniers d'effectuer auprès de tiers une ou plusieurs prestations techniques visées à l'article 46, § 1er, 2°, nécessaires pour faire passer les tests d'orientation susmentionnés. Le document délivré par le médecin ou l'infirmier indique l'identité de la personne recevant l'autorisation nécessaire pour exécuter les prestations techniques autorisées ainsi que la durée de cette autorisation et les éventuelles conditions supplémentaires posées par le médecin ou l'infirmier pour exécuter la ou les prestations techniques. Le Roi fixe la liste des tests d'orientation diagnostique concernés et les finalités de ces tests, les conditions de réalisation de ces tests, ainsi que les conditions auxquelles la formation et l'autorisation octroyée à son terme doivent répondre.

The Art. 124 does not refer to educators and other professionals active in institutions for people with ID who do not comply to the criteria reported in the 1°. Educators are currently facing the risk of prosecution for illegal nursing practice. There is at the moment a proposal for a law on cooperation between people from the patient's environment and HCP outside a health care institution and on the delegation of certain medical services.[53] This proposal extends the exception for the legal practice of nursing to people who are in contact with the patients in their daily life within the family and to people who are in contact with the patient in the wider social context (without family ties, in the context of their profession or as volunteers). This proposal was the subject of the Opinion 2022/03 of the CSNPH – NHRPH.[54] The CSNPH – NHRPH pointed out, among others, the lack of clarity regarding the exact and concrete scope of the delegation as the proposal suggests that the authorisation be given to one person only, but this does not consider the collective structures. It also questions the scope of the condition "*en-dehors de l'exercice d'une profession*" (lit.: outside the scope of a profession) for those working in the context of the daily living support. There is also a lack of clarity regarding the insurance cover for non-professionals as well as the organisation of the support and the training for non-professionals. For the CSNPH – NHRPH, this delegation should be accompanied by a re-evaluation of nursing fees and an increase in the salaries of non-nursing professionals who will be responsible for these delegated acts.

2.4.5 *Familiarity*

People with ID need to be aware of the existence of the services but also need having access to appropriate information related to health, health care services, patient rights and other aspects related to health and wellbeing. Information is expected to be provided by official public authorities in an easy-to-understand manner. Familiarity includes the concept of health literacy as the patients should be able to use the information to make decisions for their health and wellbeing. [55, 56]

Currently, the official websites of the health care authorities such as those of the National Institute for Health and Disability Insurance (RIZIV – INAMI), of *MaSanté - MijnGezondheid*, of *Infosanté – Gezondheidenwetenschap* or of the Federal Public Service (FPS) Public Health have no version in Easy plain language (websites were consulted in 2021).

2.4.6 Reachability

There is no compulsory clinical gatekeeping system for general practitioner (GP), dentists, psychologists and medical specialists. Patients can nevertheless be referred via their GP to specialists and benefit from an increased reimbursement. This increased reimbursement is granted once a year per specialty, provided that the patient has a global medical record. Medical specialties are gynaecologist/obstetrician, internist, cardiologist, ophthalmologist, geriatrician, neurologist, ENT doctor (nose - throat - ears), gastroenterologist, psychiatrist, urologist, paediatrician, rheumatologist, stomatologist, neuropsychiatrist, pneumologist, dermato-venereologist and endocrino-diabetologist.

There is a clinical gatekeeping when it comes to nursing care, physiotherapy care, speech therapy and other benefits provided by allied health care professionals as a prescription is required to obtain the reimbursement.

Specific measures also exist to improve access to transportation, depending on the degree of the disability.[57]

2.4.7 Functionality

The reimbursement of a benefit by the compulsory insurance cannot take place if a federated entity is already involved in the reimbursement of the same benefit, in accordance with Art. 2 of the Regulation of 28 July 2003, implementing Art. 22, 11° of the Law on compulsory health care and allowances, and Art. 136, § 2, of the Law on compulsory health care and allowances coordinated on 14 July 14 1994 (both of which prohibit double financing).

This rule is also applied in practice to nursing care in Art. 8(3) of the nomenclature of health care services.

This division of competences and the prohibition of double financing must therefore be considered when considering these matters.

In the case where compulsory insurance can intervene:

- RIZIV – INAMI regulations are not linked to regional regulations or to the approval of residences for the disabled people.
- There is currently no strict definition of the places of delivery of the benefits included in Art. 7 and 8 of the nomenclature and, consequently, there are no definition of "home or temporary or permanent residence for disabled people". It is therefore necessary to look at the local and factual circumstances to determine whether the place of residence must be considered as “the patient’s home” or as a “temporary or permanent residence for disabled people”. One can consider here, for example, the characteristic that the HCP can take care of a group of patients at the same address with one trip, which saves time and travel costs. There are ongoing discussions regarding the definition of the “place of residence” in order to account for the emerging forms of residence for people with ID.
- Institutions where many disabled people live together and are accompanied day and night are considered as "home or temporary or permanent residence for disabled people".

In recent years, however, various new, often more alternative or informal forms of living have developed, in which people with disabilities live together in small groups, with, for example, advice and care 'on the spot'. For RIZIV – INAMI, it is less clear here whether this is a "*temporary or permanent home or residence for people with disabilities*" or the "*patient's home*". An investigation of the *Dienst voor geneeskundige evaluatie en controle – Service d'Évaluation et de Contrôle Médicaux* of RIZIV – INAMI highlights the need for a reformulation of the places of service in the nomenclature for physiotherapists and home nurses in order to create more clarity for patients and care providers in the field. This issue is currently under discussion.

2.4.7.1 Adapted nomenclature

Alongside the specific benefits covering the health care related to the management of the disability as such[kk], the nomenclature of mainstream care (*gewone geneeskundige hulp – soins courants)* includes specific benefits for people with ID.

For these benefits, the nomenclature does not define the status of people with disability nor does it link to the disability allowance granted by the FPS Social Security. The nomenclature only refers to the place of care and not to a specific status. Moreover, there is no distinction due to the nature of the disability and, to our knowledge, none of the sickness funds makes such distinction either.

These benefits concern:

- **Inpatient and outpatient dental care for children and adults** (from 18 years on). For children and adults with disabilities, professional debridement is reimbursed 4 times a year, while this is limited to once a year for the general population. The continuity rule[ll] does not apply to professional debridement performed in individuals with disabilities. Dentists can charge a dedicated supplementary fee in patients with special needs when performing certain dental procedures (i.e., professional debridement, dental extractions and some restorative care). This fee is fully covered by the compulsory health insurance. When a dentist wants to charge these fees and/or use the codes dedicated for professional debridement in patients with disabilities, (s)he must consider whether a patient is able to acquire or maintain 'normal' daily oral hygiene for his/her age without the help of a third person. If this is not the case, the fees can be used; the dentist must record in the patient's file the rationale and evidence for using them. The use of the fees remains the responsibility of the treating dentist; no specific medical certificates are needed.
- **Physiotherapy**: specific benefits for health care delivered at community home or in an institution for people with ID (litt. *tijdelijke of definitieve gemeenschappelijke woon- of verblijfplaats van mindervaliden − domicile ou à la résidence communautaires, momentanés ou définitifs, de personnes handicapées* (Section III a, Art. 7 of the Nomenclature – physiotherapy).
- **Nursing care:** specific benefits for nursing care at community home or in an institution for people with ID (section 3°bis, Art. 8 of the Nomenclature - nursing care). Nurses cannot attest the following benefits for people with ID living in community home or institutions: palliative patient, supplementary fees for palliative care, diabetes management and nursing consultations. The rationale beyond the difference in nursing care for people with ID in private home (*woon- of verblijfplaats − domicile ou résidence*) and community home (*gemeenschappelijke woon- of verblijfplaats − domicile ou à la résidence communautaire*) lays on 1) the absence of transportation fees when living in a community home; 2) the assumption that the community home can provide support to supplement nursing care.
- **Paediatricians and GP** can attest a home visit (either at the person's private housing or institutions for people with ID) (section C, Art. 2 of the Nomenclature – consultations, visits and counselling; psychotherapies and other benefits).
- **Medical specialists** can also attest home visits (either at the person's private housing or institutions for people with ID). This can only occur at the request of the GP, and the medical specialist should address a written report to the GP (benefit 103073). Transportation costs can be

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[kk] These could concern, i.e., all the benefits delivered in the framework of the Rehabilitation Convention 950 for persons with locomotor and neurological disabilities. New-born children with a Down Syndrome are also in the list of children who can benefit from a cardiac telemonitoring at home.

[ll] Continuity rule: The reimbursement for professional debridement is halved for those individuals for whom no reimbursed dental procedures have been recorded in the preceding year.

invoiced (section C, Art. 2 of the Nomenclature – consultations, visits and counselling; psychotherapies and other benefits).

2.4.7.2 Coping with complex situations

Benefits reserved to physicians

For the GP, the nomenclature plans a supplementary fee for an “unusual” consultation, i.e. the first consultation or visit by the GP coordinating the global medical record when the patient aged of 75 and older is returning home after a hospital stay of at least 14 days (benefits 101032, 101076 for consultations; benefit 103095 for supplement; benefits 103132, 103412, 103434 for a visit). This consultation or visit should aim at explaining and planning the follow-up of the patients. GP can also charge a supplementary fee when visiting a patient at the hospital, once a week, with the obligation of reporting the results of the concertation with hospital specialist in the patient medical record (benefit 109723).

The nomenclature also includes the possibility for a specialist in medical oncology of having a consultation of at least 30 minutes (see Royal Decree 5 October 2018 (in force 1 December 2018) with erratum 6 December 2018 – benefits 350070 and 350092). However, this covers only patients who had benefited from an intervention of a limitative list (see Art. 11 of the nomenclature).

For all patients, specialists in internal medicine can attest a benefit 102955 or 102970 for a first consultation with examination on the basis of the existing elements in the medical file of a patient presenting a complex pathology without a precise diagnosis and for which treatment has not given sufficient results. [58]

Multidisciplinary concertation

In situations where the patient is staying at home and is expected staying at home for at least one month with a diminution of physical autonomy, a multidisciplinary concertation can be organised between HCP and supporters in the framework of an integrated health care service at home, under the authority of the federated entities. The patient (or his/her representant) should also attend the concertation. This concertation aims at establishing a health care plan for the patient and, to this aim, should use a validated assessment tool.

The benefit 102223 involves the multidisciplinary geriatric assessment of the patient by the geriatrician, with report to the GP (related benefits: 599045 and 597623). This assessment should include a functional, physical, mental and social assessment, through validated tools. This is therefore limited to patients aged of 75 years and older.

The nomenclature also includes specific fees in some specialities for the coordination and/or the multidisciplinary concertation such as the benefit 350276 for the multidisciplinary concertation in oncology (follow-up concertation) as attested by the coordinating physician or the benefit 477724 corresponding to the coordination of the diagnosis and treatment plan by a multidisciplinary team caring for a hospitalised patient with a stroke as well as benefits related to the multidisciplinary concertation for spine problems (Art. 2 – section B/1. Multidisciplinary concertation).[58]

2.4.7.3 Health topics

- Mental health and psychiatric care

In 2015, the Superior Health Council (HGR – CSS) of Belgium provided an expert opinion on policy interventions for people with a dual diagnosis (intellectual disability and mental health problems) in Belgium.[59] The HGR – CSS notably mentioned that *“although networks are beginning to be set up to deal with dual diagnosis, the situation is not equivalent between regions (Brussels is particularly short of services). In addition to a structural offer of services in the mental health and disability sector which is not easily accessible for people with a dual diagnosis, there are also some projects initiated specifically for this population to address difficulties encountered in the field, but which are still isolated or of precarious status”* (translated from *Conseil Supérieur de la Santé* (2015), pp 32-33). To date, the recommendations of the HGR – CSS are not implemented.

A previous KCE report also pointed out this lack of response for those with a double diagnosis.[60]

Mental health care is under the regulation of the federated entities, operationalised – among others – in the mental health care networks.[61] There is no specific mention of an adapted offer for people with ID in the convention between the network and the RIZIV – INAMI: each network has the therapeutic freedom of planning an adapted offer for this target group.

- Speech therapy

The monodisciplinary speech therapy is under the regulation of the RIZIV – INAMI while the interdisciplinary speech therapy is under the regulation of the federated entities (regions or communities depending on the place of delivery). The nomenclature establishes the (clinical) conditions to be met in order to benefit from a reimbursement for speech therapy (see Art. 36 of the nomenclature for the details).

2.4.8 Comprehensibility

Comprehensibility refers to the extent to which the patients are aware of the reason for the intervention and the way in which the problem should be approached. Besides the quality of the communication between the professionals and the patients, two federal initiatives currently exist to improve comprehensibility: intercultural mediators and experts by experience.

Verrept & Coune define "*intercultural mediation as a set of activities that aim to reduce the negative consequences of language barriers, socio-cultural differences and tensions between ethnic groups in health care settings. The final purpose is to create health care services that are equally accessible and of equal quality (outcome, patient satisfaction, respect for the patient's rights, etc.) for [migrants and ethnic minorities] and 'indigenous' patients. Intercultural mediation tries to achieve this by improving communication and thus acting strategically on the relationship between the provider and the patient. In this way, the patient's position in particular, but also the provider's, is strengthened so that health care is better tailored to the patient's needs and the provider is able to provide efficient care*".[62] Intercultural mediation is available in general and psychiatric hospitals on site (in a selection of institutions) and per videoconference. Funded by the FPS Public Health, intercultural mediation is free and can be requested either by the patients or by the professionals. Alongside interpretation, intercultural mediators help to elicit health beliefs, cultural norms and values. When it comes to intellectual disability, it could help people with ID and the supporters with a migrant background to establish a positive relationship with the HCP. The communication skills of mediators are likely to contribute to the comprehensibility, especially as the mediators are used to communicate with people with comprehension problems due to linguistic and cultural aspects.

Experts by experience are coordinated by the Public Planning Service Social Integration (PPS Social Integration). Experts by experience are people who have experience of poverty and social exclusion, and who use this experience to improve the accessibility of services. They are integrated in different public services such as the RIZIV – INAMI and a selection of health services, including services of the mental health sector. But there is currently no expert by experience whose experience is living with an intellectual disability.[63] They could directly intervene with people with ID and their supporters but could also support HCP in their management of people with ID and their supporters.

2.5 Conclusion

Access to health care for people with ID is mainly addressed in a perspective of affordability, that is the financial access to health care. The health insurance has several (automatic) measures that will help to cover the (extra) costs of health care. In the other dimensions of access to health care, as described in the 7B framework, people with ID have, in general, access to the same services and benefits as other people covered by the national health insurance and under the same conditions. Extra benefits exist regarding dental care. Identified limitations apply to the place of health care delivery and are not specific to people with ID as they also apply for people living in psychiatric institutions or in nursing homes. The only limitation in coverage clearly stated in the nomenclature concerns benefits related to speech therapy.

This lack of difference between people covered by the national health insurance and people with ID could therefore give a false impression of an equitable and accessible system for people with ID. If the system is quite equitable because it ensures the same access for the same needs, it may lack equity as specific needs require specific responses. We can, for example, point out that the apparent lack of information on patient rights in an Easy Read language does not support equity. If mental health services or palliative outreaching teams are available for the Belgian population, there is no information whether they provide an offer adapted to people with ID. It can also be noted that the legal framework is lacking as far as the delegation of nursing acts in collective structures is concerned. In that sense, improving access to health care for people with ID requires improvement across the 7 dimensions of access, as these dimensions are in permanent interaction.

Besides, this description is theoretical and does not reflect how these measures are implemented. At practice level, personal experience of access of people with ID could vary from no access to preferential access, with extra support to care for the specific needs of people with ID. If the patients can choose their health professional under the 2002 Law on patients' rights, the professional can also "choose" their patients (except in emergencies). For example, a physiotherapist could decline a request for follow-up for a patient with a respiratory problem if he or she has specialised in sports physiotherapy, a general practitioner could refuse to take on an additional patient because his or her caseload exceeds his or her availability, a nurse could decline a request for home care for a child because he or she does not have the appropriate training, or a psychiatrist could decline a request for follow-up for a person who does not speak his or her own language. A professional who does not feel competent to provide care to a person with an intellectual disability is therefore entitled to decline the request for care if the professional organises the continuity of care. These discretionary decisions are therefore not officially documented although they may constitute a major barrier to access the existing services.

To our knowledge, there is currently no specific project at the RIZIV – INAMI aiming at improving access to health care for people with ID. However, as the 2022 budget does include transversal initiatives with a focus on care pathways and trajectories, this may constitute an opportunity for improving health quality of people with ID. The pluriannual budget trajectory may also lead to initiatives targeting this specific population[mm]. Several allocations of the budget target the prevention which is a clear request expressed in the study. The budget for “*Meer psychiatrische zorg, maar ook in somatische zorg voor jongeren met psychiatrische problemen*” could notably be used for youth with double diagnosis (ID and mental health diseases), and in the management of anxiety and challenging behaviour when accessing health care services. The support to “advance care planning” can also be beneficial to people with ID to improve the coherence around and their implication in their care, especially since the population of people with ID is ageing. The appropriate care section is also relevant to them: more physiotherapy in case of mobility restriction due to brain problem associated to the ID; involving the pharmacist in the daily management of treatment (adherence, side effect detection, overmedication avoidance); day-hospital for grouped care under sedation, including support to hospital for the accommodation of the accompanier; and support to transport and dental care, for example by giving incentive to dentist for expertise in dental care for people with ID (specialised training).

Some of these differences in health care access are illustrated in the Chapter 3 while solutions developed at local level to reduce the access problems are presented in the chapter 5.

[mm] See more on the RIZIV – INAMI website: https://www.riziv.fgov.be/nl/themas/financiering/Paginas/kick_off_uitgebreid_verzekeringscomite.aspx

3 CHAPTER 3: QUANTITATIVE ANALYSIS OF HEALTH CARE USE

3.1 Introduction

This chapter aims at analysing existing Belgian data related to health care use to highlight potential disparities between people with ID and people without ID.

A recent Canadian study[64] on the healthcare services utilization among people with and without ID showed that there were varying differences in health care utilization with some over- or underuse compared to the general population. For example, significantly more consultations in general medicine and psychiatry were reported for people with ID while the rate of physiotherapy consultations and consultations in optometry/ophthalmology was significantly lower in this group. Consultation rates in dentistry and psychology were in turn similar between both groups. Consequently, due to the heterogeneity within the groups of people with ID, stratified analyses are needed to indicate if severity of disability could influence the healthcare services utilization.

3.2 Data sources

There is currently no database nor registry to identify people with ID in Belgium, similarly to the situation in other countries.[31]

Health Interview Survey

The Belgian Health Interview Survey (HIS) provides an overall picture of the health status of the population and allows to identify the main health problems, as well as the social and behavioural factors that influence them. This information enables health authorities to pursue a proactive health policy aimed at improving public health and addressing the needs of groups at risk[nn]. However, although the HIS includes 2 questions on disability (cognitive and communication difficulties), these can only be linked to the identification of persons with intellectual disability in a very approximate way. In the 2018 version, only 22 people with severe or profound intellectual disability were included in a total sample of 10 000 participants. This proportion is well within 20% (proportion of people with ID with severe or profound disability) of 1% of the population (estimated percentage of people with intellectual disability in Western populations). The sample size is therefore insufficient for valid statistical analysis, meaning that the HIS could not be used to document the current health status of people with ID in Belgium. This is in line with the findings in the systematic review of Peterson-Besse et al. (2014)[65] : the lack of inclusion of people with intellectual disability in population-based surveys compared to other subgroups of people with disability, indicates that it is important in further research to examine disparities by level of disability and by disability type.

Linkage between existing databases

Contacts have been taken with the DG Persons with Disabilities of the FPS Social security to identify people with ID who claimed benefits or other forms of assistance. After filling in a form for the claim, a medical evaluation (among others) is carried out for persons claiming income replacement or integration allowances, or the acknowledgement of the disability. The medical doctors reviewing the claim can record a diagnosis based on the International Classification of Disease (ICD); this is not needed for a claim for additional familial allowances. Persons who were diagnosed an ICD-10-CM code of F70 – F79 (intellectual disabilities) or F84 (pervasive developmental disorders, e.g., autistic disorder) were identified as people with ID (without further information). Additional information on the recognition process is presented in chapter 2.

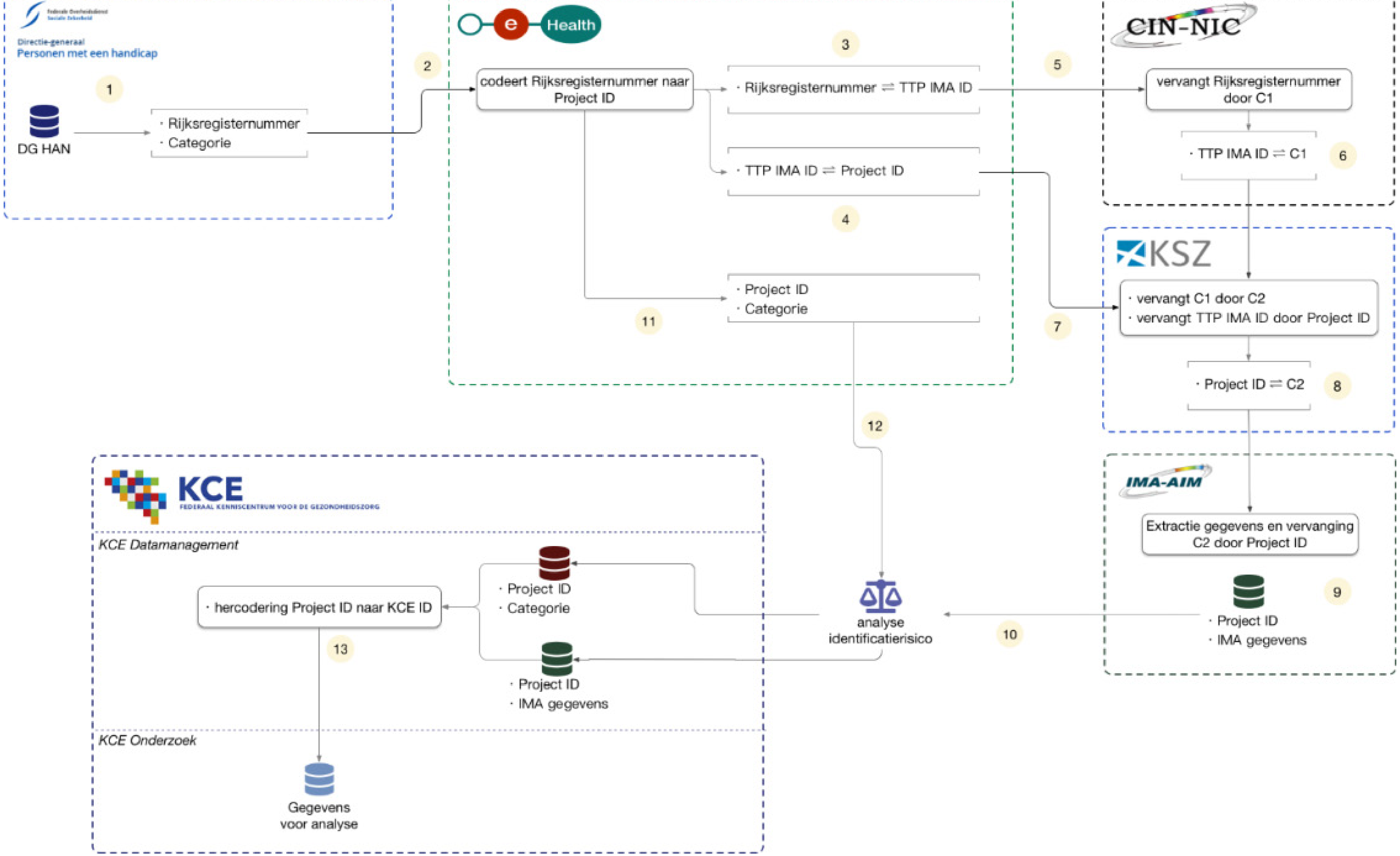
[nn] https://www.sciensano.be/en/projects/health-interview-survey

To estimate the health care use, we opted for the study of the administrative records of the reimbursed health expenditures for the years 2014 to 2019. These administrative data are available from the Intermutualistic Agency (IMA – AIM). IMA – AIM is a non-profit organisation that manages and analyses information on all reimbursements related to the compulsory health insurance, collected by the Belgian sickness funds on all insured citizens[oo]. These data cover all reimbursed services (consultations, pharmaceuticals, diagnostic and therapeutic procedures) and some patient socio-demographic characteristics as well as social security related data to the extent they influence reimbursement.

An authorisation of linkage of both databases from FPS Social security and IMA – AIM was requested at the Social Security and Health Chamber of the Information Security Committee (ISC). The authorisation was received on 9 November 2021. The linkage of both databases (see Figure 4) was managed by a trusted third-party (eHealth) and made available to KCE researchers on 5 October 2022.

[oo] See more on IMA – AIM here (in French or Dutch): https://www.ima-aim.be/

Figure 4 – Linkage procedure of data from FPS Social security and IMA – AIM



Details are available in the decision of the ISC (CSI/CSSS/21/432).

To compare people with ID's reimbursed health expenditures, two databases from IMA – AIM were used the *Échantillon Permanent – Permanente Steekproef* (EPS) and the IMA – AIM Atlas.

The purpose of the EPS is to provide a permanent access to a representative sample of the IMA – AIM data to Belgian federal and federated institutions, conditional on their missions[pp]. The EPS is composed of randomly drawn members of the Sickness Funds, stratified by age and gender, approximately 1 in 40 for members younger than 65, and 1 in 20 for members aged 65 and older. The purpose of the larger sample of the 65 years and older is to increase the precision for this group, which has relatively more health expenditures, and in whom the older age groups would otherwise become too small. The sample is longitudinal and contains data since 2002. Every year, an additional sampling like the original sampling compensates for members lost to follow-up due to decease or other reasons[qq]. The IMA – AIM Atlas is a database published by the IMA – AIM containing data about demographic and socioeconomic variables, health status, access to care, prevention, consumption and organisation of health care[rr].

3.3 Methods

Analyses have been focused on health services not linked to the people disabilities in order to be able to compare health access between people with ID and the Belgian population (or a representative sample of it, i.e., the EPS). The selected interventions concern prevention (cancer screening), contacts with health care practitioners, having a global medical record (GMD – DMG, *globaal medisch dossier – dossier médical global*) and diabetes follow-up.

The billing codes used from the EPS inferred to the population level have been compared to the number of cases (i.e., reimbursed health services for Belgium for a year) in the Documents N to check representativity.

The analysis is performed using SAS software™ (SAS/BASE, SAS/STAT and SAS/GRAPH), version 9.4 M5 for Microsoft Windows and Microsoft Excel.

3.4 Limitations

The persons identified as people with ID from the FPS Social security database may not be representative of the population with ID in Belgium as it only includes adults who have applied for a formal recognition of their handicap.

There is no diagnosis or information in the data describing their disability, level of impairment, activity limitation or participations restrictions: these data could influence the health needs and therefore may contribute to the explanation of differences in health care use. Moreover, these data do not include contextual and socioeconomic information such as household revenue or social deprivation index of the neighbourhood.

The place where they live (on their own, with their family, in an institution…) is unknown: as shown in the chapter 2, the place of residence is likely to influence the access to health care services and health care benefits. This could have been of added value of comparing the health care use by place of residence in order to identify more specific solutions. Therefore, the triangulation of data sources (see chapters 4 and 5) allow for a comprehensive overview of current needs and problems experienced in the different places of residence.

Reimbursed health expenditures do not cover all health care received, nor do they reflect the persons health (care) needs or experiences. There is no

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[pp] See also art. 278 of the Programme law (I) — 2002-12-24

[qq] Details on the EPS can be found on https://metadata.ima-aim.be/fr/app/bdds/Ps and on https://www.inami.fgov.be/fr/publications/Pages/echantillon-permanent.aspx.

[rr] The Atlas is available online at https://www.ima-aim.be/Atlas-AIM

centralised information about the expenses related to health care covered by the personal assistance budget (see Chapter 2).

These limitations, along with the selection bias (only persons who made a claim for benefits for income replacement or integration allowances, or the acknowledgement of the disability and whose diagnostic was recorded as ICD-10-CM code were included) means that the results presented in this chapter must be taken with caution. As suggested in Chapter 8, there is a need for improving the monitoring of the health care needs of people with ID.

The databases used to compare with the people with ID also have some biases than could not always be averted. The IMA – AIM Atlas covers the whole population (unlike the database for people with ID). The EPS has an oversampling of the 65+ population, while the database of people with ID contains very few persons aged 65 or over; this can be explained partly by the fact that some people with ID have a lower life expectancy due to their condition, but also because persons aged 65 or over cannot claim benefits for replacement income at the FPS Social security. People with ID were not excluded from these 2 databases, which will decrease the importance of a difference between the two arms.

3.5 Results

3.5.1 *People with ID demographics*

The database from FPS Social security identifies 17 155 persons with ID for the period 2014 to 2019. In population table of the IMA – AIM database, 17 090 of these persons were retrieved, and 17 072 had reimbursed health expenditures (health care or medication). This is far below the expected figures for Belgium (in the range of 1%, which would be above 100 000 citizens).

The age and gender distribution are represented for the first and last available years in Figure 5

. There are no persons aged under 15; the median age is 21 (IQR=16) in 2014 and 26 (IQR=15) in 2019. The difference can be explained by the fact that persons aged 18-21 years persons claiming benefits ask for additional familial allowances, for which no diagnosis (ICD-10 code) is required, meaning that none of these persons cannot be identified as persons with ID.[ss] The proportion of women is 39.3% in 2014 and 39.5% in 2019. The median age is younger than expected for the persons with ID population: this is due to the fact that diagnosis (ICD-10 codes) have been recorded only since 2013 (with a gradual implementation of the medical expertises).

By comparison, the EPS distribution is shown Figure 6. The oversampling of 65 years old and over is obvious. The median age is 49 (IQR=42) in 2014 and 50 (IQR=43) in 2019. The proportion of women is 53.0 in 2014 and 52.6 in 2019.

[ss] Persons aged just above 21 in 2019 claiming of income replacement or integration allowances or the acknowledgement of the disability will get a diagnosis, and thus can be identified as persons with ID. Their health expenditures will be available from the start of the studied period (2014), when they were 5 years younger (and thus in the 15-19 age category, see the left graph of Figure 5).

Figure 5 – Population pyramid for people with ID in 2014 (left) and 2019 (right)

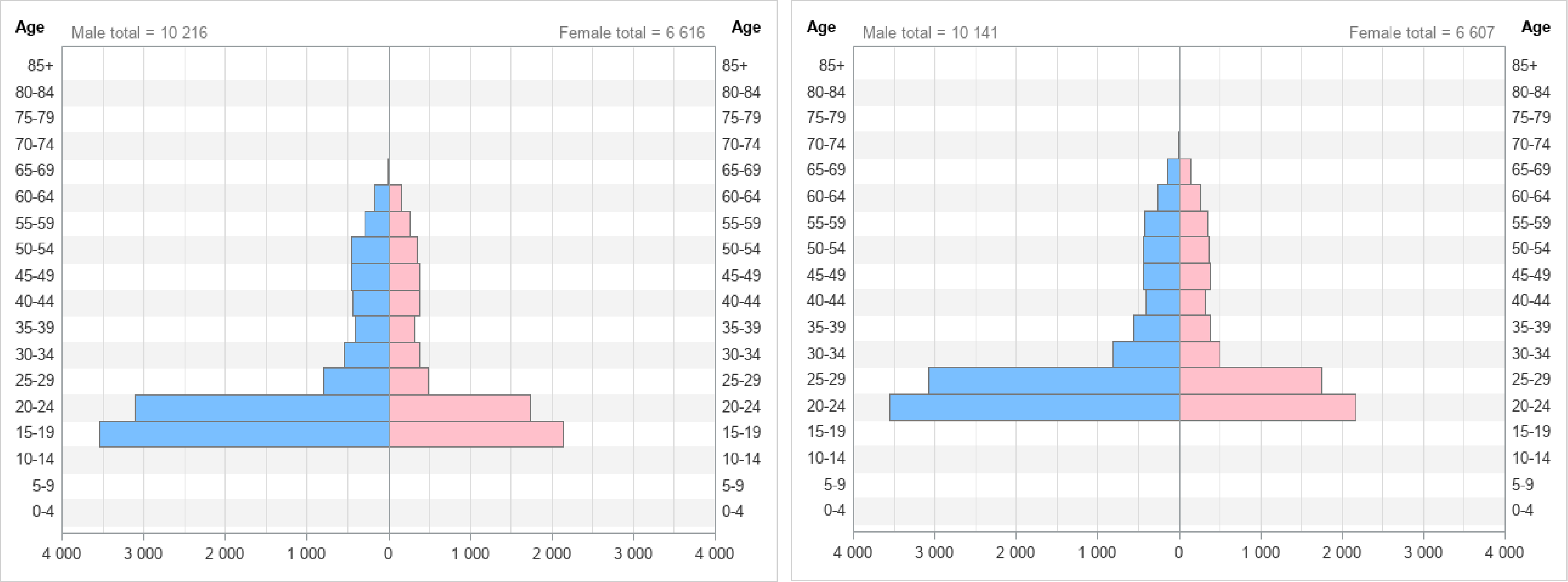
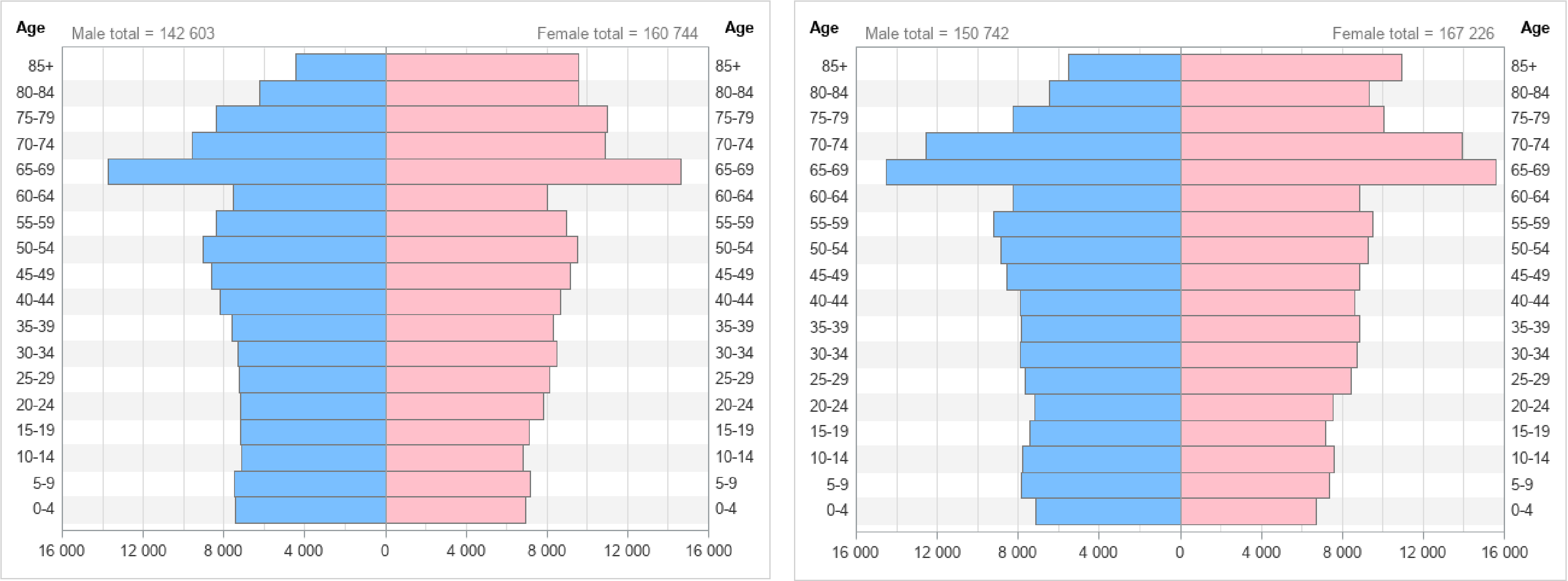


Figure 6 – Population pyramid for EPS in 2014 (left) and in 2019 (right)



3.5.2 *Breast cancer screening*

Women aged 50 to 69 years are invited to take a breast cancer screening every two years through an organised programme started in 2001 in Belgium, the screening programme meets with mixed success (far from reaching the target European target of 75%[66]), especially in Brussels capital region and Wallonia[tt]. Therefore, to better capture the actual coverage, diagnostic examination is often also included. Figure 7 shows a small difference of screening coverage between people with ID and the general population (26.8% and 32.2% in 2019, respectively), while Figure 8 shows a larger difference for women who had a mammography, being within the screening programme or via a diagnostic examination (42.6% for the people with ID and 59.7% for the general population in 2019).

This relative lower participation rate to breast cancer screening in people with ID, compared to the general population, is in line with the results found in the quick scan of the literature. For example, an analysis of the UK primary care database[67] (from over 450 general practices) on the access to cancer screening (breast, cervix, bowel and prostate) comparing people with and without ID showed significant lower rates of recorded screening tests for all four cancers in people with ID. GPs were more likely to exclude patients with ID from being eligible for cancer screening, and in particular in cervical cancer screening (see next section). However, after exclusion of these patients from the main analysis, the differences in participation rate to screening programmes persisted. According to the authors of the study, it could also be possible that patients do not receive appropriate information that encourages them to be screened for cancer, or that they choose not to be screened even if they do receive such information. In a sub-analysis of the study, the authors examined the effect of social deprivation of a geographical area, with the underlying hypothesis that people living in more deprived areas may receive less care. However, the findings show the contrary: the screening rates were not more pronounced in areas of greater social deprivation. A possible explanation could be, according to the authors, that services in more deprived areas are more acclimatised to providing care for hard-to-reach groups. This kind of analysis could not be performed in our analysis, but should be taken into consideration in further research on the access to screening programmes for people with ID.

A scoping review of Peterson-Besse et al., 2014[65] identified 13 studies in which breast cancer screening was examined. Disability severity was found as a potential disparity factor, with the directionality of findings that more severe disability was related to lower clinical preventive service utilisation (including mammography and/or clinical breast exam).

The systematic review of Byrnes et al., 2020[68] on attitudes and perceptions of people with learning disability towards cancer screening programmes in the UK (see Chapter 4 for more details on the results of this review) mentioned in the introduction following data on participation rate to breast cancer screening: NHS digital showed that in 2015 44% of people with ID aged 50-54 years received breast cancer screening. This number is far below the national targets, as stipulated by the UK National Screening Committee, with 70% for breast cancer screening. Also, the Confidential Inquiry into premature deaths of people with ID identified that cancer was one of the most common underlying causes of death, with the uptake of cancer screening differing from that of the general population.

[tt] see IMA – AIM reports: in French or in Dutch.

Figure 7 – Breast cancer screening programme coverage

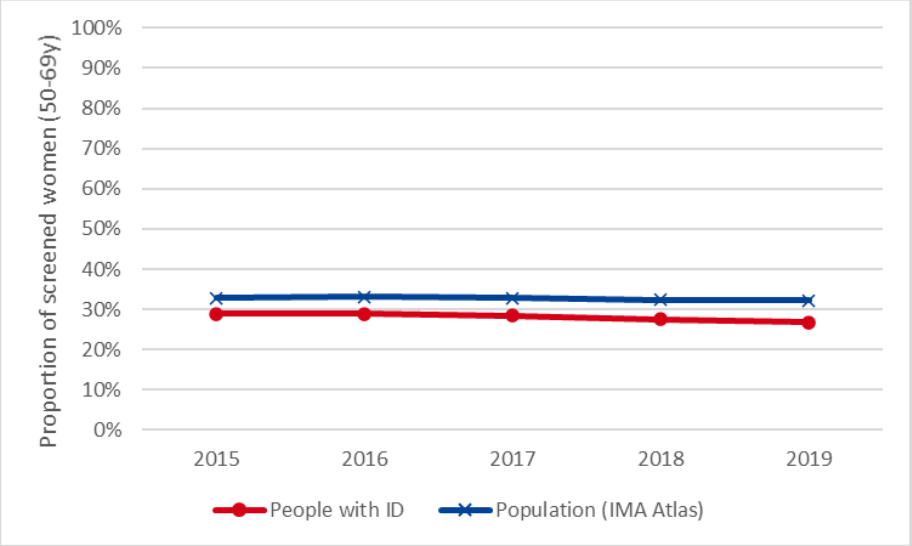
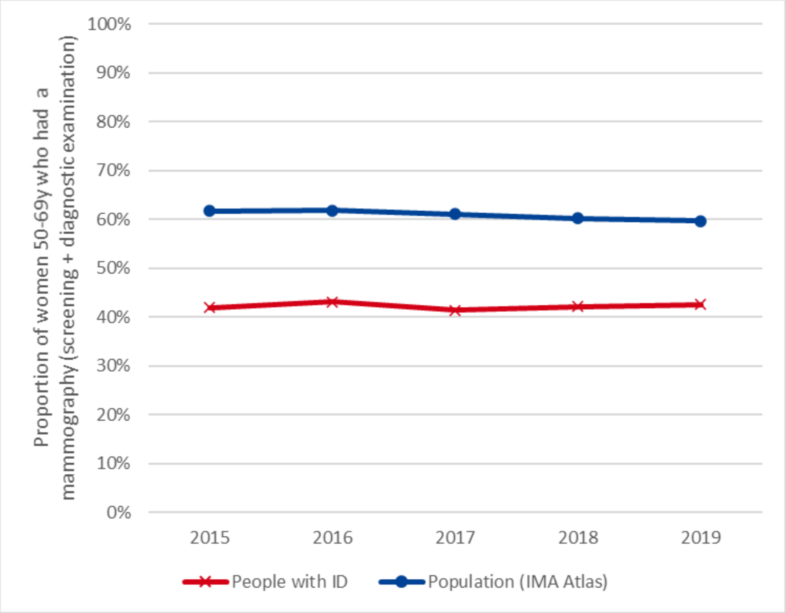


Figure 8 – Breast cancer screening programme or diagnostic examination coverage



3.5.3 *Cervical cancer screening*

While there is no cervical cancer screening programme organised in Belgium, women aged 25 to 64 years old are advised to get screened every 3 years.[uu] Figure 9 shows a gap in the coverage between women with ID (14.9% in 2019, last available year) and the general population (24.8% in 2019). The coverage of both populations has been decreasing slowly in the last years: when comparing the results for 2017 to those of 2008, the coverage has decreased from 25% in Wallonia and from 29% in Brussels. These figures come from a 2019 IMA – AIM report (in French and in Dutch),

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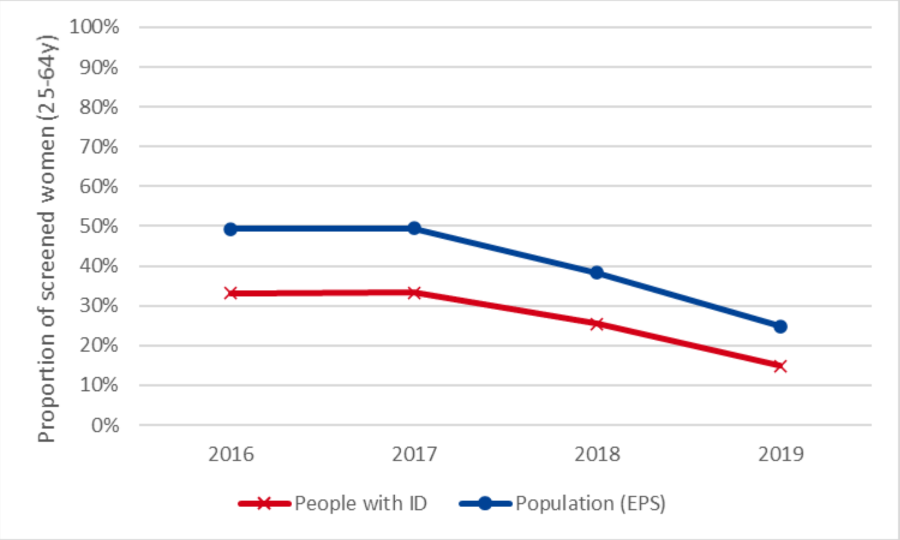
[uu] See the current recommendations here: https://www.cancer.be/les-cancers-types-de-cancers-liste-z-cancer-du-col-de-lut-rus/examens

where more analyses (by age group and socio-economic status) and explanations over the Belgian coverage historic context for the general population are provided.

The above-mentioned study of Osborn et al, 2012[67] showed a difference in recorded screening tests in people with and without learning disability, including a lower rate of cervical cancer screening tests in people with ID. The most common reasons for not participating to a screening programme, as recorded in the notes made by the GP, were refusal or being deemed inappropriate for screening. Even after excluding these patients from the main analysis, the difference in cervical screening rates persisted (unadjusted IRR=0.55, 95%CI; 0.53-0.57).

In the UK, the NHS organises, among other cancer screening programmes, a screening programme for the early identification of cervical cancer (a smear test every 3 years for women aged 25-49 years and every 5 years for women aged 50-64 years), with a national target of 80% uptake. NHS data show however (according to the references cited by Byrnes, 2020[68]) a much lower participation rate (in 2015, 24,8% of people with ID aged 55-64 years, received their cervical cancer screening). These data should be interpreted with caution, due to the different age group in the comparison, and the lack of information of the participation rate in the general population.

Figure 9 – Cervical cancer screening coverage



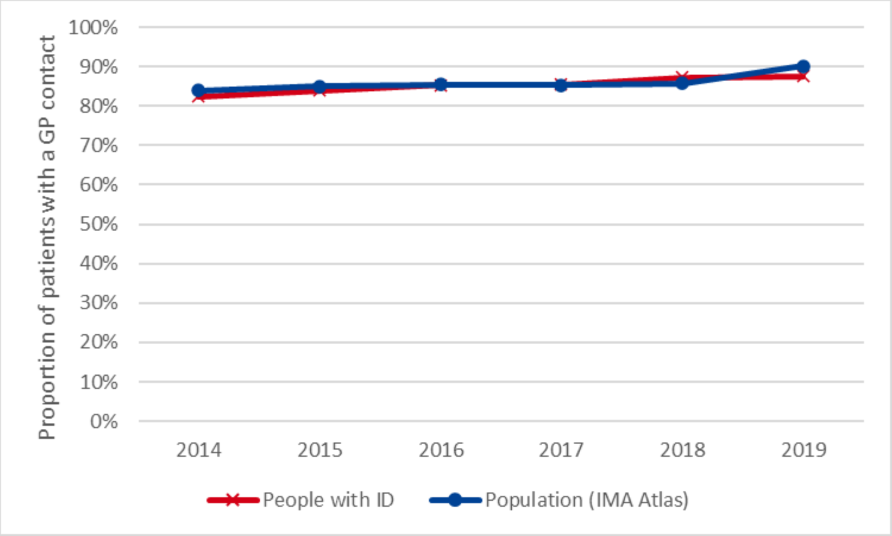
3.5.4 Contact with a general practitioner

Most of the population has at least one contact with a general practitioner (GP); people with ID are no exception, with 87.5% of them having a contact with a GP in 2019 (vs 90.1% for the general population), as illustrated in Figure 10.

Analysis of Belgian data on healthcare utilisation in people with and without (all types of) disabilities[69], showed that a similar percentage of people was found with at least one medical act recorded in the 7-yr observation period, however differences were found in the place of care: people without disabilities were more seen at the GP's office whereas people with disabilities were more visited at home by the GP. Also, more visits per individual were recorded in the subgroup of people with disabilities. A similar trend was found concerning visits to medical specialist: more people with disabilities consulted a medical specialist and a more frequent number of consultations were recorded. Also, the number of people and the number of emergency medical care provided by the GP was higher in individuals with disabilities compared to the subgroup of people without disabilities. No differences were found in emergency consultations with the medical specialist between both subgroups. However, these results should be taken with care as there is no distinction of the type of disabilities: people with severe physical disabilities such as a neurological problem may have more comorbidities than a person with a low intellectual disability. Similarly, there is no indication that the consultations with specialists are part of the regular health care.

A similar study was performed in Belgian children with and without (all types of) disabilities[70] and a higher rate of healthcare utilization was found in the subgroup of children with disabilities: more children with disabilities had a registered contact with a physician (in at least 4 of 7 observation years), also the rate of 3 or more home visits was higher in children with disabilities, a higher proportion of children with disabilities was seen by a medical specialist and a higher rate of 3 or more consultations with a medical specialist were recorded. Similar tendency was noticed for emergency consultations with the GP and emergency specialist care. Same precautions are needed in interpreting these results as there is no distinction according to the type of disability or the degree of severity.

Figure 10 – Contact with GP over the year

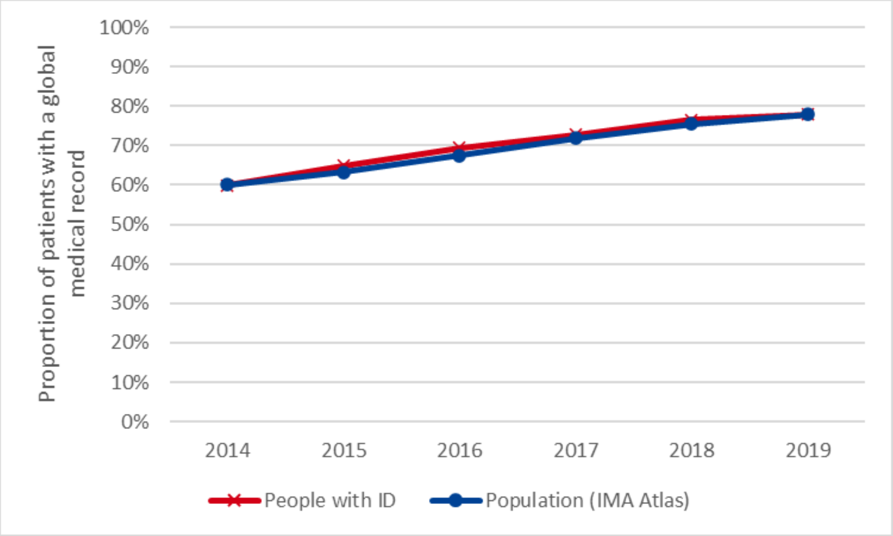


3.5.5 Global medical record

To increase information sharing between health care practitioners, people are advised to open a global medical record (*GMD – DMG, globaal medisch dossier - dossier médical global*) in order to increase the quality and the efficiency of care.[71] There is no difference between people with ID and the general population (see Figure 11), both have a coverage of 78% in 2019.[vv] In absence of additional variables, we cannot distinguish these results according to the place of residence or to the region, as there is a different approach regarding the application of the GMD – DMG in Flanders and Wallonia.

[vv] In the general population, the coverage is lower for 0-14 year old and higher for the 65 years old and over (there are no persons aged under 15 and very few aged over 65 in the people with ID database); broken down figures by age category are available online in the IMA – AIM Atlas.

Figure 11 – Global Medical Record



3.5.6 *Contact with a dentist*

Follow-up of dental health care has been measured by the proportion of the population having at least one contact with a dentist in two separate years over 3 years, i.e., for 2019, a person with at least a contact in 2017 and 2018, 2017 and 2019 or 2018 and 2019 is considered as followed up. People with ID are visiting the dentist less often than the general population as show on Figure 12 (49.8% vs 65.8% in 2019[ww]).

A Belgian study on oral healthcare utilisation in adults with all types of disabilities (Leroy et al, 2013)[69] compared the number of contacts with a dentist to people without disabilities. Although about 90% had at least one contact with a dentist during the 7 observation years in both groups, less than half of them had regular contacts with a dentist (which was defined as at least one dental visit registered in at least four of the seven observation years); furthermore, in both groups, about half of the individuals contacted a dentist at least once a year, the differences between both groups are observed in more specific care visits. For example, over the seven observation years, emergency oral health care was recorded in about half of both subgroups, but the number of emergency visits per individual was much higher in the subgroup with disabilities. A similar result was found in the consultations with an oral surgeon: significantly more adults with disabilities consulted this specialist. However, radiographs were significantly more frequently taken in the subgroup without disabilities. The authors mentioned that taking radiographs can be extremely difficult in some groups of individuals with disabilities. They may be afraid of the apparatus or find it difficult to hold the application tool for intra-oral radiographs or find it difficult to sit still during exposure. The authors emphasise that this may result in an increased risk for undiscovered oral pathology or in the contrary the premature extraction of some teeth due to poor clinical appearance while radiographic images might have sustained their preservation.

A similar study was performed on oral healthcare utilisation in children (Leroy et al, 2013)[70] and similar results were found compared to the study on adults with and without disabilities: a similar low number of children (approximately half of the children) had a regular contact with a dentist (defined as at least one dental visit registered in at least four of the seven observation years), but the number of emergency visits were higher in children with disabilities. This could indicate, according to the authors, that some children with disabilities were only taken to the dentist because they needed urgent dental care. Like the adults, radiographs were more frequently attested in the subgroup of children without disabilities. Similar reasons to explain the potential underuse of radiographs in children with disabilities were cited by the authors (fear, difficulty to hold still).

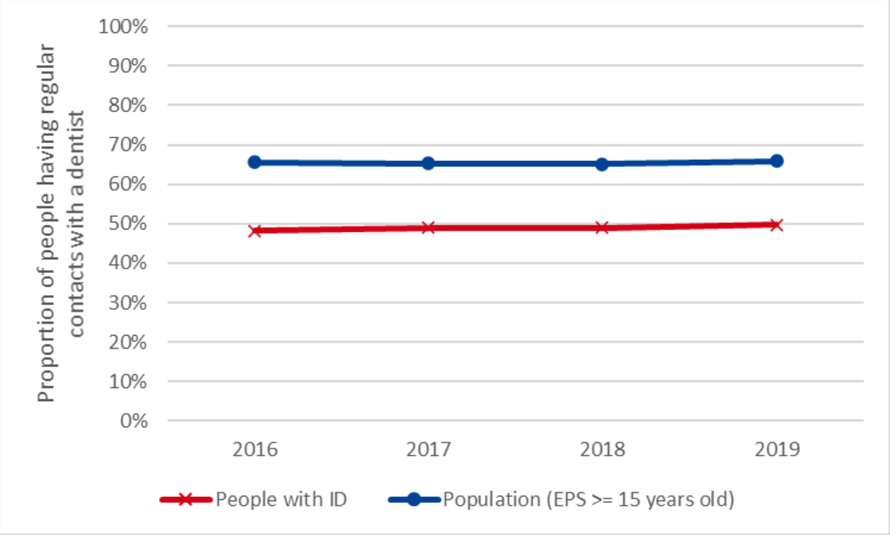
[ww] The proportion observed is higher in the EPS than in the IMA – AIM Atlas (available online) because for the EPS, persons aged under 15 have been excluded for a better comparability.

These two Belgian studies indicate a difference in oral health utilisation between people with and without disabilities; however, further analysis is needed in different subgroups, such as people with ID.

A systematic review of Ward et al, 2019[72] on oral health of adults with ID, concluded that the poor oral health remains a high burden and that there is a need to raise awareness, and for policies on effective daily oral care and appropriate service provision. Similar results were found, as cited in the Belgian studies and our analysis, on the lower dental care utilisation and poorer oral health status in people with ID. Also, a poor quality of life was associated with oral disease. Comparing the residential settings, a poorer oral health was reported in adults with ID living in an institution compared to adults living in a community-based setting. In this review, the authors point out in the discussion section on the association between periodontitis with cardiovascular disease, coronary heart disease, diabetes mellitus, respiratory diseases and obesity (in the general population). However, the prevalence of these systemic diseases is already elevated in adults with ID, and so periodontitis could be a higher burden in this group. This interrelationship between oral and systemic disease may create greater oral health inequalities for adults with ID.

The analysis of Gilbertson et al, 2019[73] on the use of different preventive care services in children with fragile X syndrome, showed some particular results: on the first sight no difference was found in children with and without ID who had seen a dentist at least once a year (75% in children with ID compared to (studies citing a range of data) 52-81% of all children with special health care needs. However, the authors argued that their finding was still in line with previously published results, which showed that dental care was the most common unmet healthcare need): biannual visits are recommended as a preventive measure, and while the individuals in their cohort are visiting the dentist at least annually, they may not be attending every 6 months or seeking preventive care services.

Figure 12 – Regular contact with a dentist

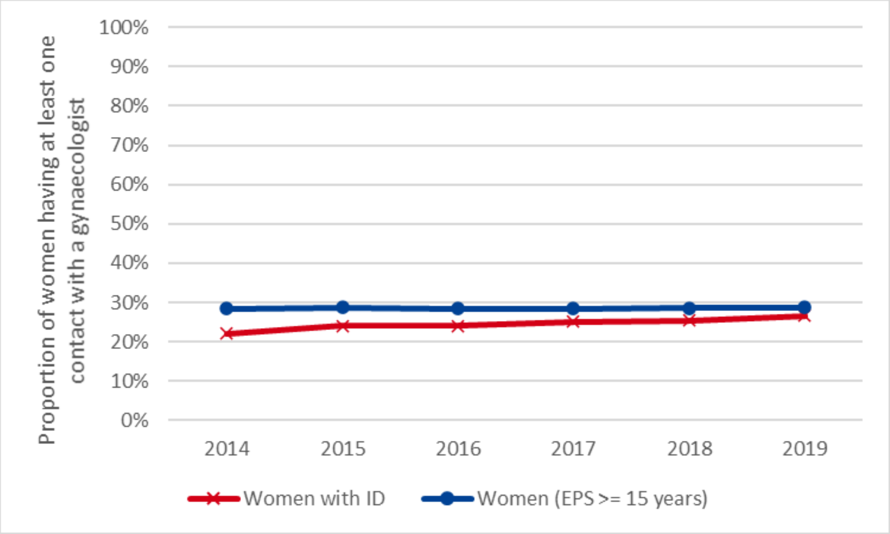


Some dentists services in the nomenclature of health are aimed at persons with disabilities[74]. Very few people with ID from the database from FPS Social security made use of them: between 2.5% in 2014 and 3.3% in 2019. When looking over the period 2014-2019, 7.4% of the people with ID had at least such a service billed.

3.5.7 Contact with a gynaecologist

There is a difference in the proportion of women who have at least a contact with a gynaecologist per year between people with ID and women from the population, but the gap shrinks over time (see Figure 13): from 6.4 percentage points in 2014 to 2.0 in 2019.

Figure 13 – Contact with a gynaecologist

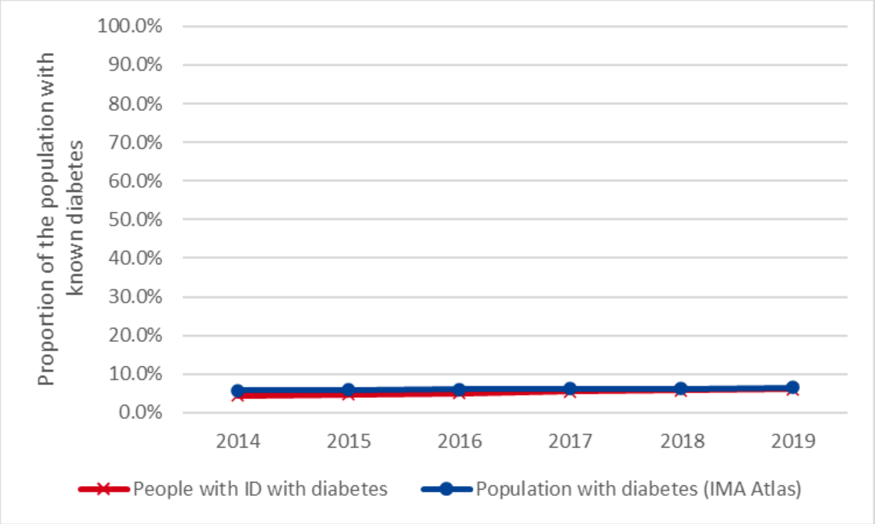


3.5.8 Diabetes

A recent meta-analysis[75] on the prevalence of diabetes in people with ID demonstrated that people with ID are at an increased risk of diabetes (compared to the general population) and therefore routine screening and multidisciplinary management of diabetes is needed. The authors emphasised in the discussion about the retrieved results that people with ID should be considered as a high-risk population that needs proactive screening for diabetes (screening should begin as early as 30 years of age). No significant gender difference was found in the prevalence of diabetes, however other differences were found: the prevalence was higher in people diagnosed with Prader-Willi Syndrome (and therefore regular evaluation of glucose levels and glycosylated haemoglobin is recommended in this subgroup). The higher morbidity in people with ID is associated to a combination of lifestyle factors (e.g., smoking), social determinants of health and discrimination or other barriers in accessing health services; all these factors could have a greater impact as people with ID age.

In the data, we identified people as diabetic if they were prescribed medication to treat diabetes (ATC2=A10) or if they had adhered to a convention, programme or care pathway for a given year. People with ID do not present a higher proportion of patients treated for diabetes with medication than the general population as illustrated in Figure 14 (in 2019, 6.1% for the people with ID vs 6.5% for the general population).

Figure 14 – Proportion of population treated with diabetes medication



To improve the follow-up of patients with diabetes, RIZIV – INAMI has instituted several measures, among them conventions, programmes and care pathways. Also, an indicator to monitor the follow-up based on medical guidelines has been set up and is available in the IMA – AIM Atlas. This indicator measures whether the patient has the following 5 tests each year:

- at least two records of HbA1c measurements during the year
- at least a record of serum creatinine measurement during the year (with a 3-month grace period: 12 months of year y + the first 3 months of y+1)
- at least one record of microalbuminuria (with a 3-month grace period)
- at least a contact with an ophthalmologist (with a 3-month grace period)
- at least one record of lipid profile (with a 3-month grace period)

Indicators for diabetic patients are measured separately for patients treated by insulin and patients (aged 50 years and over) treated by oral medication. Figure 15 and Figure 16 show diabetic patients with a convention, programme or care pathway: people with ID have a greater proportion of patients enrolled that the general population for patients treated with insulin, and there is no difference for patients treated orally.

Figure 15 – Diabetic patients treated with insulin with a convention, programme or care pathway

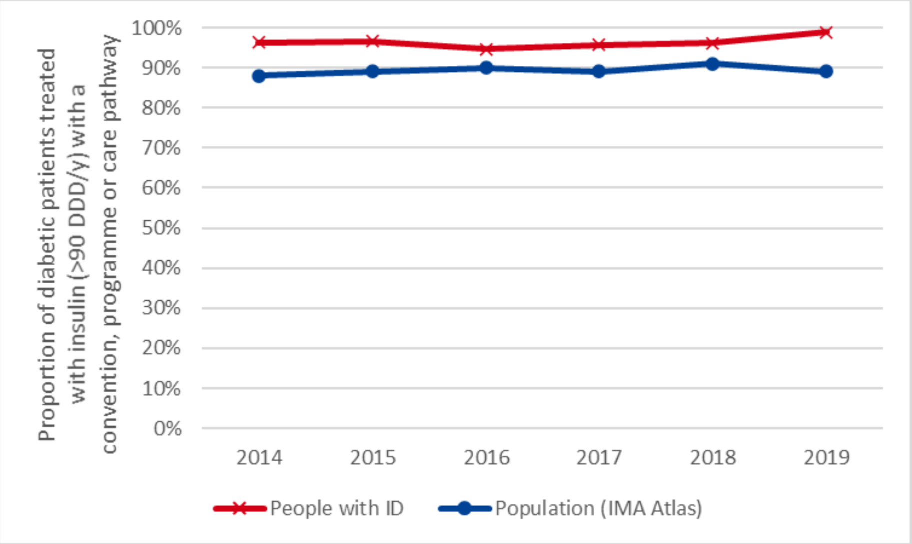
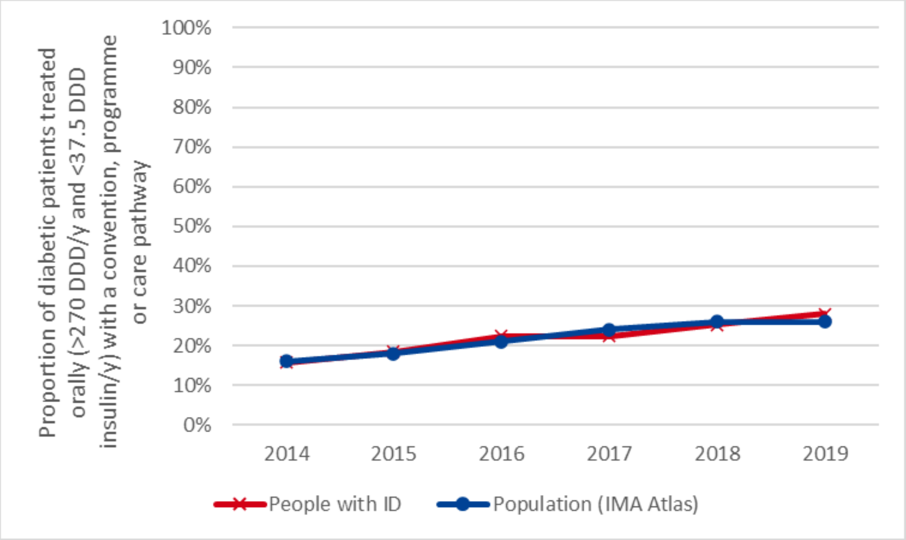
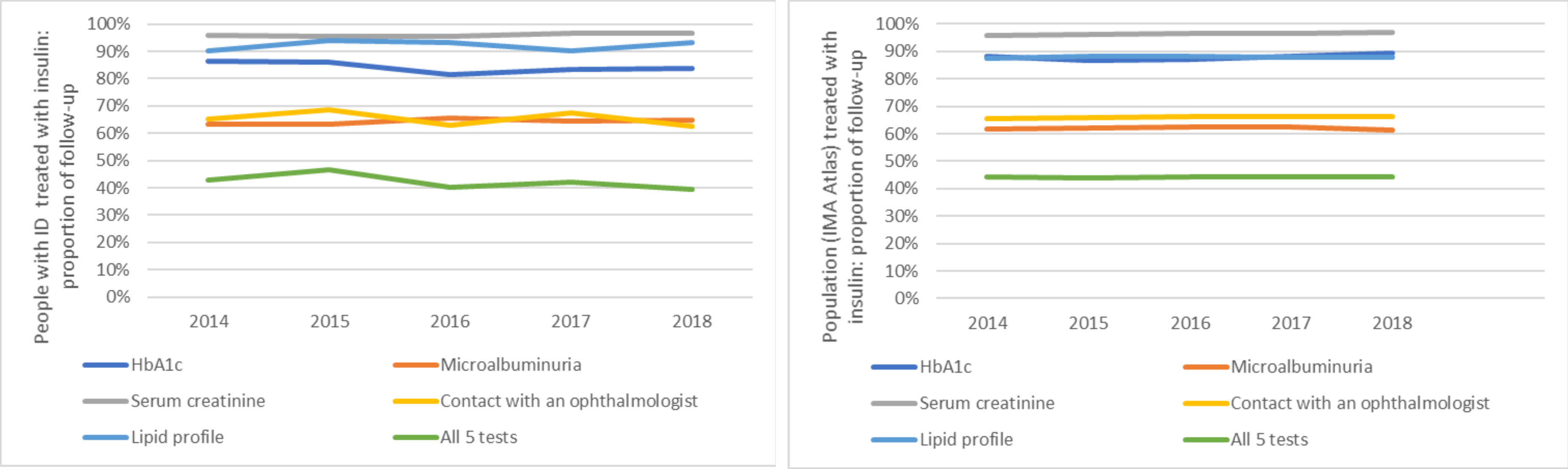


Figure 16 – Diabetic patients (aged 50 and over) treated with oral medication with a convention, programme or care pathway



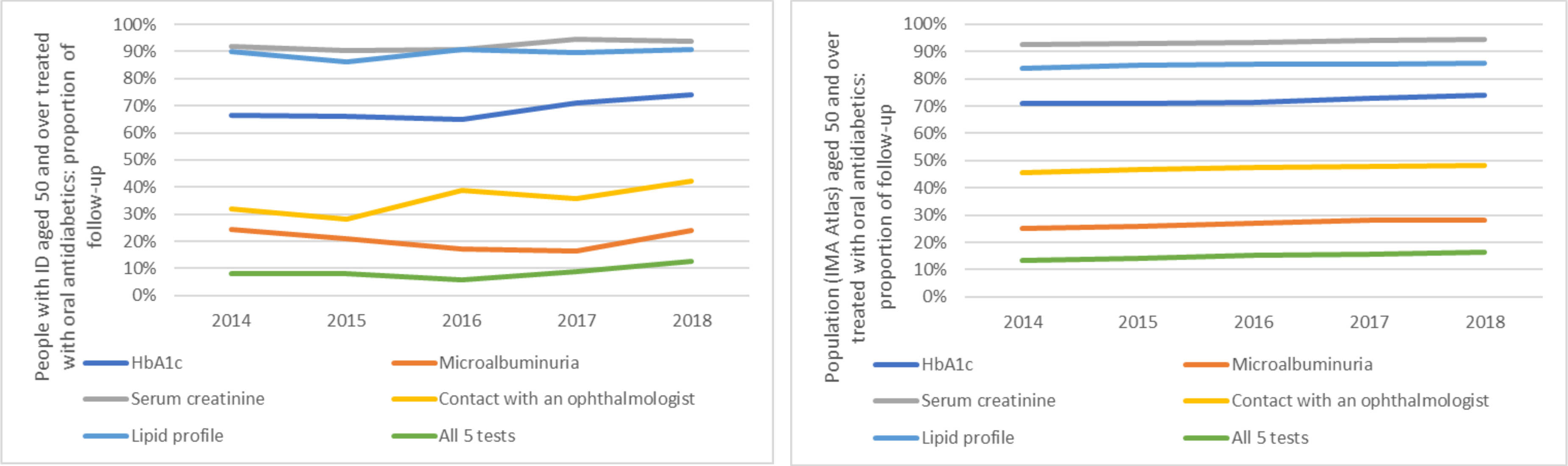
The follow-up of patients measured by the five tests is at the same level for patients treated with insulin between people with ID and the population (IMA Atlas) as shown in Figure 17: around 40-45% of the diabetic patients get the 5 tests each year.

Figure 17 – Follow-up of diabetic patients treated with insulin: people with ID (left) and population (IMA Atlas, right)



For the diabetic patients treated with oral medication 50 years old and over, the proportion of patients getting the five tests each year is smaller, and a bit lower for people with ID compared to the general population (12.9% vs 16.3% in 2019).

Figure 18 – Follow-up of diabetic patients (50 years old and over) treated with oral medication: people with ID (left) and population (IMA Atlas, right)



3.6 Conclusion on data analysis

Although possible selection bias of the people with ID dataset and the possible difference in population structure between the people with ID and the datasets taken to represent the population (EPS or IMA – AIM Atlas), there is a trend in access to reimbursed health services: people with ID tend to have a lower access to services than the general population, except for contact with a GP, GMD coverage and diabetes follow-up.

Further efforts are needed to obtain an accurate and up-to-date overview of health care use and health care needs of people with handicap. This overview should also include contextual variables, such as the place of residence, and socioeconomic variables in order to better adapt the responses of the health care system to people with ID.

4 CHAPTER 4: INTERNATIONAL LITERATURE SCAN ON BARRIERS AND FACILITATORS

4.1 Introduction

4.1.1 Theoretical considerations

Researchers can study determinants to understand why disparities exist in access, receipt, use, quality, or outcomes of health care.[76] Barriers and facilitators are such determinants.[77] Factors are considered as barriers if they impede implementation of, or adherence to a defined action, in general, or to a guideline, in a medical context[78] while factors are considered as facilitators if their presence promotes the implementation of, or adherence to this action or guideline.[78] It is possible to act on barriers to solve them. Any action which can solve a difficulty or unravel a complex situation can be called 'solution'. The goal of this chapter is to identify barriers and facilitators to health care access for people with ID. Findings of the literature scan about solutions are presented in the Chapter 6 which summarises data retrieved by different research methods including the literature scan.

4.1.2 Methods

A quick scan of scientific and grey literature was performed in March and April 2021, with an update in March 2022. The aim was double: first to give a global overview on barriers and facilitators and second to identify barriers in three specific health contexts: cancer screening programme (prevention), dental care (chronic care) and emergency care (acute care). The focus was put on findings in foreign countries.

Although the grey literature search aims to retrieve only data on access to health care for people with ID and not with any disability, some reports on people with disability in general were used for their content on people with ID (see Box 8). The search focuses on summary of evidence to get the global overview.

The starting key words for the grey literature search in Google were: 'access to health care', 'people with intellectual disability' and 'barrier or obstacle or facilitator or enabler or solution'. Then a snowballing strategy was adopted. Main keywords for the search in scientific literature (in Medline database) were: 'intellectual disability', 'developmental disability', keywords for pathologies associated with intellectual disability such as 'Down syndrome' or 'Rett syndrome', 'health services accessibility', and 'healthcare utilization'. Selection of studies was based on following exclusion criteria: studies only reporting data on the differences in health status (e.g., prevalence of comorbidities), studies with focus on physical and/or sensory disabilities, studies performed in developing countries, studies on access to assistive products, and studies performed before 1990. The aim of the search in scientific literature was to found studies reporting perceived barriers and facilitators by the persons with ID, their supporters and the professional health caregivers, related to three particular care situations (cancer screening, dental care and emergency care), therefore studies on access to other care services were excluded. The choice for these three care situations was made on comparability with the general population: the three situations are situations that a person without ID could probably also encounter. The barriers found in the selected studies are analysed per target user, i.e., the person with ID, his supporter and the professional health caregiver who is (often) not experienced in the provision of care to a person with ID.

Studies only reporting quantitative data on differences in access of care between persons with ID and the general population were used as background information for the chapter on Belgian data on access to care.

4.1.3 Limitations

The analysis of the grey literature showed that public health organisations mainly addressed the issue of access to health care for all people with any types of disability. Only few works focused on the sub-population of people with ID. For example, the WHO, the CDC and the *Institut de Recherche et Documentation en Economie de la Santé* (IRDES) have all published global reports on the health of people with any kind of disability.[8, 32, 79, 80] This global approach aims to not categorise people with disability through the medical aspect and thus to avoid further stigmatising one type of disability over another. Only a few organisations specialising in the care and support of people with ID specifically published on this sub-population and were identified in this quick grey literature scan: Specials Olympics (supported by CDC) and Public Health England. Consequently, opinions and online publications of university experts like Ruth Northway (University of South Wales) were also integrated in this overview.

Only an overview of the international literature was planned and led. When a summary of evidence was available, the information was directly extracted from the review or the report without reading the primary source on which the document was based. The reason is that the researchers decided to devote the time available mainly to collecting qualitative data from Belgian stakeholders (see next chapters) rather than conducting an exhaustive literature search. To avoid uncomplete referencing, the primary source used by reviews' authors were yet cited in this work as second referencing.

Internal discussions on the scope lead to the decision that this chapter will focus on health care and not on well-being. So, although we are plenty aware that well-being is the best base of a good health, this project wants to specifically deal with the practice of the health care providers as defined by the FPS Public Health: doctors, nurses, physiotherapists, clinical psychologists, nurse auxiliaries, dentists, pharmacists and midwives.[81]

Some methodological aspects were also found as a limitation in the analysis of the quick scan of the literature. As explained in the methods section, the researchers made the choice for a quick scan of literature with less certainty to comprehend all published studies related to the topic. This could be obtained with a more systematic review of literature, but in the scope of this report the choice was made to focus on the qualitative approach within the Belgian context (see following chapters). Within the retrieved studies, authors reported quantitative comparative data between people with ID and the general population, but without reasoning how these differences in access to care could be explained. Not many studies were found in which people with ID were interviewed on their perspective. Also, the choice for three specific care situations, excluded studies reporting barriers related to other types of care services. The three care situations are more intended as illustrations of care situations, and not as representative for all types of barriers encountered by persons with ID.

Also some elements hampered the ability to generalise the retrieved findings to the Belgian context, such as variety in definitions of intellectual disability, limited study designs (e.g. focus groups with only community nurses instead of a variety of HCPs), and restricted explanation of the reasoning behind the perceived barriers. Across the retrieved studies, no clear, harmonised definition could be identified. Even within the reviews, the authors mentioned the variety in applied definitions in the primary studies, including multiple levels of disability. In the majority of the retrieved studies, no differentiation was made in severity of the disability. Also in most studies a mix of disabilities was included and compared to each other. This was out-of-scope for this project, in which the focus was on people with intellectual disability.

In order to overcome these limitations, the choice was made in this project to organise consultation rounds with professionals from disability services and with people with intellectual disability (and their supporters).

4.2 Results

The retrieved literature sources by the quick scan and related to the different types of barriers are listed in Box 8. The literature results on the three health services (cancer screening, dental care and emergency care) are presented in the following related sections in this chapter.

Box 8 – Identified sources on barriers in grey literature

Identified sources in grey literature on barriers concerning people with any disabilities

WHO – World report on disability – 2011[8]

WHO – Fact sheet : Disability and Health– 2021[32]

CDC – Common barriers to participation experienced by people with disabilities – 2020[79]

CDC – Disability and health state programs - 2021[82]

IRDES – l'accès aux soins et à la prévention des personnes en situation de handicap – 2020[80]

ANESM – Qualité de vie : Handicap, les problèmes somatiques et les phénomènes douloureux - 2017[83]

Identified sources in grey literature on barriers concerning people with ID

CDC – CDC and Special Olympics : Inclusive Health – 2021[33]

CDC and Special Olympics – Health Disparities for People with Intellectual Disabilitie [25]

Specials Olympics – Inclusive Health Principles and Strategies: How to make your Practices Inclusive of People with Intellectual Disabilities[24]

Special Olympics – Healthy Communities[84]

Public Health England - Population screening: reducing inequalities for people with a learning disability, autism or both - 2021[85]

Ruth Northway, University of South Wales – Equality and Equity of Access to Healthcare for People with Intellectual Disabilities - 2017[31]

4.2.1 Different types of barriers

People with ID can be healthy but experience significant barriers to access the health care and public health system.[2] Organisations involved in the health of people with ID have classified those barriers into categories to help professionals involved in health policies and laws, programming, services, training programmes, research, and funding, making their practices inclusive for people with ID.

On the one hand, the US CDC identified the following categories of barriers experienced by people with disabilities (all types and not only people with ID): attitudinal, related to communication, physical, related to policy, programmatic, social and related to transportation.[79]

On the other hand, Special Olympics identified quite similar categories for people with ID. Some examples are given to illustrate each category: Attitudinal barriers; communication barriers; policy barriers; programmatic barriers; social barriers; and physical barriers.[24]

Based on these two categorisations and data on categories by experts such as Northway from United Kingdom[31] and Paignon from Switzerland [86], an adapted categorisation of the barriers was developed to be used in this report. So, a category on knowledge and skill barriers was added to the category proposed by CDC and SO. The policy and social barriers were merged into a single category. And finally, the category “physical barriers” was included in the category “programmatic barriers” as both are mainly related to structure and organisation constraints. The retrieved data were organised according to this adapted categorisation. The content of this chapter follows this categorisation.

4.2.1.1 Attitudinal barriers

Attitudinal barriers consist in stigma, stereotypes and misconceptions about people with disability and is reflected in the negative attitude of HCP and health services staff towards people with ID and their supporters (Pelleboer-Gunnink et al. (2017) cited by Northway, 2017) . The following misconceptions are given as examples:

> *“People with ID are psychiatric patients”*[86]
>
> *“People with ID do not understand anything”* [24]
>
> *“People with ID cannot improve their health”*[24]

Those misconceptions can lead to negative consequences like missed diagnostic or treatment (physical problems viewed as a part of the intellectual impairment, or certain treatment options not offered to people with ID), denied healthcare admission, and HCP and staff members not listening to some people with ID and supporters explanations.[31] Another consequence can be to admit people with ID in closed psychiatric wards instead of somatic wards.[86] Even if those discriminations can be unconscious[31], or related to fear amongst HCP and staff, people with ID can still be denied access to quality healthcare. Those negative attitudes often originated in or are reinforced by a lack of awareness of what ID means and what are the specific needs of people with ID, inducing amongst HCP and staff a feeling of helplessness.[86]

In return, people with ID and their supporters are also concerned by stereotypes against HCP and staff. People with ID and their supporters may present negative attitudes like avoidance or reluctance to health care, in particular when they have experienced previously lack of respect, pain related to health care or bad treatment.[8]

4.2.1.2 Communication barriers

Communication barriers can vary according to the different protagonists involved: HCP and people with ID and their supporters, and HCP between each other.

The use of complicated or technical language with long sentences or dense forms or words with many syllables represents the main communication barrier between a HCP and a person with ID.[31] For example, people with ID may not be aware of certain treatment options because they receive an explanation in a way that cannot be understood. Medical communication tools (folders, posters, etc.) may also not be adequate.

The lack of interpersonal skills of HCP is another barrier which leads to insufficient and unclear communication, such as a lack of active listening which induces that accompaniers must repeat over again the same info about the people with ID they care for.[31, 86]. Also too limited available time is a component explaining the insufficient communication between HCP and people with ID and their supporters, inducing notably a lack of discharge instructions about treatment and diagnostic[8].

Another main communication barrier quite common on the overall health care system concerns the lack of communication between HCP. But in the case of people with ID, communication between HCP takes even more importance.[86] Hogg et al. (2001) state that access of people with ID to primary health care provision may be restricted by lack of pertinent information on the medical history of the individual.[87]

4.2.1.3 Knowledge and skill barriers

Knowledge and skills barriers concern all protagonists: the HCP, the supporters and the people with ID.

HCP usually do not know the clinical signs specific to people with ID, their specific health care needs and what disability is and leads to. Hogg et al. (2001) report that the access of people with ID to primary health care provision may be restricted by lack of training on intellectual disability itself or lack of training on health issues relative to older persons with ID.[87] In particular, HCP lack skills to care for people with ID with behaviours viewed as challenging: they interpret those behaviours like symptoms of psychiatric disease instead of somatic symptoms and/or pain.[86] Some HCP even avoid to perform clinical exams of people with ID by fear of mistakes or by powerless feeling related to lack of knowledge. All those issues lead to underdiagnosis of somatic issues, insufficient pain medications and inappropriate health care delivery. This can even include that non trained supporters are asked to perform basic health care (feeding, bathing, etc.) or even medical acts (removing stitches, making bandages or administrating medication).[86].

The lack of knowledge also concerns the information about the supports and services specialised in ID issues and the understanding of the legal requirements on consent.[31] Hogg et al. (2001) state that access of persons with intellectual disability to primary health care provision may also be restricted by lack of understanding on the physicians part concerning informed consent issues.[87]

According to Northway (2017), the lack of knowledge of HCP is partly explained by the insufficient research on the (health) needs of people with ID, including the lack of specific data. For example, people with ID are absent from many public health surveys.[31] Also the lack of time for HCP devoted to training during the working hours is a programmatic issue directly leading to lack of knowledge and skills of HCP about ID.[86]

People with ID and their supporters lack skills and knowledge to recognise the health problems and to communicate it to HCP. It is frequent that people with ID think they are not sick enough to ask for help and care. Once the problem is acknowledged, people with ID can express differently their healthcare needs to their supporters, which can delay the use of health care. Finally, people with ID and their supporters do not always know where to go to find help and care. [88]

4.2.1.4 Programmatic barriers

Programmatic barriers are multiple and directly related to organisational aspects inside organisations like implementation of reasonable adjustments or healthcare coordination. The best example of programmatic barriers is the perceived inflexible appointment scheduling system. Fixed slot of time for appointment (e.g. 20 minutes/slot) prevents the HCP to adapt the time spending with the patient according to the needs, leading to insufficient time for good care delivery to people with ID.[31]

The absence of pathway adapted to people with ID, or simply the lack of availability of services or professionals specialised in ID issues within the usual care organisation, are other programmatic barriers encountered in the current health care system.[31] Hogg et al. (2001) state that access of persons with intellectual disability to primary health care provision may be restricted by the absence of an ID specialized professional in back-up for complex medical conditions, notably when difficulties appear in undertaking medical examination because of communication problems or behaviour perceived as challenging.[87]

The programmatic barriers already emerge outside health care organisation when transport is not available to health care services or orientation signage in doorways are not adapted.[8, 31]

4.2.1.5 Social and policy barriers

Policy barriers arise from lack of laws and regulations requiring equitable access at every health programme, for example, the absence of law regulating the financing for extra time required during medical appointment with people with ID.[31] But not only the need for new laws is pointed out; also the lack of enforcement of existing laws or official documents is of concern. One example is the denial by organisations to set up reasonable adjustments.[31]

Social barriers faced by people with ID are directly related to the impact of social determinants of health like the lack of financial resources with no reimbursement of the extra time appointment cost required for comprehensive healthcare[8]) or no money to afford the transport to come to the consultation.[8]. In addition, the financial resources of the supporters is also important as people with ID are often reliant to upon a third party both to recognise signs of ill health and to go to consultation but the supporters cannot easily take time-off[31].

The lack of time is a barrier caused by many determinants which have in common that they could be solved by political decisions. Lack of time prevents HCP to understand and cope with the complex situation of people with ID.[8]. Barriers to health care access in specific contexts

A (non-exhaustive) search in scientific literature revealed different types of barriers perceived by people with ID, their supporters and/or the HCP in three selected contexts. e.g., cancer screening programme, dental visit and emergency care. The barriers are described per actor (person with ID, supporters and HCP).

4.2.2 Barriers to specific services and programmes

4.2.2.1 Access to cancer screening programmes

International and Belgian data show a difference in cancer screening rate between women with and without ID to the detriment of women with ID (also see Chapter 3: Quantitative analysis of health care use). In the analysis, no specific differentiation was made between the different procedures within a screening programme, for example the clinical breast exam and the mammogram in the breast screening programme, and the Pap test and pelvic exam in the cervical cancer screening programme.

Table 3 gives an overview of the selected studies on access to cancer screening programs.

Table 3 – Key Characteristics of studies related to access to cancer screening programs

References	Study design	Health intervention	Definition of people with ID	Main findings related to the perceived barriers
Taggart et al., 2011[89]	Focus groups (n=6) with community nurses (n=29) and residential staff (n=16)	Breast screening service in North Ireland	No definition was given on women with intellectual disability	Deficit of knowledge by the participants on risk factors for breast cancer Lack of access to 'user-friendly literature' to support the women with ID Lack of knowledge about (the need for) breast screening by women with ID, as a result of poor literacy skills, limited communication skills and level of understanding Negative emotions, attitudes: fear of undressing, fear and anxiety, discomfort and pain, overall stressful experience Physical barriers: practical considerations, additional health problems Lack of importance given to the need for breast examination (by supporters): not a priority, taboo subject Lack of health promotion and education on societal level: lack of advertising, importance and literature in relation to breast screening for women with ID
Barr et al., 2008[90]	Focus groups (n=6) with women with sensory, physical, psychiatric and cognitive/intellectual impairments (n=42)	Mammography screening in USA	Noninstitutionalized women who self-reported one or more disabilities, aged 40-69y, resided in Connecticut. Within the 6 disability-specific focus groups: a cognitive/intellectual group, living independently and a cognitive/intellectual group, living in group homes were identified.	Physical access Beliefs about vulnerability: worry about family history of breast cancer, not understanding mammography procedures and seeing oneself in a weak position when encountering the health care system (expressed by women with cognitive disability living independently) Lack of social support: women with cognitive disabilities living in group homes perceived that staff responsible for their medical appointments reacted negatively to taking them for these visits Physical discomfort and pain: lack of sensitivity by facility staff
Watts et al., 2008[91]	Literature review	Cervical screening in English published studies	Search terms included women with learning disabilities and women with mental handicap. No further definition was given.	Administrative errors: not being invited Not registered with a GP Assumptions made about women with learning disabilities: 'learning disability' as reason for GPs to remove women from the screening list even though they are eligible for screening due to target payment for the GP and judgements made about their disability and not about them

References	Study design	Health intervention	Definition of people with ID	Main findings related to the perceived barriers
				as women (thinking women are not sexually active), underestimation of increased vulnerability to sexual abuse Perceived (by the GPs) difficulties in obtaining consent due to communication issues or the main carer makes the decision for the woman they care for Attitudes of carers (due to lack of knowledge about cervical screening): misbeliefs that women are not sexually active, that women would not understand the procedure of the smear test and that cervical screening was perceived uncomfortable and unnecessary for women they cared for Beliefs and experiences of women themselves: anxiety, embarrassment (even more if test was performed by male clinician) and pain associated with the test, previous negative medical experiences, lack of understanding about the purpose of the test Lack of accessible information: unlikely to understand the invitation/results letter Physical difficulties: when getting on the examination table, or muscle spasms or pain
Byrnes et al. 2020[68]	Literature review	Cancer screening programmes in the UK	People with a learning disability: someone who has a significant reduced ability to understand new or complex information to learn new skills, with a reduced ability to cope independently, which started before adulthood, with a lasting effect on development (Department of Health, 2001)	Lack of support to attend screening: trying to make a balanced decision between benefits of screening and likelihood of distress, making decisions on behalf of persons with learning disabilities without discussing with them Lack of supportive attitude by screening staff: use of inappropriate language and mannerisms, lack of encouragement Lack of awareness of screening in women with learning disabilities: lack of understanding about the procedure, its importance and potential consequences of not attending, not able to understand the information in the invitation letter Feelings of anxiety and fear throughout the screening programme: fear of the unknown Experiences of pain during and after screening Professional practice barriers: doubts by the care professionals if screening is beneficial or appropriate for

References	Study design	Health intervention	Definition of people with ID	Main findings related to the perceived barriers
				persons with learning disabilities, misbeliefs that cervical screening is not required due to lower level of risk (misbelief that women are not sexually active)
McIlfatric et al. 2011[92]	Focus group (n=1) and telephone interviews (n=14) with healthcare professionals (primary healthcare staff n=8 and breast care staff n= 10)	Breast cancer screening in North Ireland	Women with intellectual disabilities: no further definition was given	Lack of knowledge and awareness of breast cancer and breast screening by women with ID: lack of ability to self-examine, lack of awareness and understanding of breast care and prevention, poor literacy skills to understand the invitation letter and general poor attendance for screening Lack of support to women with ID due to lack of health promotion and provision education and support Barriers related to personal aspects of women with ID: cognitive deficits, communication issues and level of understanding, mobility and physical health, inability to give consent for the screening procedure and subsequent treatment Barriers attributed to carers: lack of carer support, carer attitudes (not considering screening appropriate or as a priority) Practical barriers: transport, timing of appointment Barriers attributed to healthcare professionals: attitude and (lack of) experience of working with ID, GPs as gatekeepers to access breast screening services
Swaine et al. 2013[93]	Narrative review	Breast and cervical cancer screening	Women with intellectual disabilities: no further definition was given	Barriers related to screening: lack of knowledge of needed health screenings, unprepared for exams, experience of anxiety about receiving exams, reliance on caregivers (women with ID who live with family caregivers are much less likely to receive screening compared to women who lived independently or in residential care facilities) Increased risk for sexual abuse: women who have experienced rape or molestation are likely to be more fearful of exams or procedures Lack of training or knowledge by physicians and health care staff Pejorative attitudes: incorrectly assuming women are not sexually active, caregivers decline screenings that are recommended by a physician

References	Study design	Health intervention	Definition of people with ID	Main findings related to the perceived barriers
Swaine et al. 2013[94]	Semi-structured interviews with female familial caregivers (n= 32)	Cervical and breast cancer screening in USA	Women with intellectual disability: no further definition was given	Caregivers' belief about unnecessity of breast exam History of sexual abuse Not feeling comfortable with breast exam due to lack of explanation on the procedure, male doctors and unfamiliarity with the doctor, generally shy or embarrassed about being touched Discomfort of the mammogram Misbelief by caregivers that women with ID were not sexually active Not feeling comfortable with cervical screening: lack of explanation on the procedure, lack of presence of caregiver in the room, general embarrassment or shyness with private nature of the exam, women's lack of sexual experience Organisational barriers: problems with Medicaid coverage
Merten et al. 2015[88]	Literature review	Cancer screening	No definition was given	Colorectal screening: behavioural disorders, inadequate staff training and low medicalization Breast screening: insufficiently trained health care providers and low primary care attendance, no referral or invitation for screening, lack of understanding, fear and physical limitations, urban residency, being single, severity of disability, lack of information, misunderstanding screening process, embarrassment, having a guardian, no health coordination, not prepared for mammogram logistics and poor understanding of rationale Cervical screening: being single, being younger than age 35, not having tubal ligitation surgery, physician confidence, lengthy screening process, insufficient reminder system, low demand, perceived difficulty using appointment system, not understanding health care system, poor liaison with specialists, inadequate physician communication, physician discomfort, lack of assistance, communication difficulties

Barriers reported by people with ID

- Lack of knowledge about the need for health screenings

  Poor literacy skills of women with ID combined with limited communication skills and level of understanding often leads to a limited knowledge about (breast) cancer and the need for regularly undertaking self-examinations and going for breast screening. The awareness of the need for screening could only be achieved by informing the person on the procedure and the understanding of cancer screening.[89] The invitation process through individual invitation letters requires the ability to read and understand the information within and to make an appointment for screening.[89] Also difficulties using an appointment system or an insufficient reminder system were reported.

- Unpreparedness for exams

  The lack of familiarity of some people with ID with the screening procedure was perceived as an important barrier for participation to a screening programme.[89] HCP mentioned also behavioural disorders as one of the barriers to cancer screening.

  An adequate preparation of the woman with ID prior to the exam was reported as one of the most common facilitators of successful cancer screenings.[89] An example of preparation is to achieve a certain degree of familarity with the screening environment and the equipment used. Also access to 'user-friendly literature' will support the women with ID.[89]

- Beliefs about vulnerability

  Women with ID living independently reported worries about a family history of breast cancer, not understanding mammography procedures and seeing oneself in a vulnerable position when encountering the health-care system.[88, 90] The causes of this perceived vulnerable position were not further examined by the authors, therefor it is difficult to fully understand and link potential solutions to this barrier.

- Experience anxiety, fear or discomfort during exams

  Their psychophysical experiences, such as feelings of anxiety and fear throughout the screening programme ('fear of the unknown') and the experiences of pain during and after screening, make the women with ID feel uncomfortable during the procedure.[89, 90] Family caregivers reported that lack of explanation of the procedure, a male doctor and lack of familiarity with the doctor, were the main reasons why women felt uncomfortable with breast exams. Also women who were generally shy or embarrassed about being touched or to undress, perceived those exams more uncomfortable.[89] Previous negative medical experiences were also reported as a barrier to (cervical) cancer screening uptake.[91]

  Additional health-related problems, such as physical disabilities or co-existing mental health conditions were reported as barriers to refuse to attend for breast screening.[89]

  Family caregivers explained also that discomfort during the pelvic exam/Pap test was because of the women's lack of sexual experience (being intimate with anyone).[94] These experiences of anxiety or pain can be more outspoken in victims of sexual assault. As women with ID are at higher risk to experience rape or molestation, their history of sexual abuse can negatively affect the participation to a physical exam, especially the Pap test (in cervical cancer screening).

  Family caregivers reported also the need for anti-anxiety medications or sedatives to tolerate the exam.

- Reliance on caregivers

  People with ID often rely on family caregivers to schedule, coordinate, and accompany them to the medical appointments. This reliance might affect the participation rate to screening programmes: women who live with family caregivers are much less likely to receive recommended screenings as compared with women who live independently or in residential care facilities.[93] Another study mentioned the lack of social support, illustrated by the example that women with cognitive disabilities living in group homes perceived that staff responsible for their medical appointments reacted negatively to taking them for these visits.[90]

- Physical inaccessibility

  Both women living independently or in a group home reported that the participation to a screening programme depends also on the physical access, e.g. transportation barriers, navigating towards and in the care facility, etc.[90] In the UK, registration with a GP is required, so if a woman with ID is not registered with a GP, she might not be invited to a screening programme.[91] This is often the case in women living in a residential setting which has a unit doctor, so there is no need for registration with a local GP. It would be the responsibility of the staff in the residential care setting to ensure the registration with a GP and that eligible women are placed on the invitation (and recall) list.

- Inability to give consent for the procedure (and consequent treatment)

  From a healthcare professional perspective, the issue of (not) being able to give consent was identified as a barrier for making decisions around breast cancer screening, for example how do professionals advise someone with ID to consent and, if they cannot, who will consent for them.[92]

Barriers reported by the supporters

- Caregiver's belief that exams are unnecessary

  A common reason for nonreceipt of Pap/pelvic exams was the women's lack of sexual activity and therefore the family caregivers believed it was unnecessary to put their family member with ID disability through the cervical cancer screening procedure.[91] Women with ID living in a group home perceived that the staff responsible for their medical appointments sometimes reacted negatively to taking them for these visits.[90] Also the need for breast screening is often not seen as a priority by the supporters. In some families the participation to such screening programs, could even be a taboo subject.[89]

  Also the misbelief that women with ID who underwent a (partial) hysterectomy, do not need further Pap test, was commonly reported.

- Presence of family caregivers not allowed during the exam

  Caregivers emphased the importance of being in the same room with the participant during the exam and stated that they would not allow an exam outside of their presence. Family caregivers reported that their presence in the room calmed the participant.

- Feeling uncomfortable with the exam

  The own (negative) experiences of the family caregivers influence their decision about the necessity of these exams for their family member with ID.[91]

Barriers reported by the HCP

- Lack of training or knowledge related to ID

  This lack of or inadequate training or knowledge could even lead to detrimental attitudes about people with ID.[88, 89]

  Next to lack of knowledge about the disability itself, the lack of a positive and encouraging environment for screening could hamper the participation to a screening program. For example, using appropriate language and attitude, or providing encouragement improve the experience of people with ID.

- Misbeliefs

  Incorrectly assuming that women with ID are not sexually active, could result in not recommending Pap tests for those women.[91] Also GPs perceived diffciulties in obtaining consent due to communication issues with the person with ID or in other cases that the main carer takes the decisions for the woman they care for.[91]

- The GP as gatekeeper

  In the UK, lists of women who are about to be invited are send to the GP: they are the ones deciding if the women with ID should be invited for screening or not. ID is sometimes considered as a reason to remove women from the screening list even though they are eligible to participate to the screening program.[91] Some of the persons with ID are however not registered with a GP.[91] However, this gatekeeping system was also considered as a facilitator since the GPs know the people with ID and their family well and it may be appropriate for them to indicate that they are not eligible for breast cancer screening.[92]

- Gender of the health care professional

  The feeling of embarrassment by the person with ID was reported to be more present if the procedure of cervical cancer screening was carried out by a male clinician.[94]

- Lack of health promotion and education

  According to focus groups with community nurses and residential staff, no (or too little) attention is given to health promotion and education in daily life of people with ID.[89]

Barriers not mentioned

Barr et al. (2008) compared the barriers to participation in mammography in different groups of women with disabilities (physical, psychiatric, vision, hearing, ID living independently and ID living in group homes). Women in the ID groups mentioned the fewest subthemes (withing the four themes of access, beliefs, social support, and comfort/accommodation). Economic access barriers, scepticism about the screening programme, or stress or burden of thinking about, arranging for and having a mammogram were not mentioned.

4.2.2.2 Access to dental care

Recent Belgian data show an underuse of dental health services in children and adults, resulting in poor oral health. Comparison in access to dental health services between people with and without ID show an even lower utilisation rate of these services by people with ID (see Chapter 3: Quantitative analysis of health care use).

Next to the more common barriers across different care services (as mostly described in the section on cancer screening, and not summarised in this section), more specific barriers related to dental health services were reported across the retrieved studies.[95-97] Table 4 presents the key characteristics of studies related to access to dental care included in this study.

Table 4 – Key Characteristics of studies related to access to dental care

References	Study design	Health intervention	Definition of people with ID	Main findings related to the perceived barriers
Gerreth and Borysewicz-Lewicka et al., 2016[95]	Questionnaire survey among parents/caregivers of children with ID (n= 264)	Dental care in special-care schoolchildren with ID in Poland	Children with disability: students, aged 6-18y, attending eight special-care schools in Poznan (Poland). The information about the degree of child's disability (mild, moderate, severe and profound) was taken from school documentation.	Long waiting time Dentist reluctant to treat the child (more common in group of children with severe and profound and moderate ID) Lack of information where child can be treated by dentist High costs of dental services Inconvenient opening hours of the dental office Location of dental surgery too far from place of residence (more common in children with severe and profound ID) Architectural limitations in dental surgery (more common in children with severe and profound ID) Timing of subsequent visit was not fixed and discontinuation of treatment (more common in children with severe and profound ID)
Chadwick et al., 2018[96]	Questionnaire survey among adults with ID and their caregivers (n=372)	Daily oral and dental care among adults with ID in the UK	Adults with intellectual disabilities: the degree of ID was gathered from clinically held record.	Cognitive factors: lack of knowledge or understanding how to brush their teeth appropriately and maintain their oral health, negative attitude towards toothbrushing, inadequate brushing (and too short), being easily distracted, forgetting to clean their teeth (more common in people with ID who were more independent or living alone) Physical and sensory factors: physical impairments affecting manual dexterity and physical functioning, sensory problems (not liking to be touched around their faces), sensory impairments (visual impairment), oral health problems interfering with oral care and making toothbrushing more difficult and distressing (e.g., loose teeth, ulcers, dry mouth), cranio-facial and oral tone differences (high muscle tone, dysphagia) Behavioural factors: obstructive or uncooperative behaviour (e.g., grinding their teeth, shutting their mouth, not permitting others to support them), aggressive, self-injurious and socially inappropriate

References	Study design	Health intervention	Definition of people with ID	Main findings related to the perceived barriers
				behaviours (e.g., screaming), behaviours attributed to ongoing mental health problems Affective factors (alongside behavioural issues): person's mood, lack of motivation (sometimes accompanied by mention of poor general personal care and hygiene), fear and anxiety, disliked daily oral care Lifestyle factors: smoking, diet, eating sugary foods, regular use of medication Lack of caregiver support: lack of interpersonal and observational support strategies (e.g. prompting, distraction, encouragement, rewards, etc), lack of direct support to carry out the oral care routine, lack of familiarity with the person, not having sufficient time to support oral care, misbeliefs and concerns (e.g. brushing bleeding gums would hurt the person, concern that person would become aggressive), reluctancy due to negative prior experiences, lack of advice and support how to support someone Insufficient equipment and adaptations: type of toothbrush used (co-occurrence with oral sensitivity), reluctancy to use toothpaste or mouthwash to avoid swallowing it Lack of individualized oral care routine: not incorporated in a person's daily routine, lack of a supportive location, influence of caregiver's body language
Ummer-Christian et al., 2018[97]	Literature review	Dental services in children with ID	Children with intellectual and developmental disabilities: ID often co-occurs with many other forms of developmental disability, in particular autism and cerebral palsy, therefore intellectual and developmental disabilities was a key search term to identify the population.	Barriers related to accessibility: transportation issues, structural barriers (long distance between home and dental office), physical inaccessibility of dental clinics, poor parking facilities Barriers related to availability: lack of awareness with carers failing to see oral health as priority, limited access to oral health information appropriate for persons with ID, limited access to information about available services, payment options and urgent care, difficulty locating dental practitioners who were willing to treat a person with ID, lower offer of dental practitioners in non-metropolitan cities

References	Study design	Health intervention	Definition of people with ID	Main findings related to the perceived barriers
				Barriers related to accommodation: long waiting periods for making an appointment, long waiting time in the clinic, lengthy appointments, appointment schedules do not fit in family routine, insufficiency of treatment facilities (lack of equipment, failure to provide special modifications (e.g., sedation)), lack of scheduling next subsequent appointment by dental practitioners with discontinuation of treatment Barriers related to affordability: financial constraints for the carer, unwillingness of dental practitioners to accept the children's insurance, refusal of dental practitioners to see children with ID even if they are being enrolled in government funded programs, no reimbursement for dental practitioners for their additional time managing children with ID Barriers related to acceptability: lack of knowledge, attitudes and skills of dental practitioners, dental staff apprehensive about assessing children with ID, dental practitioners report themselves inadequacies in their knowledge, training and exposure to treating children with ID Barriers related to appropriateness: fear of the dental practitioners, dental chair, equipment noise, communication difficulties, lack of cooperation of children with ID during dental treatment

Barriers reported by people with ID

- Severity of the intellectual disability

  Often the severity of the ID determines the access to dental care services: whereas children with mild degree of ID are commonly treated in outpatients' dental clinics, children with a more severe degree (moderate to profound) were treated in hospital settings (often due to the choice for treatment under general anaesthesia).[95] The severity of disability played also a role in the satisfaction of parents/caregivers about dental treatment (a higher percentage of satisfied parents in children with a mild to moderate disability) and in reported barriers (less or even no barriers were reported by parents of children with mild disability).[95]

Behavioural factors, such as obstructive or behaviour viewed as challenging, and affective factors (such as mood and motivation, fear and distress, and dislike oral care and toothbrushing) can impede daily oral care.[96]

- Physical impairments

  Daily maintenance of oral health requires a certain physical ability of the person, such as manual dexterity and physical coordination. Also cranio-facial or oral differences, sensory impairments (for example fear to touch the face, or dislike for noise of the battery toothbrush), existing oral health problems and dysphagia (including eating, drinking or swallowing problems) can affect daily oral care.[96]

  People with severe and profound ID have often also physical impairments and the related mobility problems (e.g. wheelchair). An adapted dental office and equipment would facilitate carrying out the treatment in optimal conditions.[96, 97]

- Lack of knowledge about (daily) oral health

  Understanding how to brush one's teeth and maintain oral health, why it is important to brush, the ability to concentrate and to memorise oral care and toothbrushing, were reported as cognitive barriers to maintain daily oral health.[96] Being able to follow oral care instructions and having a daily routine were considered as facilitators for toothbrushing and oral care.

- Unhealthy lifestyle

  Factors such as smoking, sugary food and medication use, can affect oral health of people with ID.[96]

Barriers reported by the supporters

- Lack of awareness about the importance of oral health

  Caregivers failing to see oral health as a health priority is considered by who as an important barrier in the accessibility to dental care. Also unawareness of disability-related dental problems hamper the timely provision of dental care.[96, 97]

- Lack of caregiver support towards the person with an ID

  In order to overcome the cognitive factors related to the ID, support strategies (such as prompting and reminding, reassurance and encouragement, watching and monitoring, persuasion, coaxing, rewards and distraction) and direct support by carrying out some or all of the cleaning of the teeth, are considered as primary facilitators. However, this requires a significant effort and time investigation by the caregivers.[96]

- Lack of training of the caregiver

  Informal caregivers reported not to know how to support carrying out oral care routine.[96]

- Caregiver concerns and beliefs

  Personal concerns or beliefs of the caregiver could hinder daily oral care, for example fear for aggressive behaviour of the person with ID as reaction on unwilligness, or worries to hurt the person.[96]

- Lack of familiarity of the caregiver

  Some people with ID will only accept supervision during daily oral routine by staff with whom they are familiar and like.[96]

Barriers reported by the HCP

- Inadaptation of organisational aspects of care to the needs of people with ID

  The systematic visit to the dentist was often hampered by organisational issues, such as long waiting time to secure an appointment or long waiting time in the waiting rooms of dental clinics, high costs of dental services, inconvenient opening hours of the dental office, architectural obstacles (such as physical access to the dental office, parking facilities), etc.[95]

  Where one might expect that informal caregivers would prefer a longer consultation time, the retrieved studies pointed out the opposite: lengthy appointments and appointment schedules which do not fit with their family routines, were frequently reported as an organisational barrier.

In daily oral care routine, the unadapted equipment could hamper the execution of this routine. The appropriateness of equipment is mainly determined by preferences of the person with ID (for example, preference for a specific type of toothbrush or toothpaste), and/or physical impairments (for example, use of dental suction tool in people with dysphagia or environmental adaptations for a wheelchair user).[96]

- Negative attitude of the HCP towards people with ID

  The supporters reported that dentists were reluctant to treat their child, and this was more common in children with severe, profound and moderate disability. This reluctancy could be due to a lack of knowledge and skills, and communication barriers in relation to people ID.[95]

- Poor continuity of care

  According to the supporters, less than half of the dentists made an appointment for the next visit, and this is more often seen in case of children with moderate and with severe and profound ID. Also the timing of the subsequent visit was often not fixed, resulting in a discontinuity of care.[95]

- Lack of offer of dentists specialised in care of people with ID

  The lack of information where the person with a disability can be treated by a dentist is considered as a major barrier to receive appropriate dental care. Also location of the dental office (and its related transportation issues) plays a role in accessibility, and in particular for those with severe and profound disability.[95, 97]

4.2.2.3 Access to emergency care

People with ID experience a greater prevalence of comorbidities and other health deficits, such as respiratory diseases, gastrointestinal disorders (e.g., peptic ulceration and gastric cancer), dental diseases, sensory impairments and are most likely to experience complications and side effects due to polypharmacy. These health aspects increase the risk of accidents, including trauma and falls, and contribute, with other physio-pathologic factors, to the poorer quality of life, the increased risk of mortality and the shorter life expectancy. The higher risk of accidents participates at a higher attendance and admittance rate to acute care hospitals compared to the general population, although other factors like poor access to primary care also contribute to the high rate to ED. However, only a few studies were found on those organisational and behavioural barriers related to the access to the emergency department. Table 5 presents the key characteristics of studies included in this section.

Table 5 – Key Characteristics of studies related to access to emergency care

References	Study design	Health intervention	Definition of people with ID	Main findings related to the perceived barriers
Sowney and Barr et al., 2006[98]	Focus groups (n=5) with accident and emergency nurses (n= 27)	Access to accident and emergency units in North Ireland	Adults with intellectual disabilities: no further definition was given	Lack of knowledge: no preregistration education or practice experience, this lack of knowledge affected also their confidence and competence in caring, confusion with the terms used to describe ID Lack of basic understanding of the nature of ID was also related to the reduced ability to pick up cues that might be demonstrated by individual's behaviour, which could lead to either over-investigation or diagnostic overshadowing Lack of awareness of professional support available Inability to cope with the support of the patient's carer Experience of fear and vulnerability in caring Dependence on carers to provide them information in order to carry out a holistic assessment and then to provide care Reliance on carers to give consent on behalf of the person with ID
Sowney and Barr et al., 2007[99]	Focus groups (n=5) with accident and emergency nurses (n= 27)	Access to accident and emergency units in North Ireland, with focus on communication difficulties	Adults with intellectual disabilities: no further definition was given	Difficulty in understanding needs: lack of knowledge of the nature of ID, perceived time constraints inhibiting interactions, communication with the patient side-stepped to get the job done, less time and attention given to the health needs assessment, difficulties in understanding patient's non-verbal communication (particularly in assessing pain), this may result in overuse of investigations Lack of accompanying documentation: inadequate available documentation from nursing/residential homes, absence of key information Difficulty informing, providing choice and gaining consent: questioning the need for consent, difficulty in empowering adult patients with ID to be able to make informed decisions, use of carers to help bridge communication gaps, seeking 'proxy consent' from a relative, not being aware of guidelines on consent
Lalive d'Epinay Raemy and Paignon, 2019[86]	Working groups sessions (n=60)	Access to hospital care (including	Patients with intellectual and developmental disabilities: including autistic spectrum disorders and severe disabilities	Lack of awareness of HCP on specific health issues for patients with ID, which resulted in a poor healthcare coordination and reduced quality of care: lack of

	emergency care) in Switzerland		organisation of necessary support for ED discharges during the night, time pressure in ED hampering the HCP to take the time to organise such support Communication and information transmission issues between hospital staff, families and supported residential accommodations: lack of time to read the large medical files of people with ID when admitted, Lack of training or insufficient training of HCP and hospital staff on ID Inaccessibility of hospital facilities and building for patients with ID

Barriers reported by people with ID

- Fear in an unknown situation

  This fear was perceived to be related to receiving insufficient or inadequate information about their care.[98]

- Lack of possibility to give consent to treatment

  Emergency nurses rely often on the accompanying carer for more background information on the patient; however, this dependency on the carer leads also to a misunderstanding that it was the carer who, on behalf of the person with ID, should consent to examination and treatment (the so-called “proxy consent”). Even in case of consent given by the person with ID, additional consent by the accompanying carer is requested.[98, 99]

  This affects the rights of people with ID to assert control over their own body and to make decisions about their care. Nurses reported also difficulties in empowering adult patients with ID to be able to make informed decisions.[99]

Barriers reported by the supporters

- Lack of confidence in nursing staff

  This is mainly related to the lack of understanding of the nature of ID by the nursing staff in an emergency department (see further).[98, 99]

Barriers reported by the HCP

- Lack of understanding of the nature of ID and related health care issues

  Due to lack of training and understanding of the needs of people with ID, HCP in the ID are less able to detect cues that might be demonstrated by the person’s behaviour (i.e. the patient’s behaviour is being considered as an aspect of ID and not as a crucial indication that there is something wrong and thus failing to identify or treat a new or emerging condition).[86] The clinical competences of the staff in the ED are also often questioned by the informal caregivers. Even the confidence of the nurses themselves in caring was affected by this lack of knowledge.[98] Nurses emphasised the essential role of the presence of carers accompanying and remaining with the patient.[98]

- Poor communication with the person with ID (and family)

  Communication difficulties are reflected in difficulty in understanding needs, informing patients and difficulty in gaining consent. Also due to perceived time constraints within the ED, communication with the patient is often neglected or reduced to a minimum. Emergency nurses reported also difficulties in understanding patients' non-verbal communication, particularly in assessing pain, often resulting in an overuse of investigations which may add to the patients' distress.[98]

- Poor information on admission

  The lack of relevant documentation accompanying the patient was also considered as a contributory factor to poor communication.[86] Emergency nurses suggested that the provision of appropriate documentation, including information on the individual's preferred communication methods, would enhance interaction with the patient.[98] No studies were found in which other types of care professionals reported their perceived barriers related to the communication and information transfer between home setting and ED.

  Next to a lack of information on the medical history and personal background of the people with ID, there is also a lack of awareness of emergency nurses on how to access expert advice to support them during the provision of care.[98]

- Perceived risks to other patients and towards themselves from people with behaviour viewed as challenging

  Nurses reported an inability to care for an adult with ID without the patient (informal) caregiver. They reported even experiences of fear and vulnerability in those situations.[98]

4.3 Conclusion

Table 6 illustrate the main barriers identified in this chapter. Tables with a comprehensive view of barriers retrieved from the literature scan are available in the Appendix 3.

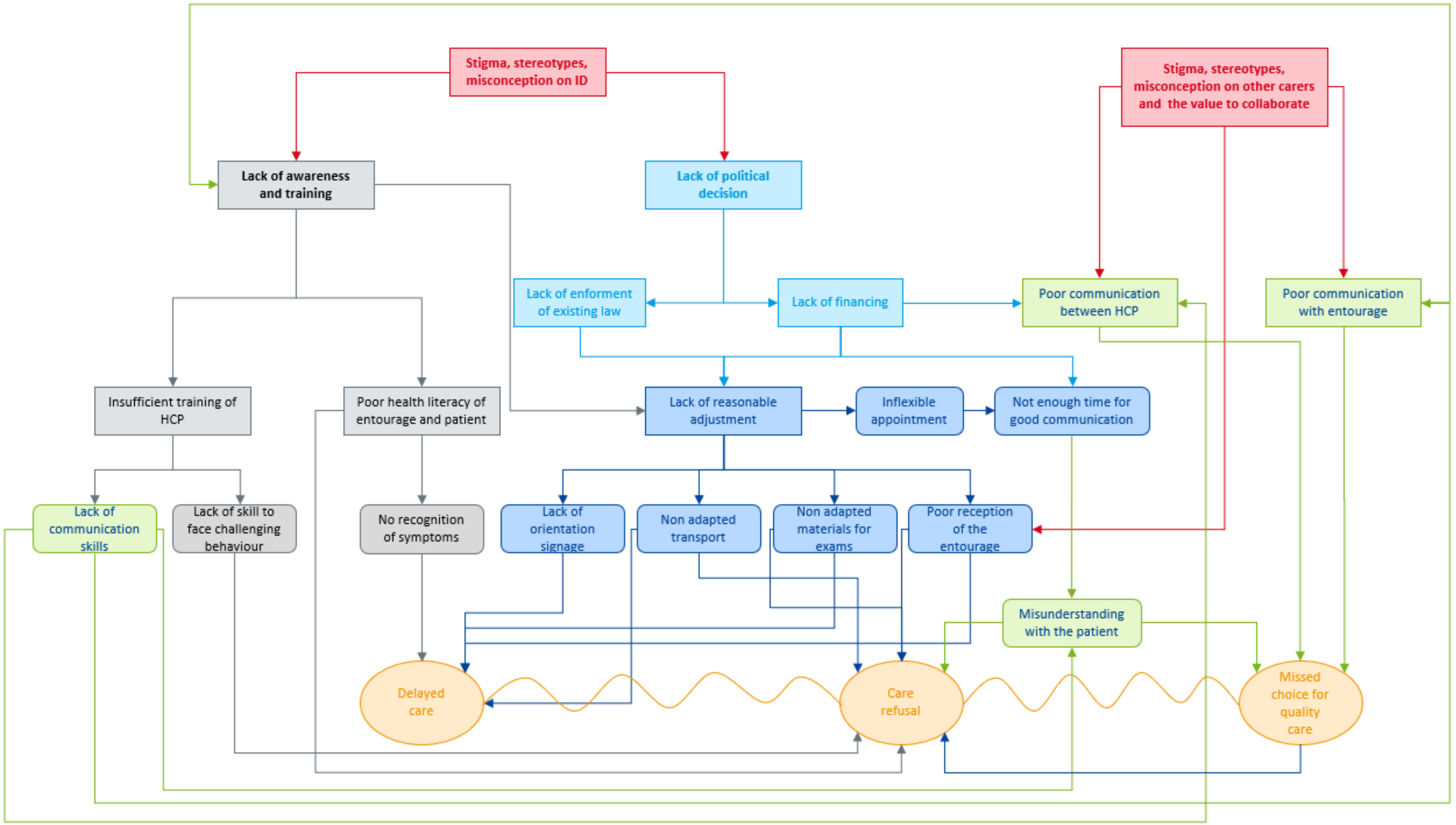
Table 6 – Summary of barriers identified in the literature

Category	Description	Example	Consequences
Attitudinal	Induced by stigma, stereotypes and misconceptions	"People with ID cannot improve their health"	Missed diagnostic or treatment
Communication	Induced by a lack of adaptation to the patient's need Induced by poor transmission of information between HCP	Use of medical jargon Medical report not including info on patients' specific needs	No opportunity of treatment choice Waste of time
Skills and knowledge	Induced by a lack of awareness and training	Lack specific skills to care for people with ID particularly concerning the behaviours viewed as challenging Health literacy of people with ID and supporters is poor: no recognition of symptoms	Missed diagnostic or treatment Delayed care
Programmatic	Induced by a lack of reasonable adjustments	Inflexible appointment scheduling system Lack of orientation signage adaptations	Not enough time for good communication Lost patient not on time to appointment
Social and policy	Induced by a lack of political decision	Lack of financing Lack of enforcement of existing laws	Not enough time for good communication Lack of reasonable adjustments

Barriers to access to health care for people with ID fall under different categories but some barriers can fall in several categories like the lack of time to follow training which can be a programmatic barrier and a knowledge barrier.

Most of barriers are interacting and influencing each other. Attitudinal barriers are likely to influence indirectly almost all barriers, and directly the knowledge and skills barriers and the policy and social barriers. HCP need to feel involved to follow a training on care for people with ID, or decision makers must perceive the added-value of enforcing actions supporting more equity for people with ID. Programmatic barriers are influenced by attitudinal, policy and social, and skills and knowledge barriers, reasonable adjustments being dependent on financing, quality control, concern and awareness in a health-care setting. Finally, communication barriers appear, mostly, as resulting from the other types of barriers. This occurs, among others, when HCP negatively value the interprofessional collaboration, when managers do not allow for flexibility in the appointment system or when there is no public funding for longer consultation time: all these elements together are likely to induce a decrease of communication quality between the HCP and the patient, the supporters and his/her colleagues who can, in turn, lead to misunderstanding. Patients with ID can then experience missed opportunity to choose quality care or can refuse care, with, as consequence, inequity in health care access (see Figure 19 for more details).

Figure 19 – Relationships between different barriers



Red: Attitudinal barriers; Grey: knowledge barriers; Light Blue: policy barriers; Green: communication barriers; Dark Blue: direct consequences to barriers; Orange: final consequences of barriers impairing high-quality care

5 CHAPTER 5: BARRIERS TO HEALTH CARE ACCESS IN BELGIUM FOR PEOPLE WITH INTELLECTUAL DISABILITY

5.1 Introduction

5.1.1 Aim

Barriers to health care access for people with ID were firstly identified by the grey and scientific literature scan (see Chapter 4 on international literature on barriers). Based on these results, we then collected data on barriers as experienced by people with ID and their supporters in Belgium. This step aims at confirming the presence of similar barriers in Belgium and to identify if additional barriers are faced by Belgian people with ID and their supporters. A qualitative approach based on “patients’ journeys” was used to reach those objectives (see Appendix 4).

5.1.2 Method

This part of the research relies on a qualitative approach, with 2 consecutives phases: 1) probing the experiences of professionals in the disability sector who help people with ID at all stages of severity to access health care services and providers; 2) probing the experiences of people with mild ID and one of their informal caregivers (when he or she was available).

Nominal groups with professionals

Four nominal groups gathering 6 participants from the disability sector were planned, 2 groups in Dutch and 2 in French. The participants were grouped according to the context of work, i.e., the ambulatory setting and the residential setting. The aim was that each group includes different professional profiles and different type of practice context within the two different setting. For example, the group of participants from the residential setting was planned to include a specialised educator or family helper, a nurse, a director, a paramedical staff, a physician and a social worker. However, the availability of the professionals was very low, preventing to gather the number of participants as firstly planned. In total, 7 nominal groups were organised, including 17 participants.

The professionals were recruited by direct contact (first by email then by phone) mainly through contact information available online. We aimed to recruit one professional among each type of services described in the chapter 2.

They were consulted during online nominal groups (using Zoom© software), facilitated by KCE researchers from June to December 2021 [100]. The principle of the nominal groups is to collect the experiences and opinions of the participants in writing and orally, giving the opportunity to participants to express themselves in their favourite way. In the preparatory stage, the participants completed a document aimed at describing the barriers and facilitators that could arise during three fictive care pathways of a person with ID by following the outline of a “patient journey” (see the schema of the 3 pathways in Appendix 4) The "patient journey" is a conceptual support consisting in the elaboration and progressive enrichment of a care pathway by describing all the practical steps in detail of a fictitious patient, called "persona".[101-104] A care pathway is composed of steps that the "persona" will have to go through when seeking and receiving care. The research team developed the first version of the “patient journey” based on the exploratory interviews conducted in the scoping phase of the project and the scan of the scientific and grey literature (see Chapter 4). Three health care situations were developed: an acute, a chronic and a preventive situation. The choice of themes for each of the three journeys (acute, chronic and preventive) was based on three criteria: the care situation is frequent, its management is systematic[xx] by health professionals and its objective is not focused on the disability problem.

Before the group discussion, the participants sent to KCE researchers their written document by e-mail. During the group discussion, all the elements submitted in writing were presented in an online interactive table via the *Miro.com©* platform, allowing each participant to enrich the discussion around the proposals already formulated in writing. Each nominal group concluded with a discussion on possible solutions (whose results are described in Chapter 6). Finally, all the data were included in a common summary report which was submitted to the participants for approval during a final review stage. No new barriers were reported as missing, only some remarks on the wording.

Interviews with people with ID

People with mild or moderate ID and, eventually, their informal carer were consulted in individual or paired online interviews.

The interview was supported by an interview guide written in Easy Read format (*language Facile à Lire et à Comprendre – eenvoudige taal*) addressing the barriers as experienced by the people with ID themselves (Appendix 4). Participants were also given the opportunity to suggest possible solutions that could improve the barriers they had encountered (see Chapter 6).

This part of the project was approved by the Erasmus-ULB ethics committee (P2021/358). The participants had to be volunteers, able to express themselves orally, have access to a digital support allowing them to communicate by video conference and give their informed consent. The informed consent was translated into Easy Read language under the supervision of experts of this language. The researchers were trained in the written and oral practice of ‘Easy Read language’ to consider the needs of the participants with ID.

The participants with ID were recruited via sheltered workshops (*Entreprises de Travail Adapté – Maatwerkbedrijven*) or via associations of people with ID and relatives. Each person with ID could be accompanied by a person of his/her choice.

Prior to the data collection interview, the researchers contacted each participant via video conference to explain the principle and content of the informed consent, answer the participants' questions and guide them through the electronic signature. The whole organisational procedure for the interviews is described in Appendix 5. During the interview, the researchers used illustrations retrieved from the website *SantéBD* to facilitate the sharing of each participant’s experiences of their chosen care pathways (see Box 15).

A total of 5 interviews took place in October and November 2021.

Data analysis

Data from nominal groups and interviews were directly analysed in an integrated way, using a stepwise approach. The data was first analysed according to the stages of the ‘*patient journey*’ inside each care pathway. This first step allows for the identification of cross-cutting themes across the different pathways. It also leads to the identification of barriers and facilitators for people with comprehension problems: comprehension problems could be related to ID but also to other (non-exclusive) factors such as sensorial impairments, other neurological or cognitive troubles as well as cultural and linguistic factors.

In a second step, the cross-cutting themes were analysed according to the 5 categories of barriers previously identified in the literature: (i) attitudinal barriers, i.e. barriers related to the attitude of the protagonists; (ii) barriers related to communication; (iii) barriers related to lack of knowledge and skills; (iv) barriers related to the organisation of services; and (v) barriers

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[xx] Systematic management of the health problem should be understood as a management of the situation based on common guidelines and procedures with few or no variations according to local practices.

related to policy and social issues (see Chapter 4: International Literature scan on barriers and facilitators).

In a third step of the analysis, an intermediary document gathering all results was reviewed by parents of people with (severe) ID to ensure the results also reflect the perspectives of those hard-to-reach for cognitive or practical reasons. Additional data were included in the report.

In a final step, data gathered by *Altéo* Liège during discussion groups with parents of people with ID were added to the analysis to complete the report with the perspective of relatives of people with severe ID. *Altéo* is a non-profit association of able-bodied and disabled people aiming at and enabling ill, disabled, ageing and people with loss of autonomy to maintain or (re)find their place in society. This decision was taken after reviewing the comments collected in the third step: problems were still too focused on low to mild impairments rather than on those living with severe disabilities. Instead of conducting additional interviews, it was decided to integrate the data collected by *Altéo* Liège from 2017 to 2019.[105] It should be noted that the work conducted by *Altéo* aimed at supporting the lobbying work of parents and were collected during a discussion group without a research objective. The author of the work gave the authorisation to quote interviewees. These data then serve to complement the primary data and contributes to the validity of the findings.

Quotes issued from the interviews are included in the text to illustrate the findings: these have been kept in original language but have been edited for length and clarity.

5.1.3 Limitations

People with ID and their supporters constitute a heterogeneous group, with a wide diversity in expectations, needs and abilities. By combining interviews, nominal groups and revision of intermediary documents, the research team tried to collect as best as possible the experience of people with ID and of their supporters. However, despite the investment of the research team (specific training, adaptation of the research tools and procedures), only people with mild or moderate ID were able to participate in the interviews. This is in line with the findings of a scoping review on research interviews with people with ID.[106] People with severe ID may have a different experience that may influence the solutions to be developed. Therefore, to come closer to an understanding of their experiences, this project also includes some data from scientific literature and experiences of their supporters. These indirect data could not replace the direct information that one may obtain when interacting with the person with a severe or profound disability. However, communication with these people is challenging and needs further research to develop appropriate ways of involving them into research. To our knowledge, this project is one of the few, in the Belgian healthcare research field, giving the possibility to people with ID to express themselves.

Similarly, recruitment via sheltered workshop and patients or family associations of people with ID induces a selection bias: people with ID who had no contact with these two channels cannot receive the information. As such, the data could reflect a better situation than it is. Moreover, accessing people with ID living in institutions was not successful: their perspective could have also influenced the findings, as they have a different experience than those living at home. However, as professionals from institutions were also involved, the experience of these people was also considered. Furthermore, despite the researchers' efforts, recruitment via those two channels did not allow the expected 6 patients to be recruited: additional recruitment from the researchers’ environment was necessary. To reduce the impact of the selection bias, additional sources of data were added to the interviews to collect data on healthcare access experiences for people with ID, like scientific publication or supporters’ opinions.

Interviews and nominal groups were conducted during the Covid period: as a consequence, all data were gathered online. Saarijärvi and Bratt consider that online interviews and face-to-face interviews produce similar results.[107] They mainly highlight issues related to the technological components (stability of the Internet connexion) and confidentiality of the exchanges if another person is present in the room but not visible. However, these findings were based on interviews with a general population and not with people with ID. Face-to-face interviews may have helped the researchers to create a stronger bond with the participants. However, in this research, participants to the interviews were encouraged to have a supporter attending the interview to act as a facilitator. This was of added-value as the facilitators were able to repeat the questions in a more adapted manner: this generates richer data than couldn’t have been obtained without their support. The presence of the facilitators is recommended as they also contribute to a reassuring environment.[106]

Because of organisational constraints and the difficulties in recruiting people with ID, only 5 interviews were conducted. Despite this low number of participants, the content of these interviews was quite like the findings emerging from the nominal groups. Besides, these findings mainly reflected the perspectives of people with low or mild impairments rather those with severe limitations. Consequently, additional data sources were consulted to obtain a more complete overview of the problems as experienced by these people.

The research protocol initially planned 4 nominal groups of 6 participants. Due to organisational constraints and as the groups were organised during the Covid pandemic, 7 groups of 2 or 3 participants were finally organised. If the limited number of participants may have limited the use of the nominal group technique, the data retrieved from these groups were rich and dense as the participants had more time to go deeper in their explanations.

5.2 Barriers and facilitators identified by field stakeholders from the disability sector and health care users with ID

This section presents the barriers and facilitators for people with ID when seeking care in acute, chronic and preventive situations. Results on solutions are presented in chapter 6.

The results are organised in 2 sections: 1) Barriers for all and for people with any specific needs; 2) Barriers specific to people with intellectual disability.

Inside each section, results are presented according to the 5 categories of barriers: (i) attitudinal barriers, i.e., barriers related to the attitude of the people involved; (ii) communication barriers; (iii) knowledge and skills; (iv) programmatic barriers; and (v) policy and social barriers - as used in Chapter 4.

In total, 7 nominal groups were organised. The nominal groups were composed of professionals active in the disability sector in Belgium: 9 from the residential sector and 8 from the ambulatory sector; 7 Dutch-speaking and 10 French-speaking. Participants were medical doctor, nurse, psychologist, pedagogue, educator, dietician, director, family helper, and social worker. Other participants had been contacted but could not participate mainly due to lack of time.

Three of the participants to the interviews were accompanied by an informal caregiver, always one of their parents. Two participants were interviewed, either alone after decline of the parent regarding the full autonomy of the person or accompanied by a professional from the disability sector in charge of the health follow-up on request of the person. One participant does not show up.

5.2.1 Barriers for all and for people with any specific needs

From the nominal groups, it appears that some of the barriers concern the access to high quality care for all users of the health care system. They particularly affect people with special needs, such as people requiring the presence of a caregiver, some people under personal and property administration, some people requiring assistance with activities of daily living, or some people whose health condition requires adjustments to usual care procedures due to appliances, limitations of movement, allergies and intolerances, dietary requirements, sensory impairments, etc. The group of people with special needs includes but is not limited to people with ID.

5.2.1.1 Attitudinal barriers

Attitude towards people

Participants pointed out that **the personality of those involved** (health care professionals, administrative and support staff in the health care system, patients, informal caregivers, professionals from the disability sector) influences the access to high quality care.

> *"Wat ook typisch is bij [naam van de patient], is dat ze bij een eerste ontmoeting met mensen, vaak veel schaamte heeft, dat ze zowat wegkruipt. Dat vindt ze dan heel moeilijk en als je dan een dokter hebt die niet echt tegemoetkomend is, en geen verbinding probeert te maken, dan klapt ze dicht en laat dan geen emoties meer blijken. Veel hangt af van de vriendelijkheid van de dokter." (Parent 3)*

As stated by participants, most of HCP are empathic but do not always listen to the explanations of the supporters.

In the case of people with special needs, the **role of the supporters** is perceived as more important and influential than for patients without special needs as they know the needs of the one, they care for and have the experience on how to meet these needs

Some participants first mentioned **the lack of empathy** of reception or health care staff, particularly about the family and friends, who do not feel listened to or heard. The reception stage on arrival at the emergency room is an example of a key moment when the person seeking care and his or her family feel the importance of dealing with empathetic staff.

Participants also mentioned the **lack of direct contact** with the patient or the supporters contributing to the perceived lack of empathy.

> *« […] Le neurologue nous avait dit « allez aux urgences au [nom de l'hôpital] parce que moi, je suis au [nom de l'hôpital] ». Donc moi, je pensais rencontrer son neurologue […]. Mais alors, malheureusement, le neurologue n'est pas venu. Il a donné toutes les instructions par téléphone et ça, je trouvais un petit peu, un peu dommage. S'il était dans le bâtiment, je trouve un peu dommage qu'il ne soit pas venu. Enfin bon, il n'avait peut-être pas le temps ». (Parent 2)*

The **attitude of the supporters** was cited by some participants as a potential barrier that can hinder good quality health care: participants highlighted that some members of the supporters (informal or professional) may at times be emotionally "too" involved in decisions and discussions, and others "not enough" concerned. The attachment of the professional supporters to the person with special needs can induce inappropriate attitude and may – for example – become a barrier to the timely introduction of palliative care appropriate to the medical situation or may lead to overtreatment.

Attitude towards health care system

According to participants, **prevention seems to receive less priority** by families, professionals in the disability sector and even HCP. Some participants noted less attention for preventive care, particularly in relation to a poor understanding of the objectives of prevention and to the overwhelmed situation due to daily imperatives. As pointed by some participants, people usually focus on immediate health needs rather than on long term benefits. The threshold for access to prevention is also considered too high.

Some participants also reported that few professionals appear being interested in positions as health care coordinator for people with ID.

5.2.1.2 Communication barriers

Communication problems between HCP and the patient/supporters

Some of the barriers cited by participants target the understanding between HCP and patients, which in turn impacts the flow of information. In any care pathway misunderstanding increases the risk of low-quality care, even though when the patients have comprehension and expression problems. Understanding difficulties are not only particular for people with ID, but could affect a broader group of patients, e.g., persons who do not speak the local language, etc.

The use of **medical jargon** was raised as a barrier impacting the quality of follow-up. Some professionals in the disability sector reported the need to recontact the HCP to be informed of the care to give or organise because neither the patient nor the supporters understood the instructions provided by the HCP. So, although the information had been provided, implementation of the health recommendations at home or in the institution was not taking place because the information was not provided in an understandable language adapted to the level of comprehension of the patient and the supporters by the HCP.

In addition, participants reported that some HCP **fail to discuss with the supporters** preventing also a good flow of information. The same problem also arises during ambulance transfers when the supporters is excluded.

The loss of information was also noted with nurse shifts, especially if the supporters is not accepted in the room permanently.

Communication problems between HCP

The discharge from the hospital was identified by participant as a relevant example of high risk of **loss of information**: for example, some participants reported that documents were missing at hospital discharge after surgery. Moving to another region or transitioning to adulthood are also cited periods of risk for loss of information.

Another communication problem between HCP is related to, as explained by participants, to insufficient referral. The patient and the supporters are therefore alone to identify the **“right” professional** for chronic follow-up. This phase requires a lot of energy, time and investment for the supporters and induces delay in care.

Additionally, the lack of **coordination and cooperation between different professionals** was reported by participants. As they pointed out, a team of professionals who are in tune with each other would deliver better quality care.

> *“Ik [vader] ben er, maar ik ben er ook niet. Hij [huisarts] is echt gericht naar [naam van de patiënt]. Maar het heeft ook wel even geduurd voor we een huisarts vonden waar we een goeie klik mee hadden. Zodra we de juiste verzorgers hebben gevonden, houden we ze”. (Parent 1)*

5.2.1.3 *Skills and knowledge barriers*

Lack of digital and health literacy can be a barrier to health care and can contribute to the overcrowding of ED. This could happen, among other examples, when people go to ED rather than to book an appointment (online or not) because they find it easier or because they lack knowledge on what is appropriate according to the health situation.

Poor knowledge on the necessity and appropriateness of medical practices can also lead to a refusal of certain invasive examinations out of fear for privacy or physical or psychological integrity.

The insufficient **communication skills** of some HCP were pointed out by participants, particularly when it came to announcing bad results or in case of acute medical situation. Participants noted the **lack of listening skills** of some HCP: they do not listen to difficulties related to the disability expressed by the person with ID or the supporters.

5.2.1.4 *Programmatic barriers*

There is no uniform **procedure for the accompaniment of person with special needs** in health care settings. According to participants, accompanying people with comprehension difficulties 24/7 during their hospitalisation is the exception rather than the rule, for adults.

> *“Dat is mijn grote schrik dat nu hij volwassen is, dat hij alleen in het ziekenhuis zal moeten blijven. Maar er zou een nieuw beleid zijn dat personen met een beperking toch een vertrouwenspersoon bij zich kunnen houden. Anders ga je beelden krijgen van “de koppige mongool”. […] Er moet steeds iemand zijn die de vertaling kan zorgen. Voor mensen in een voorziening, is dat een probleem. Stel daar meer eens een opvoeder vrij om die persoon dan te gaan begeleiden. Ook dan zou ik pleiten dat er iemand op die dienst dan is, die de gebruiksaanwijzing kent en respecteert.” (Parent 1)*

The recent situation of COVID-19 is an extreme example because no accompaniment was accepted anywhere in any circumstance.

> *« J’avais un peu peur parce que c’était le moment où on était encore confiné. Et je ne savais pas si on allait me laisser entrer ». (Parent 2)*

As there is no possibility of accompanying a person with disability, several consequences could be observed: extended procedure, experienced fear by the patient, clinical examination not conducted according to medical standards, etc.

> *« Mon fils handicapé mental avec des troubles autistiques devait subir une IRM de la tête. Il est de nature angoissée. J’ai expliqué qu’en raison de son handicap, il n’expliquera rien par lui-même, d’autant plus qu’il est angoissé face aux examens médicaux. « Mais votre fils est adulte ». J’ai dû rester dans la salle d’attente*

> *pendant plus d'une heure trois quarts. J'ai fini par interroger une infirmière qui entrait avec un autre patient. « On a dû chipoter longtemps car il refusait la piqûre », m'a-t-on expliqué. Si on m'avait laissé entrer, j'aurais pu dédramatiser. L'IRM a eu lieu sans piqûre, donc sans produit de contraste. Les observations ont donc été moins efficaces. En sortant, il avait les yeux rouges, il avait pleuré. On aurait gagné du temps et surtout évité du stress si j'avais pu l'accompagner ». (Retrieved from Altéo, 2019)*

In the hospital setting, some psychiatric **services** lack of equipment **to support the daily life activities of dependent patients,** for example, there is no patient's lift. During hospitalisation, it was pointed that some daily **medicines taken at home by the patient are not immediately available** in hospitals' pharmacy. The participants also reported that the adult hospital system is **not equipped to accommodate supporters** (not possibility for overnight stays for example). Some also said that the hospital's healthcare **professionals are very difficult to reach** (by phone) from outside the hospital.

Participants highlighted that the structural implementation of reasonable adjustments necessary for the reception and care of people with specific needs is described as **partial adjustment**, meaning not lasting in time. When efforts are made to adjust the structure for one person with specific needs, the adjustment ends when the patient leaves.

In the ambulatory setting, participants reported situations where there is **no professional who** structurally and fully **coordinates health care** around the person with specific needs: neither GP nor family helper. Family and friends cannot fully coordinate hospital and outpatient care, even if they are aware of the person's social and medical situation.

Moreover, in all settings, the **long waiting time for medical results** is reported to cause significant anxiety for the patients and their supporters.

5.2.1.5 Policy and social barriers

From a policy perspective, participants pointed out that the **health care system does not recognise the specific needs of some patients** for understanding. A good example of this lack of acknowledgement according to participants is the perceived rigidity of consultation times, meaning that a consultation slot has a fixed duration, and the HCP are bound to respect it. Receiving a person with comprehension problems requires more time because of the need for clear and appropriate language and sometimes repeating information. However, it is not foreseen when making an appointment that a longer time slot will be dedicated to this specific need.

> *"Rond mondzorg, hebben we veel geoefend thuis en daardoor kan de mondzorg op de stoel gebeuren. Maar dat moet langzaam opgebouwd worden. En een consultatie duurt ook langer." (Parent 1)*

In parallel, the participants repeatedly mentioned the **lack of time of health care staff** across the whole health care system. The hospitals seem particularly under pressure, which prevents it from adapting to the specific needs of the patients. The situation is worst when people in need of care have a severe disability that requires major logistical adaptations. This was illustrated by a participant who told the case that a patient with cerebral palsy was not fed for 3 days in hospital because the nurses did not have time. The presence of an educator was necessary at each meal to feed him. The necessary presence of an accompaniment was also reported by consulted parents.

According to participants, HCP should have the opportunity to spend a consultation re-explaining important information. However, as mentioned by participants, HCP are not considered as being the only ones responsible for the pressure on the time spent on care. In some situations, participants feel that HCP suffer from not practising their art in optimal conditions. As mentioned in the *Alteo report* and by one of the interviewed person with ID, this lack of time would be closely linked to the way hospitals are financed, as they receive a share of the medical fees and put pressure on providers to perform a maximum number of acts in a minimum amount of time.[105]

Moreover, participants highlighted that **time spent with a patient is currently the least valued in the current funding system,** which may explain why some HCP will not take the necessary time with patients who need it. It appears that doctors who wish to take this time are making a personal choice to organise themselves.

> *« Ça dépend quel généraliste. La mienne, elle consacre une demi-heure par patient pour bien expliquer. Le seul problème maintenant, c'est qu'elle fait plus les prises de sang qu'elle faisait dans le temps. Dans le temps, quand elle habitait à Bruxelles, elle commençait à 7h30 et à 7h15, il y avait déjà une file de Dieu le Père devant chez elle ». (Participant 1)*

In addition to the lack of time, the lack of manpower is also a barrier to the improvement of HC access for people with ID. Indeed, reasonable accommodation may be difficult to implement due to lack of manpower. According to participants, it seems to be difficult to find competent HCP for caring people with ID. There is a lack of HCP in institutions for people with ID. In addition, the exclusion of care from the tasks of educational staff restricts access to basic care for the beneficiaries. In the health care sector, it is also difficult to recruit HCP trained to the specificities of care for people with ID. This type of profile could however ensure the role of coordination and referral in the care of people with ID, especially in the hospital setting. It is also complicated to find mental health care professionals available to follow up people with ID (double diagnosis).

Emergency transport was also pointed out as problematic by participants. They reported that the hospital chosen by the Dispatching 112 does not consider the specific needs of a patient. The situation is most favourable when there is only one hospital in the vicinity of an institution for people with ID, so beneficiaries are always admitted to the same place.

Participants also mentioned the **inadequacy of conventional ambulances** in which wheelchairs do not fit into. As there is a lack of adapted transport for those in wheelchair, supporters can be reluctant to organize transportation when the problem is non-life threatening.

A complex social context, especially social and financial precariousness, is also reported as a barrier to (high quality) follow-up.

> *« Avec mes problèmes financiers pour le moment, c'est vraiment à la dernière limite, bon, que j'y vais quoi parce que souvent j'ai des rappels de payement qui arrivent chez moi au lieu d'arriver chez l'administrateur […] Je sais que les soins de santé coûtent cher et ma paie n'est pas extensible. Souvent la fin de mois est compliquée. En 18 ans, mon argent de poche est descendu de 100 euros semaine à 40 euros semaine. Il réduisait mon argent de poche à chaque augmentation de facture ». (Participant 1)*

For some people with ID, facing the (extra) costs related to health care constitutes a major barrier in accessing health care.

> *« Maintenant, c'est sur rendez-vous, il faut passer par son secrétariat. Et voilà c'est plus lourd depuis qu'elle [la généraliste] a déménagé son cabinet de son ancienne maison privée vers un autre cabinet plus grand mais plus cher aussi. J'évite le plus possible d'aller chez elle. Le prix des consultations a méchamment augmenté ». (Participant 1)*

> *« Par exemple pour l'oncologue, j'aurais bien voulu éviter de devoir aller chez mon généraliste pour la connerie. Je trouve inutile de devoir payer. Aller directement chez l'oncologue sans passer par le généraliste. C'est cher payer l'oncologue. Je comprends pas pourquoi l'oncologue ne prend de patients que référés par le généraliste. Ça me coûte un généraliste et un oncologue. C'est un peu idiot mais ça fait marcher leur business. (Participant 1)*

The current gatekeeping system for accessing primary care such as physiotherapy care could is also a financial obstacle as patients have to pay a consultation only to have prescription.

> *« J'évite d'aller parce que ça coûte cher. Quand j'ai besoin d'une prescription pour la kiné, j'en avais besoin beaucoup plus souvent quand je pouvais y aller toutes les semaines au lieu de toutes les deux semaines ». (Participant 1)*

Participants reported that there are family situations where no family member has any medical follow-up, notably because of a lack of social and financial resources to do it.

Key messages

- dentified barriers concern the access to high quality care for all users of the health care system and particularly affect people with special needs including but not limited to people with intellectual disabilities.
- Identified attitudinal barriers affecting all users are notably lack of empathy, supporters emotionally too or not enough involved in decision process and less priority given to prevention. Those determinants are often related to the personality of the different protagonists (patient, supporters and HCP).
- Comprehension and expression problems such as those presented by people with ID have an impact on the flow of information between HCP, supporters and patients. Medical jargon use, incoherent discourse and disruption of information flow prevent good understanding between protagonists.
- Expression and listening skills are important and require training of HCP and more involvement of the supporters in the care by HCP.
- Patients and supporters may present a weak level of health and digital literacy. The digitalisation of health care services prevents patients from making appointments.
- Insufficient referral between HCP induces slowness in identifying the “right” professional and highlighting the lack of coordination in the health sector.
- Organisational aspects like delay in communication of test results, lack of adapted equipment in hospitals or insufficient availability of HCP by phone were identified as barriers to high quality healthcare during the nominal groups.
- The current appointment system does not allow for extra time with patients with specific need and the fee-for-service health care system does not allow for taking care of complex situations.
- Policy and social barriers are related to the lack of time of HCPs, the lack of structural reasonable adjustments and the difficult social context of some people with ID.

5.2.2 *Barriers specific to people with intellectual disability*

Participants identified the following barriers that specifically hamper people with ID to access healthcare of good quality. The context of the patient's life influences the barriers encountered. A person living in an institution will not encounter the same barriers as people living independently or those living with their family.

5.2.2.1 *Attitudinal barriers*

These barriers affect all the protagonists in a care pathway, be it the patient, the HCP or the supporters. Table 7 summarises the attitudinal barriers reported by the participants to the nominal groups and interviews.

Table 7 – Attitudinal barriers reported by participants

Protagonists	Attitudinal barriers
People with ID	Being frightened by unfamiliar person or place Not coping with loneliness Care refusal/behaviour viewed as challenging Lack of flexibility/fixed time slot for consultations Great impact of a previous negative experience in health care Reluctance to change in habits Reaction of high intensity and anxiety related to pain
Informal caregivers	Reluctant to attend screening appointments, believing that the health gain is less than the effort required to carry out the test Variability and incoherence in relatives’ opinions related to health care for the cared one Professional administrators few involved in decisions concerning the person Great difficulty in getting the family to comply with diet Deciding without taking the opinion of the person with ID

Staff in the disability sector	Fear of disturbing HCP Refusal to "play policeman" for non-vital health-care directives Insufficient organisation of healthcare visits
Health care professionals	Overestimation of the capacity to deliver care by professional in institutions/Insufficient preparation of patient discharge Not talking directly and mainly to the person with ID Exclusion of the patient and the family from conversation Reluctance to care for people with ID Lack of trust in the supporters Choice of referral to a hospital ward based on the person's mental age rather than their chronological age Admission refusal in psychiatric ward or intensive care ward

Staff in the disability sector

It emerged from the nominal groups that certain attitudes of staff in the disability sector can sometimes hinder the smooth running of care: fear of disturbing health professionals, refusal to act as "policeman" when following non-critical medical instructions, and lack of anticipation in the organisation of hospitalisation of people with ID (forgetting the medical file when leaving for hospital in an ambulance, difficulty in sharing the file with the hospital because its format is not easily exportable). This can reflect among others a lack of competency to assess the need for health care.

Health care professionals

As reported by participants, some HCP do not address directly the person with ID but rather the accompanier, even when the person with ID is able to communicate.

> *« Ma fille a un léger handicap mental. Elle comprend certaines choses et est capable de s'exprimer, malgré certaines limites. Mais les médecins et les infirmières s'adressent systématiquement à moi… J'aimerais tant la rendre actrice de sa santé ! » (Retrieved from Altéo, 2019)*

This attitude even extends to the relatives in the presence of another professional caregiver. In this last situation, professionals talk with each other and exclude the patient and the family from the conversation.

It was also reported during the groups that not all HCP wanted to be trained to provide appropriate care for people with ID, or were even reluctant to care for people with ID**.** Also, some HCP questioned the validity of complaints or health problems reported by the supporters, and as consequence, did not provide the appropriate care.

> *"Anekdote over 2de voetoperatie waar [naam van de persoon] in hand kneep bij ontwaken na operatie en de verpleegkundige heeft de moeder geloofd (en pijnpomp gegeven). Als hij 6j oud was moest hij sinusoperatie ondergaan. Als voorbereiding hadden we boekje gelezen "…bij de slaapdokter", dus hij was goed voorbereid op wat er ging gebeuren. Maar bij het ontwaken, zat hij te wenen en zat naar zijn hand te grijpen. Hij weende nooit als kind. Ik zag dat hij pijn had, maar de 3 dokters rondom hem beweerden dat hij geen pijn kon hebben. Ik heb daar moeten vechten tegen 3 professionals. Ik was daar zo boos voor. Ze namen het kind ook niet au serieux." (Parent 1)*

Another attitudinal problem arises when orienting the people with ID to hospital. As reported, the choice of referral to a hospital ward may be based on the person's mental age rather than their chronological age, which may be experienced as degrading by the person and/or the supporters, for example, when an adult is admitted to a paediatric ward. This choice can also be made for organisational purpose as paediatric wards are equipped to accommodate the accompanier. But, for the participants, the choice of service should rather be discussed on a case-by-case basis, as some people prefer to be surrounded by children rather than adults. For participants of the disability sector, the presence of a member of the supporters in an adult ward is preferable to admission to a paediatric ward.

> *"Ik zou het niet leuk vinden om weer tussen de kindjes (pediatrie) te moeten gaan slapen, want ik ben een volwassene" (Participant 2)*
>
> *"Op pediatrie verblijven zou ik niet erg vinden. Liever tussen de kinderen, dan alleen tussen de volwassenen" (Participant 3)*

Refusal of admission to a psychiatric ward because the person is living with ID was mentioned by some participants. Several examples of limitations of the intensity of care were given, such as limiting admission into an intensive care unit during the COVID-19 crisis.

Finally, for some participants, hospital HCP seem to overestimate the capacity to deliver care by staff in institutions for people with ID. Indeed, the latter are mainly educators, not trained in care, unlike nursing homes with which there is some confusion. For some participants, the delivery of care is moreover outside the missions of the educators. As such, participants ask that the discharge of a person with ID is better prepared than for any others. It is important to ensure that the recovering patient has sufficiently recovered their independence, for example in terms of mobility, before leaving the hospital.

People with ID

Attitudes of some people with ID may hinder their access to care, such as being frightened by unfamiliar persons, feeling insecure in places that are new to them or not being able to stay with the supporters. It was reported that some people with ID refuse to get into an ambulance or to enter a physician's office because they do not know the place or the persons.

> *“Als ik die dokter ken, dan zou ik wel alleen kunnen gaan, toch voor kleine dingen. Maar het ziekenhuis niet, daar moeten mama en papa bij zijn.” (Participant 3)*

> *“Mocht [persoon] nu worden opgenomen, en omwille van corona, mag er niemand bij haar blijven, dan zou dat echt problematisch zijn. Dat zou tot heel panische toestanden kunnen leiden.” (Parent 3)*

> *“Soms is het wel moeilijk (om zich laten te onderzoeken) als ik de dokter of verpleegkundige niet goed ken.” (Participant 1)*

In case of challenging behaviours, hospitalised people with ID may be discharged more quickly with a condition not yet stabilised. This kind of situation is not without consequences for the supporters who must deal with heavy burden of care at home. The supporters of people with ID with behavioural problems, such as the families of patients with autism, can also sometimes be reluctant to attend (screening) appointments, believing that the health gain is less than the effort required to carry out the test or to attend the consultation. In case of (autism with) aggressiveness, empathy was reported as not always sufficient: sedation, reward or the intervention of several persons from the staff can be needed. The HCP can decide not to carry out an intervention after evaluating the extra procedure needed (anesthesia) in case of behaviour viewed as challenging.

> *“Bloedafname heeft bij hem ook al een hele geschiedenis. Vroeger werd infuus in zijn handje geprikt, maar op den duur zaten we met 5 mensen op hem en dan lukte het nog niet. Dat is ethisch totaal onverantwoord, maar dat gebeurt dus nog bij andere kinderen.” (Parent 1)*

The **lack of flexibility** of some people with ID, which is often linked to their disability, can also hamper the organisation of their care, especially when they live independently. For example, the need to allocate a fixed time slot for consultations on the same day of the week or at a specific time of the day, or to always have the same HCP to make the person with ID feel better. This can be even more complicated when the person has no formal support service.

Participants also explained the **impact of a previous negative experience** in health care that can permanently hinder the provision of the same type of care. According to the participants, changes in habits are very difficult for some people with ID to bear. The introduction of a new health habit or treatment can have a significant and destabilising impact on the person's routine. Changes in routine can trigger or maintain anxiety.

When pain or discomfort is experienced, depending on the person with ID, (s)he may act with high intensity and interfere with care when they are unable to express their complaints.

The presence of a chronic illness can be another factor that increases the anxiety of people with ID, especially if they cannot understand the ins and outs of the illness.

Supporters

The attitude of the supporters (professional or informal) regarding health issues varied greatly according to participants. It was reported that, in the institutional sector, parents of people with ID seem to be more insistent with the staff of the institution that health investigations be carried out, whereas the siblings of the same person can be less insistent.

The professional administrators of the person's property and person (*administrateur de biens et/ou de la personne – bewindvoerder*) were described as less involved in decisions concerning the person than those concerning his or her property. For some participants, certain decisions are not taken or are delayed due to the lack of investment of professional administrators in health issues. It was reported that there can be "too much" emotional involvement by the parent-administrators and "not enough" by the professional administrators, although some participants testified that the vast majority of the person's administrators, as well as the trusted persons, conscientiously exercise the right of the patient they represent.

In some cases, families decide everything for the people with ID even though they are not under administration and the law stipulates that the opinion of the patients under administration in the exercise of the patient's rights will remain paramount if they are able to express it in a reasonable manner. Hence, people with ID may be wrongly considered as children without decision-making capacity. The quality of care may then be negatively impacted, especially if the person is able to express their preferences.

When it comes to diets, some participants report greater difficulty in getting to comply with them. Several factors may explain it. A food reward system between the families and the person with ID can hinder dietary compliance. Persons with ID living in autonomy can decide what they eat, and not comply with the diet. Persons living in institutions can steal food from another resident. At the same time, medical diets may be seen as preventive measures and not a priority, whether in institution or family setting.

Emergency and life-threatening situations

In emergency situations, all the protagonists (patients, HCP and relatives) are described by participants as particularly anxious because of the instability of the situation at hand, linked to the emergency but also to the fear of misunderstanding and specific know-how; the main fear being a refusal of care by one of the protagonists. Some participants emphasised that an empathic attitude helps to improve the situation, but this is not always enough to prevent a refusal of care. For some participants, the balance between acting quickly and taking time to explain to gain adherence of the people (and the supporters) is difficult to find.

5.2.2.2 Communication Barriers

Communication barriers are at the centre of the difficulties faced by people with ID in the care pathways. Table 8 summarises the communication barriers reported by the participants to the nominal groups and interviews.

Table 8 – Communication barriers as reported by participants

Protagonists	Communication barriers
People with ID	Problems to express themselves hardly be the sole bearer of her/his medical history Diminished ability to understand the information: information must be repeated and illustrated
Supporters	Lack of time or energy inducing insufficient preparation of the person with ID to a consultation or an exam or a hospitalization
Staff in the disability sector	Lack of harmonisation of health care plan between all the protagonists: family, disability sector professionals, HCP and patient: divergent information can lead to confusion and refusal of care Relational problems between families and institutions
Health care professionals	Insufficient involvement of people with ID in the treatment plan Do not always listen to and hear the supporters: both family members and professional caregivers ER's HCP do not have the time to read or do not prioritise reading the transfer forms of patients

	Medical record does not contain the habits, preferences and abilities of the person
	Incoherence between different HCP
	Lack of a single point of contact to coordinate the care of people with ID within the hospital

One of the main difficulties of people with ID, as reported by participants, is their **problems to express themselves**. They may need more time to answer the questions they are asked. Those difficulties of expression impact the communication with a HCP when the people with ID must explain what is happening to them, what they are feeling, their symptoms, in a way that the HCP can understand. Moreover, being able to express and communicate symptoms and problems require from the person with ID a learning process that takes time and repetition. When this learning has not taken place or when the situation is anxiety-provoking, people with ID can hardly be the sole bearer of their health history because they cannot always explain, for example, where they have pain. It is also noted that suggesting answers to questions can lead to misdiagnosis.

> *Voici ce qui est arrivé à ma sœur âgée de 50 ans, en situation de handicap intellectuel : elle fait une chute dans son centre de jour. Ayant très mal à la jambe, elle n'arrive plus à marcher. On la conduit aux urgences. Le médecin qui la reçoit lui demande : « Où as-tu mal ? Au genou ? » Ma sœur répond : « oui ». Du coup, on lui fait une radio du genou. Le genou étant normal, on la renvoie chez elle sans même l'avoir auscultée ! À son retour dans son foyer, on appelle le médecin généraliste qui l'ausculte et décèle immédiatement une fracture de hanche. Retour à l'hôpital. (Retrieved from Altéo, 2019)*

Participants also said that people with ID also have a diminished ability to understand the information they receive**.** Usually, information must be repeated and illustrated to be understood**.** For example, in order to be well prepared for a complementary medical examination, the supporters must spend a lot of time to explain what is going to happen, but this time spent on explanations beforehand can prevent them from having to undergo anaesthesia.

It was also noted that people with ID are not sufficiently involved in their treatment plan. However, it is important to keep the people in the position of actors in their care. They should therefore be given all the information they need to understand any problem that is subject to a decision. This stage of explanation by the carers and their supporters is crucial: it is however often neglected due to lack of time or energy.

> *« Tout ce que je sais, c'est qu'on n'a rien trouvé. J'aurais préféré savoir plus en détails. On a su quelques années plus tard qu'il n'y avait rien, sinon je ne savais rien. Je sais pas [si le médecin traitant avait reçu des résultats], on m'avait rien dit. » (Participant 5)*

As mentioned in the previous section on attitudinal barriers (see section 5.2.2.1.), the supporters is not always listened to and heard. Furthermore, when the support team consists of family members and professional caregivers, it may be necessary for both parties to be heard for information to flow smoothly. However, it is common practice in the health care setting to include only one family member in the sharing of information. Secondly, hospital HCP, especially in ED, do not have the time to read or do not prioritise reading the transfer forms of patients, which leads to an additional loss of information. Moreover, in the case of people with ID, focusing on the medical record is not enough because it does not contain the habits, preferences and abilities of the person being cared for, as, for example, the way the people are organised to take their medications.

> *[Pouvez-vous m'expliquer ce qui s'est passé avec le médecin ?]*
>
> *« Euh, oui je dirais plus dans sa façon qu'il avait à me parler. […] Je me rappelle qu'une fois, il m'avait dit : « Ah Mr W, et alors vous avez pris ou pas un tel médicament ? » […] il avait sa façon à lui de me poser sa question. Mais alors après, quand moi je lui répondais : « Ah bien non, je l'ai pas pris parce qu'à l'époque, je me fixais sur l'heure » [le patient veut dire qu'il s'était fixé un horaire pour la prise de médicaments qu'il respectait à la minute près]. Je lui avais répondu : « Ah bien non il était trop tard, donc je n'avais pas pris le médicament en question ». Du coup, il commençait à s'énerver sur moi vraiment d'une façon assez particulière, je vais dire. Du coup moi, enfin, c'était vraiment rare que je sortais de là-bas et que j'étais pas en colère ». (Participant 4)*

In the follow-up of chronic diseases, participants from the institutional sector point out the **lack of harmonisation** of care between all the protagonists: patient, supporters and care professionals. As each of them may have a different objective for the care, good communication between them is essential, especially in large institutions. Relational problems between families and institutions can lead to a breakdown in trust and collaboration, with refusals of care due to opposition. When a consensus is not reached, i.e., when those involved have not agreed on a common care objective, the people with ID risks receiving divergent information, which can lead to confusion and unease. The same is true when the opinion of the educational staff differs from that of the nursing staff. Inconsistent speech leads more easily to a refusal of care. Incoherence can also occur between different medical specialists on the same health problem, which complicates care due to a lack of clarity on what to do.

> *On m'a dit, on va lui donner des antiépileptiques. J'ai dit : « Quoi ? Il fait de l'épilepsie ? ». [Imites le soignant] « Non, non c'est comme ça ». Non, attendez, expliquez-moi. [Imites le soignant] « Mais le neurologue est au courant ». D'accord le neurologue est au courant mais moi je voudrais savoir. « Non, non, alors on va lui prescrire de la clozapine » qu'on m'a dit et j'ai dit... [fait un aparté] Et moi je suis en contact avec beaucoup de mamans qui ont des enfants schizophrènes et je connais les médicaments. Oulla, on va lui rendre des neuroleptiques. « Ah, vous savez ce que c'est » qu'on m'a dit « mais écoutez, c'est pour son bien ». D'accord, mais il vient d'être sevré du Risperdal. Ça a été long et est-ce qu'on va retomber directement dans la clozapine ? Est-ce qu'il ne serait pas bon de contacter le psychiatre qui est en vacances jusque lundi ? Et puis, ce qu'il se passe, c'est que le neurologue est pour pousser pour les neuroleptiques et le psychiatre voudrait les arrêter. C'est compliqué et moi, ce que j'aurais voulu à ce moment-là, c'est trouver une personne qui aurait regroupé tous les dossiers, que ce soit un médecin traitant ou une personne de référence, qui prenne aussi bien contact avec le neurologue que le psychiatre et qui pèse le pour et le contre. D'autant plus que le neurologue ne veut pas parler au psychiatre et le psychiatre est demandeur et c'est toujours très compliqué. Dès que le neurologue veut augmenter les doses, le psychiatre dit « Oulala, il ne faut pas ». Nous, on est un peu perdu entre les deux sommités. C'est très difficile. Nous, n'ayant pas fait d'études, de prendre des [décisions]. Et, par exemple, l'autre fois j'avais posé une question au neurologue et j'avais dit « Ecoutez, sur Internet, j'ai vu… ». Ah beh, écoutez me dit-il, si vous pensez qu'Internet en sait plus que moi, il faut aller voir Internet, il faut pas venir me voir. Enfin vous voyez, c'est un peu compliqué. (Parent 2).*

As stipulated previously, according to participants, the HCP from the hospital sector are difficult to reach. Some participants regretted then the lack of a single point of contact to coordinate the care of people with ID within the hospital. At present, this coordination is sometimes carried out externally by the GP or by a professional from the disability sector involved in outpatient care. For the participants, this single contact person would answer phone calls and e-mails concerning the organisation of appointments.

5.2.2.3 Knowledge and skills barriers

Those barriers concern all protagonists (patients, HCP, supporters). The great diversity of expectations needs and individual capacities of people with ID requires all those involved in the care process to acquire a wide range of knowledge and skills, such as keen observation and listening skills. Table 9 summarises the skills and knowledge barriers reported by the participants to the nominal groups and interviews.

Table 9 – Barriers related to knowledge and skills as reported by participants

Protagonists	Knowledge and skills barriers
People with ID	Lack of knowledge (health literacy) about common chronic diseases: better knowledge leads to better involvement and therefore better compliance Anxiety reactions induced by information on the purpose of prevention Lack of skills in describing symptoms Do not always know how to use the Internet
Informal caregivers	Lack of knowledge (health literacy) about common chronic diseases: the knowledge deficit is even more pronounced in prevention care (lack of knowledge about healthy behaviours) Difficulty in using health assessment scales Questioned the real impact of prevention on the quality of life Interpret the situation they observe in the person with ID according to their personality Not well informed about existing financial and logistical support Do not always know how to use the Internet
Staff in the disability sector	Difficulty in using health assessment scales Questioned the real impact of prevention on the quality of life Interpret the situation they observe in the person with ID according to their personality Do not seem to receive training on health problems and related care Not trained to accompany people with ID at the end of life or with serious pathologies: difficulties, particularly about the management of physical and moral suffering
Health care professionals	Not well versed in communication techniques Not specialised in intellectual disabilities: very little knowledge about intellectual disabilities Not often confronted with this population in their practice/reflexes quickly lost if there is little opportunity to practice Misinterpret clinical symptoms as consequences of intellectual disability
System	Referring people to other hospitals with less experienced staff Lack of a centralised information system in appropriate language Information sources adapted to people with ID concerning pathologies and care procedures are not well known

Some participants explained that HCP are not well versed in communication techniques adapted to people with ID. In general, HCP who are not specialised in ID have very little knowledge about it and how to deal with people in such situation. Moreover, as mentioned by participants, as they are not often confronted with this population in their practice and are not used to caring for them, this maintains the lack of knowledge and anxiety about caring for these patients. The supporters can partly compensate for the lack of knowledge of HCP as they are familiar with the fears and potentially challenging behaviours of the people with ID they care for. But according to participants, HCP do not seem to listen enough to the supporters, which leads to delayed care and waste of time.

> *« Mon fils déficient mental était angoissé. Je sais qu'en pédiatrie certaines infirmières se chargent des gestes délicats, comme les piqûres. On les nomme d'ailleurs des « piqueuses ». J'ai donc demandé la piqueuse. L'infirmière qui était devant moi s'est sans doute sentie vexée : « Mais je suis infirmière ! » Après avoir tenté de le maîtriser seule, puis avec l'aide de collègues, sans succès, elle a fini par… appeler la piqueuse. (Retrieved from Altéo, 2019)*

Some participants regretted that, when good practices are learned in the care of people with ID, some reflexes are quickly lost if there is little opportunity to practice them daily. HCP in the vicinity of institutions for people with ID, on the other hand, can develop additional skills in the care of people with ID through their frequent contact with this population. Referring people to other hospitals with less experienced staff can therefore have a negative impact on the quality of care.

For participants, due to lack of training and practice, HCP may have difficulty recognising that a change in the behaviour of a person with ID may be a sign of pain or an acute health problem. They may also misinterpret clinical symptoms as consequences of intellectual disability and thus miss diagnoses. The supporters may have to put pressure on the HCP so that he/she pays attention to the problem, even suggesting possible diagnosis, like side-effects of medication.

Some participants even reported that the discomfort of some HCP with people with ID may lead them to make poor decisions such as not resuscitating.

When it comes to health literacy, people with ID and supporters seem to lack knowledge about common chronic diseases (diabetes, obesity, hypertension, etc.). Some participants pointed the lack of a centralised information system that is easily accessible. In general, patients and their families seem to lack information in appropriate language on preventive examinations, medical procedures in general and the management of chronic diseases in order to make informed choices. For some participants, the role of GP is central, particularly in (re)explaining a chronic disease. Better understanding leads to better involvement and therefore better compliance. Information sources adapted to people with ID concerning pathologies and care procedures exist, but they are not well known, are not/almost not used by HCP or are not transmitted to people with ID and supporters.

The knowledge deficit is even more pronounced in relation to prevention. A good understanding of prevention and its objectives must include an explanation of the notions of suffering, decline and death. However, it is difficult to know whether the person with ID has the capacity to grasp these notions without the risk of triggering anxiety reactions that are difficult to control.

Other participants questioned the real impact of prevention on the quality of life of people with ID and the cost-benefit balance of these screening examinations, the cost of which should be measured in money and human effort. Participants also questioned whether the problem being screened would be solved and whether people with ID could have access to the treatment.

People with ID may not be aware of their condition or may experience difficulties to identify it as problematic and consequently, will not seek care.

> *« Je ne crois pas que c'était de la colère […] mais il y avait quelque chose qui aurait pu, je vais dire, déclencher ça [le fait qu'il tourne sans arrêt en rond] et que j'avais des difficultés pour m'asseoir sur une chaise, même, je ne sais pas moi, 5 minutes, je vais dire. Je pense qu'il y a eu quelque chose qui a déclenché cela chez moi […] » (Participant 4).*

Moreover, the pattern of symptoms could induce anxiety or be confounded with previous health problems. The presence of a family member or of a member of the supporters able to intervene is then important, especially when the situation is not evolving.

> *« Quand il a eu son injection de vaccin, il était sevré de Risperdal depuis trois mois et ça se passait très bien. Et puis, il a fait une forte température suite au vaccin. Je pense qu'il a paniqué et y a des symptômes qui sont revenus qui faisaient penser à nouveau à une crise de schizophrénie mais différente de l'autre fois. Moi, j'ai contacté le médecin traitant qui a donné du Valium mais ça ne se calmait pas. Donc on a contacté le neurologue. Le psychiatre était en vacances à ce moment-là. Oui, j'ai eu seulement le neurologue qui m'a dit, écoutez, allez au [nom de l'hôpital]. Il ne savait plus s'asseoir. Il avait des spasmes tout le temps. Chaque fois qu'on faisait un bruit, il sursautait. […] » (Parent 2)*

Some participants reported a lack of skills in describing symptoms by people with ID or their relatives: vague description, difficult assessment of pain, difficulty in using existing scales by non-healthcare workers (pain, quality of life, autonomy, etc.), lack of information on how to use the tools correctly, which may lead to a wrong interpretation of the situation. To use the tools appropriately, the supporters need time and training, but also need to understand the added value of such tools.

> *"Toen [persoon] klein was, was het moeilijk te weten te komen of [persoon] ziek was of niet. Dus als [persoon] pijn heeft, dan gaat hij op een lager niveau functioneren en dan is het heel moeilijk om in [persoon] te geraken. Dat is dan een volledige blokkade. Maar nu hebben we al middeltjes ontdekt. Een systeem van quotering. Maar we komen van ver. » (Parent 1)*

> *"Ja, een pijnschaal zou kunnen helpen, maar dan zou je al moeten weten wat 10 inhoudt van pijn." (Parent 3)*

As mentioned by participants, the personality of the educators may also influence the interpretation the situation: for a given health issue, some will trivialise, and others will dramatize.

According to participants, educators in the disability sector seem not to receive training on health problems and related care. As a result, they do not always understand what information to pass on to the HCP in case of a problem. In addition, the institutions are not suitable for providing care. The staff is not trained to accompany people with ID at the end of life or with serious pathologies in terms of follow-up and intensity of care. Some professionals in institutions have made a personal commitment to take on the management of serious pathologies or end-of-life care in collaboration with the families, but this presents many difficulties, particularly regarding the management of physical and moral suffering.

According to participants, families lack knowledge and skills about existing financial and logistical support and how to use Internet. Families sometimes seem to be left without social support.

Interviewed people with ID explained that it is difficult to make an appointment, either by internet (lack of digital literacy) or via a secretariat.

5.2.2.4 Programmatic barriers

Programmatic barriers occur at the level of a service or an institution: they have consequences for people with ID, their supporters and HCP. Table 10 summarises the programmatic barriers reported by the participants to the nominal groups and interviews.

Table 10 – Programmatic barriers

Protagonists	Programmatic barriers
People with ID	Loss of effectiveness in understanding when consultations are long or during full days of several consultations
Informal caregivers	Family and friends also struggle to cope with the many trips to the HC centre
Staff in the disability sector	Educational teams present at weekends and at night different as those during the week
Health care professionals	Highly agitated people are sometimes denied access to consultation or care Few are not used to provide longer and more frequent consultations Even the most committed doctors do not have enough time for high quality care Group practice in general practice destabilise people with ID because they are reassured to always be examined by the same doctor
System	Payment and administrative procedures not adapted to people with ID Internal signage not adapted to people with ID Volunteers cannot be present 24/7, nor are they allowed to assist with activities of daily living Consultation's organisation not adapted: frequent delays, crowded and noisy waiting rooms, long delays in receiving results Ethical questionability of a system of identification of people with behaviour viewed as challenging to enable them to avoid (or reduce) this waiting time Lack of coordination of care: absence of an in-hospital reference person Longer and frequent visit/consultation no longer sufficiently efficient

Participants of the nominal groups identified programmatic barriers, particularly in the hospital sector, starting with internal signage not adapted to people with ID.

This first barrier was mentioned particularly during the interviews with people with ID themselves, as they reported difficulty in finding the way around (large) hospitals. Hospital signage based on the road system is mainly decried by participants as lacking clarity, especially when there are several buildings in the hospital complex.

> *« […] si je ne suis pas bien dans mon assiette et que je vais par exemple pour un examen à [hôpital 1] ou à [hôpital 2], s'y retrouver avec les marques au sol, c'est... il faut être universitaire pour pouvoir les suivre. C'était mieux quand il y avait les numéros des locaux de service. Chaque service avait son nombre de locaux, il fallait pas chercher des plombes. Revenir à l'ancien système d'indication. C'était beaucoup plus clair. Pas faire les routes compliquées. Indiquer comme ils indiquaient dans le temps, avec à chaque étage un panneau où on retrouve le service. Parce que les fléchages, c'est d'un compliqué ! Et en plus, y a aussi des fléchages pour ce qui n'est pas de l'hôpital, pour sortir de l'hôpital, pour ce qui est des services extra-hôpital comme les services de psy qui sont en dehors de l'hôpital. Bonjour les dégâts ! Il faut souvent avoir le nez collé au sol. Au risque de s'emplafonner dans quelqu'un d'autre. » (Participant 1)*

> *"De route vinden in het ziekenhuis met een cijfersysteem, dat gaat niet. Veel ziekenhuizen zijn niet toegankelijk door dat cijfersysteem voor mensen met een verstandelijke beperking of lage geletterdheid. Hij vindt niet zelf de weg in het ziekenhuis. Ik heb hiervoor al contact gehad met het ziekenhuis, maar voor hen is dat geen prioriteit. In een ander ziekenhuis werken ze met een kleurensysteem en dat werkt super. Hij vond zo de weg." (Parent 1)*

The second programmatic barrier concern the organisation of hospitalisation and consultations. For participants, the organisation of hospitals and consultations seem not to be adapted to the needs of people with ID: frequent delays, crowded and noisy waiting rooms, long delays in receiving results. All these organisational elements can have a negative impact on the behaviour of people with ID and therefore complicate their care.

> *« Les salles d'attente, elles font un peu dortoir. C'est trop petit. Surtout, souvent, les spécialistes ont du retard. Donc voilà, c'est normal que ce soit condensé. On dit à une telle heure et puis il n'est pas là parce qu'il a une urgence ailleurs. Donc ça s'entasse, ça s'entasse, ça s'entasse. » (Participant 1)*

For people with ID with behaviour viewed as challenging, waiting time can be particularly difficult to manage, both for the supporters and the HCP. Some people with ID may, for example, start shouting, refuse to sit down or disturb other people present. Some participants proposed a system of identification of people with challenging behaviours to enable them to avoid (or reduce) this waiting time, but this is questionable from a practical and ethical (privacy) point of view. However, highly agitated people are sometimes denied access to consultation or health care. For agitated participants, considering the factors that cause agitation would ensure more equitable access to care.

However, for other participants, the inclusion of people with ID must go beyond specific needs relating to comfort for them, waiting (for a long time) in waiting rooms is part of everyone's life, including people with ID. This view is not unanimous, as for other participants it seems obvious to realise that some people with severe disabilities need an over-adaptation of the environment to achieve a form of inclusion.

The supporting role of volunteers to help people with orientation and administrative tasks was mentioned during the nominal groups but they cannot be present 24/7, nor are they allowed to assist with activities of daily living.

The third programmatic barrier concerns the appropriate length of consultations. People with ID need information to be repeated several times for them to integrate it well. As a result, consultations take longer and need to be more frequent. Caring for people with ID requires a greater investment of time. However, too long consultations or full days of several consultations together also lead to a loss of effectiveness in understanding a message conveyed to a person with ID, as their concentration can wane over time. The right balance is even more difficult to find as the supporters also struggle to cope with the many trips to the health care service, as most people with ID are not autonomous in their travels.

The fourth barrier concerns the feeling expressed by some participants that there is a lack of coordination of care within the hospital. They described the difficulties encountered by the supporters in coordinating care from outside. For some participants, the absence of an in-hospital reference person specialised in the coordination and adapted approach to people with ID is a major obstacle to the quality of care provided. This type of profile would allow care staff to have a resource person in case of difficulties encountered in the delivery of hospital care to people with ID. But, even when expertise is available, for example a paediatrist specialised in Down syndrome, human resources and material are insufficient as reported by participants involved in multidisciplinary initiatives.

Programmatic barriers are also present in other health care settings than hospitals.

First, there is a lack of continuity of health care in some specialised institutions for people with ID. As reported by some participants, in some specialised institutions for people with ID, the educational teams present at weekends and at night are sometimes not the same as during the week, which can complicate health monitoring. The use of replacements to compensate for understaffing means that they may be less familiar with the person and less able to react appropriately or detect problems correctly.

Second, for some participants, GP have an important role to play in the organisation of care and follow-up of people with ID, even though, according to some participants, even the most committed doctors do not have enough time for high quality care. Consequently, the supporters take over the follow-up for prevention and suggest actions to the GP.

> *[…] En général les médecins traitants, ils n'ont pas le temps de dire : « Tiens, est-ce que tu vas bien chez le dentiste ? Est-ce que ceci, est-ce que cela ? » […] C'est toujours moi qui dis : « Tiens est-ce que D. ne devrait pas avoir une prise de sang parce qu'il y a longtemps qu'on n'a plus regardé parce qu'il avait eu du diabète à un moment donné. Ça fait deux ans qu'il prend du Metformine. Est-ce qu'il ne faut encore qu'il en prenne comme il a maigri ? Est-ce qu'on peut… ? [Imites le médecin] « Ah bein oui on ferait bien*

> *une prise de sang » fin mais, moi je me rappelle avant, j'avais mon médecin traitant qui venait et qui me disait et quoi [faire]. Il me connaissait bien. Maintenant, ils [les médecins généralistes] n'ont plus le temps. C'est vraiment ça, ils n'ont plus le temps. Si quelqu'un n'est pas derrière la personne qui est en souffrance, c'est compliqué pour elle de se prendre en charge. (Parent 2)*

Participants also pointed out that if the GP do take the necessary time, their visit or consultation is no longer sufficiently efficient, i.e., the time spent with the patient and the doctor's personal investment is no longer commensurate with the cost of a visit or consultation.

Third, group practice in general practice can also destabilise the care of people with ID because, while they are reassured to always be examined by the same doctor, this is not always guaranteed in the case of group practice such as in a medical centre (*wijksgezondheidcentrum - maison médicale)*.

The last programmatic barrier concerns the payment for the health care and the administrative tasks. As reported by some patients, the absence of a systematic application of the third payment system, sometimes justified by the HCP as administratively burdensome, has for consequences that they must carry cash money, especially when professionals have no electronic payment terminal.

> *« Par rapport aux factures des deux kinés que ce soit le kiné T ou A, en fait par rapport à la mutuelle, donc [mon frère] et moi on a droit au tiers payant. Mais en fait donc ces deux kinés-là ne veulent pas l'appliquer alors que mon frère et moi on y a droit pour la simple et bonne raison (je reprends leurs mots à eux) pour eux ce serait beaucoup trop de travail, ça leur demanderait beaucoup plus de temps. Et voilà. Mais bon tout en sachant très bien que [mon frère] et moi on y a droit et qu'ils ne le font aucun des deux. (Participant 4)*

This contributes to their anxiety and feeling of insecurity.

> *« […] Le problème qu'il avait aussi quand il allait chez le psychiatre, c'est qu'il devait payer en liquide, absolument. Il devait se balader avec à peu près 80 euros. Ce qu'il n'a pas l'habitude. Ça le stresse. C'est un peu la même chose avec le système des kinés. Ici le psy actuel, il fait le tiers-payant et en plus, il a dans son cabinet un truc pour payer avec la carte de banque. Donc c'est sécurisé pour D. Y a pas d'inquiétude par rapport à ça. On arrive déjà le cœur plus léger." (Parent 2)*

The fact that the patients have also to care themselves for the administrative procedures with the sickness funds was also reported difficult to manage and stressful.

> *« Donc D. doit aller mettre dans la boite de la mutualité les prescriptions. Et alors, il sait bien que, dans ses mains, il a 260 euros. Et ça, ça le stresse » aussi. (Parent 2)*

5.2.2.5 Policy and social barriers

Policy barriers affect several themes among different areas of competence. Table 11 summarises the policy and social barriers reported by the participants to the nominal groups and interviews.

Table 11 – Policy and social barriers

Protagonists	Policy and social barrier
People with ID	Problem of financial resources
Informal caregivers	Neither family carers nor professionals from institutions have the resources and support to provide 24/7 care for hospitalised people with ID Lack the time to organise and accompany people to preventive appointments
Staff in the disability sector	Understaffing of specialised institutions for people with ID Care personalised approach of people with ID impact the organisation of activities in institutions Health care tasks performed by educational staff Lack of a dietician or diabetes educator in the institutions Problems in recruiting HCP: lack of candidate and lack of financing
Health-care professionals	Lack of HCP competent to care for people with ID Shortage of staff to accompany people with ID during hospitalisation
System	Restricted access to some speech therapy benefits or psychological services Mobile palliative care teams at home cannot always intervene in residential institutions Problem of financial resources that prevent hospitals from financing an in-hospital reference person and initiatives in agreement with the RIZIV – INAMI Not enough emphasis on prevention: difficulties in accessing preventive care and screening; lack of funding for the prevention sector; and geographical coverage seeming insufficient
Society	Insufficient inclusion of people with ID in society: inability to change the way society views, or rather discards, people with ID Belgian legislation is too vague regarding the status of trusted persons

The insufficient inclusion of people with ID in society seems to stand out as the first policy and social barrier. Participants mentioned the difficulty, if not the impossibility, of changing the way society views, or rather discards, people with ID. The lack of inclusion also makes it less likely that non-disability-specific health care professionals will meet people with an ID and learn how to provide appropriate care to them. Indeed, for some participants, the current basic training system does not seem to offer training for all carers in the specific care of people with ID. A lack of HCP in the care of people with ID was also mentioned during the nominal groups.

The second barrier is at legal level. Some participants pointed out that the Belgian legislation is too vague regarding the status of trusted persons. The Belgian legislation uses the term "trusted person" (*personne de confiance – betrouwenspersoon*) in different situations and with tasks that vary from one situation to another. This lack of clarity regarding the status of the trusted person does not help carers to give the trusted person the appropriate role in decision-making regarding the health of the patient, which may have an impact on the quality of the care provided.

Another barrier at legal and normative level concerns the reimbursed services for people with ID. Participants reported restricted access to some speech therapy or psychological services. According to participants, some of the services are inaccessible to people with low IQ. However, people with ID expressed the right to have access to the means to improve their health and thus be able to develop their potential better.

> *"Mensen met een downsyndroom en bij uitbreiding met een verstandelijke beperking, hebben recht op een goede gezondheid en pas als ze een goede gezondheid hebben, dat ze pas kunnen ontwikkelen." (Parent 2)*

Participants also indicated that mobile palliative care teams at home cannot always operate in residential institutions, including those for people with ID.

The third policy and social barrier concerns the insufficient (public) funding. Participants explained that hospitals have put forward a problem of financial resources that prevent them from financing an in-hospital reference person for the care of people with ID. As explained in the nominal groups, initiatives in agreement with the RIZIV – INAMI have failed due to a lack of hospital resources, such as the deployment of polyclinics for Down syndrome. These initiatives must then be financed by associations but lack sustainability.

Funding issues also affect people with ID. The lack of (financial) resources can affect people with ID and their supporters when faced with the cost of consultations, especially as several consultations may be necessary to give explanations so that they are understood and retained by the person. Despite benefiting from a preferential insurability status, patients still must cover some health care expenses which can represent a high burden on their household income.

> *« Je sais que les soins de santé coûtent cher et ma paie n'est pas extensible. Souvent la fin de mois est compliquée. En 18 ans mon argent de poche est descendu de 100 euros semaine à 40 euros semaine. Il [administrateur de biens] réduisait mon argent poche à chaque augmentation de facture ». (Participant 1)*

Besides, as reported by some participants, the changes of the funding of the disability sector and the increased attention brought to personalised approach of people with ID impact the organisation of activities in institutions. People with ID have more possibilities to express their choice regarding their daily activities, which can complexify the organisation of collective activities such as vacations. For some participants, this also impacts the health care that people may obtain as they don't have the same (financial) resources.

The fourth policy and social barrier concerns the lack of support of supporters when intensive accompaniment is needed. Even when the institution has a complete staff to function daily, there is a shortage of staff to accompany people with ID during hospitalisation. Neither family carers nor professionals from institutions have the resources and support to provide 24/7 care for hospitalised people with intellectual disabilities. Families who chose to do it have to face the social and financial consequences of such decisions (quitting their job or being in a (temporary) leave).

> *" Ik heb ervoor gekozen niet te werken, zodat ik altijd beschikbaar ben voor hem, maar dit heeft andere gevolgen voor ons leven." (Parent 1)*

Consequently, to ensure a form of continuity and presence, some educational staff visit hospitalized people with ID after their shift, on a voluntary basis. This kind of empathic attitude could contribute to the risk of burnout of the professionals on mid-term, especially if there is no structural change or support brought to these initiatives.

Moreover, according to the participants, it appears that some hospital units request a 24/24 presence of an accompanier who must carry activities of the daily life and hygiene care.

The fifth policy and social barrier concerns the presence of HCP in institutions for people with ID. At the level of institutions for people with ID, several problems were identified when it comes to HCP, particularly dieticians and diabetes educators. Institutions experience problems in recruiting HCP and in financing them via specific financial mechanisms which, among other causes, contribute to a shortage of HCP in institutions for people with ID. This was reported as even more problematic for non-subsidised institutions. Consequently, as mentioned by participants, educational staff must take over the health care of people with ID, without any prior training. This complexifies the stabilisation of some chronic diseases, such as diabetes, and increase the workload of educators. Besides, the shortage of staff in institutions prevents the timely organisation of preventive appointments. Educational staff also lack the time to accompany people to preventive appointments.

The sixth barrier was mentioned in the ambulatory setting. Social support focus on the behaviour and functioning of the person with ID within his personal context, but staff is not competent to provide care or to coordinate (preventive and/or chronic) care. For some participants, this need for providing support for health care issues is beyond the role of the service and this impede their missions.

Some participants felt that there is not enough emphasis on prevention. For them, if they have more possibilities to engage on a proper dialogue on prevention, this could help to avoid heavy and invasive medical procedures, especially as some of these procedures may require assessing the risk-benefit balance for the patients. Participants pointed out the difficulties in accessing preventive care and screening and mentioned the lack of funding for the prevention sector. Some participants felt that basic screening such as hearing, vision or footwear examinations to check the suitability of shoes should be officially recommended. Reachability of preventive services is reported as insufficient because of an unequal geographical coverage.

5.3 Discussion

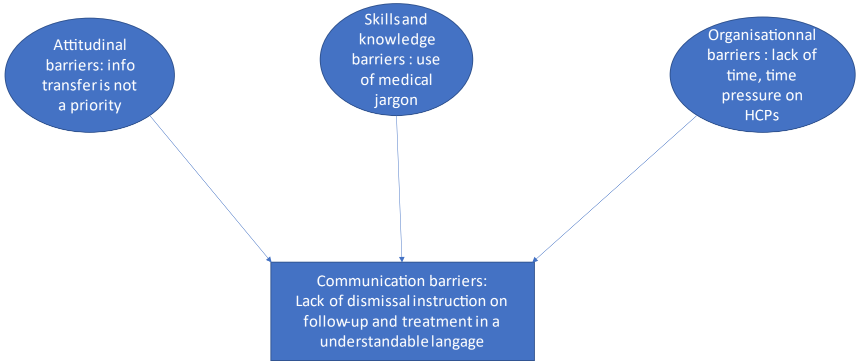
The barriers identified during this qualitative approach were the same than those identified in previous Belgian data. For example, *Inclusion asbl* reports that people with ID experience difficulties to access health care because of the fear of consultation, the feeling of not being listened to, the complexity of the information transmitted, the impression of being infantilised, the too fast speed of examinations, non-adapted structures, medical staff who are not sufficiently trained to deal with disabilities, appointments too long and too complicated, etc.[20] Also, most of the barriers identified in the international literature are similar to the qualitative data reported in this chapter (see Chapter 4: International Literature scan on barriers and facilitators). Detailed comparison between barriers retrieved by the two approaches are presented in Appendix 6 (see Table 47, Table 48, Table 49, Table 50 and Table 51).

In addition to be common amongst sources, **the barriers**, whatever the category they belong to, **are connected to each other** as illustrated in Figure 19 in Chapter 4. For example, the belief by the supporters that health gain is less than the effort required to carry out a preventive test is an example of attitudinal barrier related to the supporters (attitudinal barrier). Indeed, it may certainly hamper access to health care for people with ID, but this finding can have another meaning: although highly motivated, informal carers lack to be supported by the social and health system (policy and social barrier). This lack of support can in turn have consequence like a lack of time and energy of the supporters to prepare the person with ID by explaining in advance procedures and health issues, to avoid care refusal. The supporters, not enough supported by the system, will also lacks time to organise and accompany people with ID they care for 24/7 during hospitalisation.

Another example of connection between barriers concerns the reluctance of some HCP to care for people with ID and the misconceptions about people with ID leading to refusal of admission in some wards or service's orientation based on mental age were also described (attitudinal barrier). Although this attitude can be taken in all conscience, the lack of skills and knowledge are suggested to be also a cause of this negative behaviour. The lack of knowledge of HCP in ID matters can lead to misinterpret clinical symptoms (knowledge barrier). When the disease is manifested by behavioural change or problems, HCP feel powerless and even more afraid, avoiding examining the person. Those behaviours can also be misinterpreted as symptoms of psychiatric disease instead of somatic disease signs and pain, hampering the timely provision of health care.

Finally, communication barriers are at the heart of the difficulties faced by people with ID and their families when neither the person with ID nor the supporters have the feeling of being listened to and heard. An in-depth analysis of the shared experiences of professionals in the disability sector and of people with ID and their families shows that poor communication is not only a direct result of expression and understanding problems of people with ID nor lack of communication skills of HCP (i.e., addressing the carer rather than the person directly, being on familiar terms with the person, which infantilizes them, or using too complicated language). Communication barriers also result, indirectly, of other types of barriers such as attitudinal, knowledge and organisational barriers. Figure 20 illustrates the interaction between types of barriers. For example, the lack of time for clinical activities prevents HCP to clearly communicate with people with ID. Even the most committed doctors seem not have enough time for high quality communication.

Figure 20 – Relationship between barriers: the example of the communication



The identification of the main access barriers faced by people with ID is a valuable exercise which illustrate two statements. On the one hand, some barriers faced by people with ID prevent also the access to health care of other **people with special needs** (see below). On the other hand, the analysis of the identified barriers also shows the limit of the exercise. Indeed, some barriers which hamper the access of one person have no impact on another and inversely. There is **no list of barriers which fits for all**. Several factors influence the barriers ones can faced with and another not.

The setting in which people with ID live is one of the determinants of the barriers they encounter: people with ID living at home with or without their family do not face the same difficulties as those living independently or in institution. For example, staff shift in institution can increase the risk of lack of health information during the weekend while relatives are present during weeks and weekends. Another example is related to health literacy. People with ID living alone and with poor health literacy can be in great danger if symptoms are not identified. In institutions, professionals can have some health literacy and can sometimes have the support of HCP attached to the institution.

The ability of the person to stay focus is another example of the principles that one process does not fit all. On the one hand, long appointments or grouping of appointments better fits with family routines but on the other hand, too long consultations lead to loss of understanding by the person with ID. Anyway, appointment systems are usually reported as not flexible enough, preventing to adapt the length of the consultation to the needs of the patient. Even the way to take an appointment is problematic when people with ID and the supporters face difficulties to make a health care appointment because of weak digital skills. But in another way around, some other people will prefer digital ways than personal talks.

In the hospital setting, some people with ID may require a presence 24/7 during a hospitalization while some others don’t. Also, some will accept the presence of an accompanying staff while others don’t. However, as lack of resource affects institutions of the disability and health sector, the decision on who will stay is more related to human and financial resource than on the needs of the person with ID.

Another difference concerns the health literacy. Some people with ID and supporters may lack skills and knowledge in health notably on prevention, pain assessment, frequent chronic diseases or healthy behaviour while others are broadly informed. Lack of internal communication, incoherence in the discourse of different HCP and discontinued follow-up of information between sectors or settings will have a higher impact on continuity of care when the health literacy of people concerned is low.

The principle of inclusion also illustrates the difficulty to develop a system which could fit to all people with ID. Some people with ID will highly benefit from an inclusive health system. Inclusion of people with ID in the standard patient pathway allows HCP to be more aware of and trained to deal with people with ID, increasing their ability to improve their skills and knowledge about care of people with ID and allowing people with ID to have the opportunity to access to all types of HCP and interventions. But in other cases, inclusion can lead to difficulties in managing behaviour in the waiting room or during hospitalisation, inducing early discharge or missing care opportunities. Therefore, some participants called for in-hospital care trajectory. However, these trajectories can exist without any obligation to use them. Some profiles of people with ID will benefit more from inclusion than others for whom adaptation of the system to their needs is essential to their access to health care.

The administrative identification of people with ID on admission to hospital is also an example of the tension between inclusion and specificity: on the one hand, it may make it possible to improve the quality of care thanks to an adapted organisation of the intra-hospital care pathway dedicated to people with ID; on the other hand, it induces a stereotyped vision of the 'agitated person' who is difficult to manage, which may lead to inappropriate decisions if the principles of inclusion and tolerance are not sufficiently integrated into the hospital or if there is a pressure of profitability weighing down the care staff.

Although this research aims to analyse the barriers affecting the population of people with ID, the findings firstly highlighted that the difficulties faced by this population mirror the difficulties experienced by a wider population: people with communication problems and even those with special needs, which is even wider. Thus, in seeking to identify the barriers to access to health care affecting the population of people with ID, the participants pointed out to barriers that affect a much wider population than the scoped one. Some of the barriers identified appear to be common to most people with difficulties in understanding and expressing themselves. As well as affecting people with ID, these barriers may also affect people whose mother tongue is not common in Belgium, (older) people with sensory and/or cognitive impairments and people with other types of disability. Also, as people with ID are part of a larger group, that of people with disabilities, it is also important to remember that improving access to care for people with disabilities also includes improving physical accessibility to care facilities and devices. Internal signage or furniture are not always adapted to people with disability. Inadequate infrastructures and difficult accessibility in many places occur: lifts and escalators out of order, complicated signposting, difficulty in identifying services.

The barriers faced by people with ID can occur **at all stages of the care process or at one or more specific stages**. Time pressure was identified as a barrier which hamper quality health care at all steps of the health care process while the inadequacy of ambulance for transportation of patients in wheelchairs impact the urgent transport of some people with specific needs. Therefore, some barriers require transversal solutions, mostly on the long term, when others require a focused solution.

The **lack of time to deliver proper (health) care** to people with ID has been mentioned at several times. Similarly, to communication problems, the lack of time could be considered as the top of the iceberg of structural problems. On the one hand, there is an overall lack of (qualified) HCP within the health care system, majored by the COVID-19 crisis. The disability sector is also suffering from a shortage of (qualified) staff for providing health care. The lack of staff could explained by two main interacting motives: lack of attractivity and poor retention.[108] Lack of staff leads to increased workload and thus less time per person. On the other hand, one could say that there is a lack of time because the health care system is mainly organised on a fee-for-service basis: this form of organization is not always suitable for people in complex situations, either because of their health issues, either because of social aspects. *Inclusion asbl* suggests notably to move towards a broad definition of care by considering the needs of the patient (adapted care, empathy, accessibility...) instead of limited care to technical act.

The study of a particularly vulnerable population (in this case, people with intellectual disabilities) also highlighted some **transversal weaknesses of the Belgian health system**: inflexible consultation times that are not adapted to needs; little room for prevention, insufficient funding for coordination, insufficient involvement of patients and their supporters in decision-making; and the lack of health knowledge in the population. Institutional and policy and social awareness of these general barriers could lead to an overall improvement of the system, recognising that these general barriers may have greater consequences for people with ID as part of their differential vulnerability. These transversal barriers also lead to questioning the adequacy of the current financing of health services, which takes little or no account of the profiles of patients with cumulative frailties who may require more time for care, not to take account of clinical complexity but of complexity related to, for example, comprehension and expression disorders. The question of the participation of people with ID in decisions concerning their health emerged from the data collected and refers to the importance of placing the rights of the patient as a guiding principle for the actions of HCP and as an incentive to develop a proactive attitude of improvement and inclusion of people with special needs including people with ID.

Our findings also show that a balance must be maintained between the social and medical dimensions of disability. Although institutions in the disability sector, and especially educators, are not in the business of providing health care, it is however essential that these institutions have the capacity and possibility to give access to their beneficiaries to coherent and high-quality health care, without falling into the trap of medicalising people with disabilities.

6 CHAPTER 6: EMERGING SOLUTIONS AND EXISTING INITIATIVES TO IMPROVE HEALTH CARE ACCESS FOR PEOPLE WITH ID

6.1 Introduction

People with intellectual disabilities (ID) face many barriers to access high quality health care: attitudinal barriers; comprehension barriers; skills and knowledge barriers; programmatic barriers and social and policy barriers. These different barriers concern the different actors involved: people with ID themselves, their professional and informal environment (the supporters), the HCP and the authorities. All data collected on barriers are described in Chapter 5: Barriers to health care access in Belgium for people with intellectual disability.

It is possible to act on different determinants of these barriers to solve them. Those actions which can solve a difficulty or unravel a complex situation can be called ‘solutions. The possible solutions collected in this chapter were systematically recorded and cross-referenced with other sources of data to serve as a framework for a survey of health professionals and experts and stakeholders involved in the health of people with intellectual disabilities (see Chapter 7: Expert consultations on proposal of solutions).

6.2 Methods

Data collection

This chapter results from the triangulation of data on solutions collected by different methods. First, qualitative data on solutions experienced or suggested by people with intellectual disabilities and by their supporters in accessing the health care system was obtained as described in Chapter 5. Second, data on solutions identified by a quick scan of the international scientific and grey literature was described in Chapter 4. Third, additional data on initiatives aiming at improving the access to the health care system was collected by a grey literature search targeting the initiatives mentioned by participants in interviews or nominal groups. When several initiatives were suggested, preference was given to Belgian initiatives. If any was identified, a foreign initiative was then described. Initiatives are presented in boxes in this chapter.

Data analysis

First the solutions identified by the qualitative method were grouped according to the same categorisation as the one used for the barriers (see Chapters 4 & 5 for the presentation of the 5 themes of the categorisation). Inside each type of category, subsections were made according to dimensions of access to health care (see Chapter 1). Then a triangulation with the data from the international literature and from the Belgian initiatives was made. Practical solutions (presenting as short stories in separate boxes) brought by Belgian or foreign initiatives were used to illustrate way to implement theoretical solutions.

Quotes from the qualitative data collection are included in the text to illustrate the findings: these have been kept in original language but have been edited for length and clarity.

Limitations

Most of the solutions described in this chapter emerge directly from the experiences of professionals in the disability sector and of people with disabilities and their relatives. The suggested solutions should be seen as potential or possible solutions. The study of the relevance, feasibility and acceptability of these possible solutions will be the subject of the next chapter.

This chapter does not give a complete overview of the wide range of initiatives aiming at improving access to health care for people with ID currently existing in Belgium. In this section, a selection of initiatives is presented as illustration of possible solutions. This does not constitute an exhaustive list but rather an attempt to present the diversity and the creativity of the associations of the disability and health sectors. Moreover, the selected initiatives were not subject to an extended literature search.

6.3 Results

6.3.1 *Possible solutions to counter attitudinal barriers*

Questioning attitudes and changing habits in the health sector can help to avoid refusal of care, delayed care or the lack of high-quality care opportunity. Indeed, problems of comprehension and expression can explain non-collaboration in care (e.g., the person with ID refuses to enter the ambulance or the medical office). It is easy to figure out that non-understanding can generate anxiety which, in turn, can lead to challenging behaviour. It is often the latter that lead to a refusal of care, on the part of the patients, their supporters or even, by an HCP. In painful situations or in situations of severe discomfort, the patient may react disproportionately to care when he or she is unable to express complaints. All these situations may be exacerbated if the person with ID feels unsecure because he/she is alone, or the atmosphere is not calm.

Lack of long-term treatment compliance may be related to difficulties of adaptation of some persons with ID. This requires the HCP to adapt the usual care management protocol. This is particularly important when the treatment must be implemented for a chronic problem that requires a change in lifestyle and long-term medication. Participants highlighted possible solutions to avoid poor compliance, including empowerment, rewarding and routine, and putting humanity at the centre of the care relationship.

Two major types of actions were identified to achieve a change in attitude: 1) a need for more humanity in the relationship; 2) actions to decrease anxiety.

6.3.1.1 *More humanity in the relationship*

Empathy is a key solution that has been put forward by participants to improve the quality of care for people with ID. A parent of a person with ID explains that physicians need to step into patient's experience. Some HCP, thanks to their capacity for empathy, will spontaneously adopt an appropriate attitude when caring people with ID. Moreover, the empathic attitude should not be limited to the patients. Those around them also express the need for empathic listening. In practice, empathy is rather part of the personality but a participant in a nominal group suggests however a solution: to move towards a health system whose operating bases would favour empathic professionals. No further explanation about this suggestion was therefore shared by the participants.

Another possible solution to improve the care relationship is to raise awareness HCP and health-care institutions' administration of **the added value of the supporters**. Participants pointed out that the presence of the supporters should no longer be seen as cumbersome and disturbing, but rather as an opportunity to access additional information in order to be in tune with the patient. Furthermore, the presence of a trusted relative can reduce the anxiety of the person with ID and allow to reduce the risk of refusing care, notably because of the opportunity to demonstrate care procedures on the supporters. In some hospitals, the presence of a member of the supporters is already accepted to communicate with the person with ID during the hospitalisation. Participants from institutions explained that involving relatives increases compliance with treatment and relieves the burden on educational staff whose duties do not include care. The supporters can often provide valuable support in choosing feasible and acceptable tests. They are familiar with the fears and some behaviours viewed as challenging of the people with ID they care for. As a result, they can give an opinion on the possible impact of certain medical practices and thus allow better anticipation in order to optimise the conduct of an examination, for example. This statement was also highlighted in discussion groups on health care access organised by *Inclusion asbl* in 2019[109]: a group of participants called for recognition of the legitimacy of the supporters within hospital structures. Clarification with HCP of the legal role of the trusted or reference persons is necessary to always legitimise their presence.

> *"Anekdote dat W panisch was van plank in de revalidatie. Ik heb dat kunnen vertellen, en dan is die plank opzijgezet en dan weer langzaam geïntroduceerd. We hadden die de aardbevingsplank genoemd en dat begrip van thuis werd dan hernomen in de kiné praktijk. En dat geeft vertrouwen." (Parent 1)*

> *Donc quand on est arrivé au [nom de l'hôpital], j'ai expliqué la situation de D. et, à ma grande joie là, je dois dire, ça a été bien, on m'a laissé rester avec lui. Et ça, j'étais contente parce que je pense que D. n'aurait pas su expliquer vraiment ce qu'il avait. Mais on voyait vraiment qu'il n'était pas bien du tout. […] Tout où je pouvais aller, j'ai pu aller avec lui. Y a qu'un examen où on m'a demandé de rester dehors et d'attendre dehors mais autrement je pouvais rester avec lui (Parent 2)*

For people with ID without (available) supporters, mobilising hospital volunteers to stay close to them is a possibility expressed by participants. The ideal process is to start the accompaniment at the ED. Box 9 gives an example of this type of service.

Box 9 – Hospital accompaniers of Walpole, Belgium

WalloPoly offers a hospital support service for people with multiple disabilities. Specialised educators replace the informal caregiver who is unable to attend the hospitalised person's bedside. They look after the person's well-being while respecting his/her rhythm. This service is subsidised by the Walloon region and is subject to a charge.[20]

Details of the initiatives at http://wallopoly.be/garde-a-lhopital/

Improving mutual respect between professionals from different sectors as well as a better knowledge of each other's workings were also put forward by participants as a possible solution to avoid unconstructive attitudes such as the fear of disturbing or wrong *a priori* on the capacity to provide care in specialised institutions for people with disabilities. To achieve this, from the discussions, the following two solutions emerged: (i) increasing collaboration between the disability and health sectors and (ii) encouraging meetings between professionals during their studies or during joint training courses. One cited example of successful collaboration is the development of transfer forms by local emergency service and partner institutions for people with ID to facilitate information transmission to and from the hospital. The presence of a specialised institution in the vicinity of a hospital is perceived as a facilitator that allows HCP to gain experience through contact with referred people with ID. Another illustration of good collaboration and respect is when HCP trust the educational team to decide whether it is necessary to have a accompanier 24/7 or not with the person with ID. Participants highlighted that educators have good feeling to determine the level of presence required: on a case-by-case basis, some persons with ID can stay on their own, others need an accompanier at their side. This accompanier can even be in some exceptional and serious situation the coordinator doctor of the institution. The institution can also sometimes ask relatives to be present during transfer and hospitalisation.

As suggested during the nominal groups, there is also a **need for reducing the social distance between HCP and patients and for improving the reception** in health services to help patients or their supporters to come out of their shell and, for example, dare asking for a service, an explanation, dare saying that they have not understood (Box 10).

Box 10 – Babbelgids by Dito, Belgium

This tool helps people to discuss with their doctor. Indeed, medical visit often includes difficult vocabulary, not enough visual support and too much information in a short time. This induces a risk of misunderstanding. The Babbelgids allows to prepare the visit, to ask for help and questions and to write down the treatment and advices. The tool is available only for members but registration is free.

See more on this project on YouTube: https://www.youtube.com/watch?v=PggvdKlRJz8

As stated by *Inclusion asbl* ,"*feeling welcomed and expected by staff is a priority request of people with intellectual disability".*[20]) *Inclusion asbl* wants to promote and regulate the use of the pictogram S3A in Belgium (see chapter 1). For the time being, although some institutions are already using it, there is no official verification body to ensure that the organisation that has affixed it offers a truly adapted welcome.[23]

In the US, the CDC and Special Olympics highlight the important that reception staff offers high level welcoming attitudes (Box 11)[110],[24]

Box 11 – Communication tips for reception staff, Special Olympics

- Speak directly to the individual, not to his or her companion, and let the person finish before responding.
- If you offer assistance, wait for the offer to be accepted and for specific instructions. If you aren't sure what to do, ask.
- If you are having difficulty understanding a person, it is ok to ask them to repeat themselves.
- Operate under the assumption that people with ID are capable of making their own decisions.
- Do not touch a person with a disability or their mobility aid unless invited.
- Don't talk "down" or use "baby talk" to a person with ID, instead communicate as you would with any other person of that age.
- When speaking to someone with a vision impairment, always identify yourself and who may be with you.

According to participants, a sign of improved reception and demystification in the health sector could be that HCP communicate more likely with people outside the health sector. Indeed, as expressed in the nominal groups, a better attitude of HCP towards communication to and from outside, especially with people from outside the health-care sector will improve trust in and decrease reserve towards HCP. This interaction between the health sector and the outside world becomes fruitful as soon as there is listening and respect between the two interlocutors.

Accordingly, a careful reading of files and documents transmitted to HCP by the supporters is also seen as crucial for the continuity of care and to avoid refusal of care. Participants highlighted that any consultation to an HCP or any visit to the ED by a person with ID should be well prepared. It is therefore important to give sufficient importance to information transmission documents, especially those describing the needs and the functioning and communication mode of the person with ID. For example, participants advice HCP to review the history of consultations and written requests in the support consisting of a booklet containing the medical follow-up of the person with ID. The WalloPoly hospital passport is an example of it (Box 29).

6.3.1.2 Decreasing anxiety

Participants in the nominal groups suggested solutions for reducing fear facing health examinations by acting on: (i) environment; (ii) communication and (iii) system. If these options are not possible, alternatives such as sedation are sometimes requested, even by the person with ID himself/herself. Preventive and forward-looking vision allow to avoid useless or stressful examinations.

Acting on the environment

First, it was reported that creating a **soothing atmosphere** works to successfully care for people with ID. The creation by the HCP of an environment conducive to share information and to initiate conversations on sensitive health topics is highlighted as a solution for a better communication by SO.[24] In the nominal groups, it was said that the use of positive wording encourages habit change by people with ID. *Inclusion asbl* gives the following advices to HCP: "*Adopt a benevolent and reassuring attitude; introduce yourself, provide name tags; explain simply how the care, consultation, examinations, etc. will be carried out; explain the rules to be followed (e.g. not to move during an examination). […]; make it clear, by what you say and your attitude, that you have plenty of time for the person (if you are nervous or impatient, they [people with ID] will feel insecure and may shut down quickly, given their high emotional sensitivity)".* [20]

The dentistry service of the *Cliniques Universitaires Saint-Luc* is an example of a structure which has adapted its practice to the needs of people with ID (Box 12). International examples exist like at the University Paediatric Dental clinic in Virginia (USA), where a crossover study concluded that the cooperation to long-term dental care of children with ID was significantly higher within a sensory adapted dental environment setting than within a regular dental environment.[111]

Box 12 – Specialist dentistry service, *Cliniques Universitaires Saint-Luc*, Belgium

"The patient is of course accompanied. More than the others, this type of patients always come accompanied by their parents or an educator, as it is important that they feel safe during the examination.[…] During the first consultation, we do not carry out any treatment. It is a contact consultation, a confidence-building consultation, where we evaluate the care to be carried out. […] Our patients are mainly adults and children with motor disabilities and/or intellectual disability. Some of them rarely go to the dentist. So they often arrive in emergency situations where major intervention is required. But even more than with others, empathy, patience and speed are essential.»[112]

During a hospitalisation, participants report that it is sometimes necessary to recreate the usual environment of the people with ID to reduce their anxiety. For that, the staff should know in detail the habits and experiences of the persons. This can be achieved by a careful reading of the booklet describing those habits.

Participants highlighted that **creativity** is sometimes needed to increase trust in the care relationship, which is a condition to decrease anxiety. Amical and positive attitudes were mentioned as supporting when it comes to convince someone to go into an ambulance or attend a consultation. It is notably important to provide creative solutions to improve care adhesion. Various means can help a person with ID to stay in bed: games, books, magazines, television. In the disability sector, initiatives exist to organise holiday stays adapted to the needs of people with ID based on creative solutions (see Box 13). This same type of approach (using a matrix to assess and respond to needs) could be considered in the context of hospitalisation. A participant suggested that fun events such as 'Rock voor Specials' should be a good opportunity to screening. Special Olympics uses already this approach through play, sport and fun to facilitate access to health for their athletes (also see Box 16). Using a system of rewards to encourage participation in tests, such as fun activities or gifts is recommended by participants.

> *"Hij was na een operatie aan zijn voet, zo bang om de nietjes eruit te laten halen, dat de dokter hem even kort wou verdoven. Bij de 2de operatie, hebben ze oplosbare draadjes gebruikt (om die angst te vermijden)" (Parent 1).*

> *"Hij wou eens niet gaan liggen op de operatietafel en dan heeft de arts hem niet verplicht, maar hem eerst eens laten ademen aan het beademingstoestel en zo stapsgewijs toch kunnen verdoven" (Parent 1).*

Box 13 – JOMBA, holidays for children and young people with special needs, Belgium

These are young people with a physical or mental disability, autism, behaviours viewed as challenging, but also young people who need just that little extra attention, such as bedwetting young people. A matrix is drawn up for each JOMBA holiday (the JOMBA matrix). This helps to find, together with the right target group, the ideal holiday that suits the needs of the person (with a mental disability). The JOMBA matrix maps out what support is needed in terms of communication, mobility, structure and self-reliance.[113]

More information on the website: https://www.kazou.be/jomba/over-jomba/

Some other ways to alleviate the anxiety of people with ID were also suggested during the nominal groups. First, for those who can, the use of digital tools helps that the supporters can stay in touch with the person and support the HCP from afar. Logistical support can help people to take responsibility for their own care as independent people can use a digital tablet to communicate with the carer when difficulties appear in their health care management. Digital assistance also helps to reassure the person with ID living in autonomy, particularly when taking medication. Particularly for long-term care, recreating a routine helps: for example, the introduction of a weekly medication schedule is often welcomed. Also, organisation of guided tours of hospitals dedicated to people with ID allows to de-dramatize the hospital. This kind of event was proposed in 2019 by *Inclusion asbl* in the framework of the campaign "*Accueil… et moi !* ". Humour was also described as central to the care relationship, as participants with ID reported in their interviews.

> *"Maar onlangs hadden we een topverpleegkundige bij een slaaponderzoek. Die maakte steeds grapjes." (Participant 2)*

Acting on misunderstanding

Main aspects of adapted communication allow to improve the understanding of people with ID.

The use of an **accessible language and of images** allows to improve the understanding of people with ID when the professional aims to be understood (see Box 14).[24]

Box 14 – CDC tips for acting on misunderstanding

The CDC suggests the following[110]

- Incorporate pictures, cartoons, videos and dolls with anatomic parts when you gives medical explanations
- Allow the patient with ID to interact with the teaching materials
- Provide the materials for home to allow further discussion with close carers
- Use device and materials adapted to the cognitive level of the person

Also, according to the participants to the nominal groups, the use of illustrations, the repetition of information, as well as a range of communication skills have been reported to be useful in dealing with a person with ID.

First, it is said that speaking directly to the person affected by the care and not to the person in the room who has the best understanding level. To ensure that information is understood, the HCP should ask the person with ID to repeat the given information. For people with ID, being personally addressed by the HCP is valued.

> *"Dokter spreekt tegen mij. Het gesprek gaat echt wel via mij, het is gewoon dat ik het veiliger vind dat mama of papa erbij is. Ja, ik krijg genoeg uitleg van de dokter. Ook in het ziekenhuis. Vorig jaar ben ik naar spoed moeten gaan met een ontstoken duim, maar toen ging dat eigenlijk heel goed. Die sprak mij goed aan." (Parent 3 and participant 3)*

> *"Dit is een heel belangrijk iets. W is de patiënt en moet een bevattelijke uitleg krijgen. Ook goeie ervaringen, geen onnozele uitleg maar wetenschappelijke uitleg maar op zijn niveau. Er zijn artsen die het kunnen. Dat ontbreekt nog in de opleiding". W: "Mama is niet de patiënt, ik ben de patiënt" (Parent 1 et participant 2)*

Second, the use of language appropriate to people is an essential skill to acquire when dealing with people with ID. Avoiding medical jargon is the first step in the process of building trust and understanding. It is essential to use short sentences and simple vocabulary. When addressing adults, participants advised to avoid childish language.

> *"Participant 2: Zorg dat […] de dokter ook praat tegen mij en geen moeilijke woorden gebruikt.*
>
> *Parent 1: Ze zouden allemaal de wablieft-krant eens moeten lezen, dat is klare taal." (Participant 2 and parent 1)*

Third, participants highlighted the importance of understanding how people with ID react in general. Indeed, people with ID have a more-emotion-based functioning. As intellectual functioning is limited, people with ID tend to react by considering the affectivity they feel. He/she picks up the emotional vibrations more than the symbolism of the words. There is therefore a gap between what it said and what the person with ID understands.[20],[114]

Fourth, it is crucial to explain the plan of care to the person with **illustrated materials** (health comics, pictograms, videos, photos). Illustrations have also a role in explaining the different HCP, the different places of care or equipment and the situation to the patient. Unia suggests that HCP communicate using non-textual media such as videos to make themselves better understood. For example, a participant explained that an ED staff received a training in using appropriate tools to explain to people with ID the care that will be done with pictures and pictograms. Suitable material must be available like the set of *SantéBD* booklets which is easily accessible and addresses many health care issues (see Box 15). Using digital tablets facilitate the transmission of illustrated and animated materials.

> *"Ik denk dat dat te maken heeft met voorspelbaarheid. Het feit dat ze er meer over weet, dan kan ze beter aanvoelen wat er gaat gebeuren. Dat vindt ze wel belangrijk. Het zou wel helpen dat als er ingrepen moeten gebeuren bij personen met een verstandelijke handicap, dat filmpjes laten zien wat er gaat gebeuren" (Parent 3)*

Box 15 – SantéBD, France

Developed by *CoActis Santé Association*, *SantéBD* proposes a wide range of comic strips to prepare people with ID for medical appointments or to explain the different stages of care. There is a large number of them concerning various health services.

The *SantéBD* project was born in 2013 following the French ministerial report known as the "Pascal Jacob Report" on access to health care and health for people with disabilities. This report denounced the too numerous renunciations to care for people with intellectual disabilities and autism and the lack of communication tools available to explain health in a simple and adapted way.

The association CoActis Santé then brought together families, health and medico-social professionals, hospital federations, patient associations, institutions, etc. to create a single and free tool: the *SantéBD* tool. this addresses everyone and meets the specific needs of each type of disability: intellectual disability, autism, aphasia, sensory, cognitive and motor disabilities, etc.

SantéBD was officially launched in June 2016 with the launch of the santebd.org website and the *SantéBD* mobile application.

More information and downloadable sheets on: http://www.santebd.org

Fifth, people with ID benefit from **repetition of the information**. Several examples were given during the nominal groups. The person may visit the general practitioner for further explanation after a hospital visit. A specialist may also schedule several consultations at different times on the same health topic (see Box 12 for illustration). *Inclusion asbl* gives such advice to HCP in its awareness-raising brochure: "*It is advisable to ask precise questions; not to give too much information at once and to repeat it several times; and finally to check that the message has been understood*"[20].

> *« Avec mon fils adulte handicapé mental, nous avions convenu de demander la vasectomie. Le médecin que nous avons rencontré a d'emblée dit : « Je n'ai jamais eu une personne handicapée dans mon cabinet. » Malgré cela, nous sommes sortis très confiants. En effet, malgré son ignorance du handicap, il a pris le temps de bien expliquer ce qui allait se passer et a proposé un second entretien avant de passer à l'intervention. Sa franchise et ses explications claires ont vraiment eu un effet bénéfique sur mon fils qui a abordé le traitement avec grande sérénité. » (Retrieved from Altéo, 2019 [105])*

Members of a group of parents from *Altéo* reported the French experience of *Handiconsult*, which allows the preparation of consultation or hospitalisation care in an individualised way with fictitious situations and prior contacts with the carer[yy].

There are, however, some reservations that have been expressed by participants about the repetition of information. On the one hand, if a consultation lasts too long, the concentration of some people with ID may decrease over time and the message may not be fully understood. On the other hand, HCP lack time to explain several times with different materials and may thus rush in trying to do so in a short amount of time, bombarding people with information.

Acting on the system

Some of the solutions proposed by participants concern a broader and flexible vision of health care system. Indeed, a preventive and forward-looking vision can allow to avoid difficult situations while empowerment of patients can improve compliance. Changes in practical organisation like flexible appointment system and emergency consultation in general practice can also improve the access to health care.

A preventive vision of care would make it possible to avoid heavy consequences in terms of suffering or denial of care for some people with ID and difficult decisions for their supporters. Some participants therefore suggested that prevention should be given greater importance and that participation should be optimised, by writing invitation letters in Easy Read format. The organisation of an annual preventive health check-up was also mentioned as done in Canada.[115, 116] Some systematic check-ups already exist in some places. They concern cardiology, ophthalmology, dentistry, orthopaedics or ENT.[117] An example is given by the Healthy Athletes Programme of Special Olympics (see Box 16).

Box 16 – Screening programme of Special Olympics

Since 1997, Special Olympics Healthy Athletes® offers free health screenings and education to Special Olympics athletes in a welcoming, fun environment. They offer health screenings in eight disciplines: history and physical exam; vision; audiology, dentistry, prevention and nutrition, emotional health, physical therapy and podiatry) (see also Chapter 1: Introduction).

More on the website: https://www.specialolympics.org/what-we-do/inclusive-health/healthy-athletes

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[yy] Handiconsult is developed at the CHU Amiens, France: https://www.chu-amiens.fr/handiconsult/

Next, participants highlighted the importance to have a **forward-looking vision** as wondering whether any feasible treatment is available for this person before undergoing a diagnostic exam. It is therefore suggested to be cautious about screening which can trigger anxiety, and to always anticipate the beneficial options for the patient in case of a positive result. For example, *Inclusion asbl* suggests involving the supporters in the preparation of consultations and hospitalisations: "*Anticipate the reception by preparing the consultation or examination in advance with the person and/or their informal caregiver. It is important to talk with the educators or the resource person before the medical visit to get to know the patient's sensitivities better and thus reduce psychological obstacles"* (Adapted form [20]*)*. Participants highlighted the added value of notifying in advance hospital staff of the arrival of a person with ID at the consultation department: it allows to improve the punctuality (avoiding delay and long waiting time in waiting room) and to plan more time for the consultation slot. Before an arrival at the ED, a phone call made by the supporters is precious in order to prepare the reception.

> *« Je suis content des soins à part le fait de la double prise de sang et la double prise de tension ». (Participant 1)*

According to participants, **empowerment of patients** is important to improve the quality of care and especially compliance. But it requires to help the person to be able of being an actor in his/her own health pathway. To do this, the person needs to be informed in an understandable way so that he or she can take a stand. Discussing with the person with ID is the priority as pointed out by participants. The same finding is shared by *Inclusion asbl* [20], by the results of the scientific literature analysis[118] and by the CSNPH - NHRPH in its opinion n°8 of 27/03/2020.[119] The ideal is to provide the opportunity for the people with ID to explain how they prefer to be cared for. Notably for long-term care, involving the people in the care planification, especially by asking what is important to them. This helps the people feeling more concerned by a change induced by a new condition or treatment.

Tools exist to collect the opinion of people with ID on their care preferences (see Box 17). According to a participant of a nominal group, people with ID must be informed about the examination to be carried out; if they do not want to carry out the examination, their choice must be respected. People with ID could also express whether they prefer to be admitted in an adult unit or in paediatrics. For the Convention and the UN Committee, the free and informed consent of the patient to medical treatment is essential for the provision of health care to persons with disabilities.[1] Moreover, the CSNPH – NHRPH insists that the patients' choices can also be expressed by their legal representative, if the patients are no longer able to do so (in accordance with the provisions of the legislation on patients' rights.[119]

Box 17 – Smile Booklets "Ma Santé", *Inclusion asbl*, Belgium

The Smile Booklets aim to enable people with intellectual disabilities to express their needs and improve their quality of life. There is one booklet concerning each activity of life: work, family, food, journey, rights, etc. A booklet has been specifically developed on the issue of health. The content of the booklet includes definitions and explanations in Easy Read format about health and rights of the person in the health sector, 16 sections collecting data on the opinion of the person about different aspects of health care and a last section for personal notes.

The booklet Ma Santé (My Health) is available on https://www.inclusion-asbl.be/wp-content/uploads/2018/10/Livret-Smile-4-Ma-sant%C3%A9.pdf

According to the international literature, it is advised to embed people with ID into health institutions organisational culture, and, as such, promote diversity.[24] Such cultural change are essential to fight attitudinal barriers. It requires that not only HCP changes its mind but also the managers (see Box 18)[86]. The establishment of **partnership with local associations for people with ID** is a good way to learn how to develop inclusive practices, to hire people with ID for a meaningful job, and to challenge negative attitude amongst staff.[84],[33] Both conscious and unconscious discrimination amongst healthcare staff contribute to inequities in health [120,31]. Also in the primary care, people with ID ask for more collaborative relationship with their provider in managing their health conditions and status. It was shown in Australia that simple human interaction with people with ID is an effective mean to increase GP's attention to health needs of people with ID and to improve health promotion and disease prevention amongst them [121,122,8.]

Box 18 – Care path for people with ID, *Hôpitaux Universitaires de Genève,* Switzerland

This large-scale project at the *Hôpitaux Universitaires de Genève* aimed at adapting the internal care system to the needs of people with ID and notably to change HCP and staff attitude. The official commitment of the hospital's director gave a boost to the initiative and made it possible to change the status of people with ID from invisible to the one of a vulnerable population with specific needs. A charter has been established, the adequacy of care for people with ID has been integrated into the hospital's strategic plan and quality of care programme.[86]

Adaptability of the appointment system to the situation of each people with ID is required according to participants. First, for those who lives in autonomy, it is important that the HCP agrees to plan consultations respecting the routines and the need for regularity of the person with ID. For example, one participant suggested that consultations should be scheduled at a fixed time: always on the same day of the week and always at the same time of the day. The aim is to establish a routine, a logic in the follow-up and appointments. Second, difficulties can also arise when there are delays or crowds in the waiting room. For this reason, it was reported that morning appointments were preferable. Third, it is also reported to keep the same carers: group practice in general practice can also destabilise the care of people with ID as they are reassured to be seen by the same HCP. It was also advised, in the nominal groups, to plan the medical appointment outside the usual schedule of the usual activities of the person to improve the adhesion and decrease the anxiety.

> *“We waren iets te laat, maar K was al helemaal gespannen. Op het blad stond er een specifiek uur, dat leidt tot onnodige spanning. Ik heb haar wel moeten geruststellen.” (Parent 3)*

> *« […] chez la kiné, je sais que c’est le mercredi à 15h une fois tous les 15 jours. Voilà. C’est important comme ça je ne m’emmêle pas les pinceaux. Parce que changer … Pour le dentiste par exemple, c’est pareil, c’est le matin à 10h soit le mardi soit le jeudi. Ça ne change pas d’heure et de jour. J’ai un bon feeling pour persuader les médecins […] C’est parce que je parviens à l’imposer. Y en a certains qui ne veulent pas que le patient impose ses jours et ses heures. C’est moi qui insiste pour que ce soit [comme ça] » (Participant 1).*

> *“Ik heb geen voorkeur voor tijdstip (ochtend of avond), hangt eerder af van mijn planning van vrijwilligerswerk” (Participant 3)*

Another vision of the health care that could be a positive change for a better access to health care for people with ID is the way that HCP see and use **sedation**. From the nominal groups, it appears that sedation is not used often enough, especially for blood sampling. Emla®[zz], MEOPA[aaa] and hypnosis should be considered more often. It is suggested to raise awareness and train HCP on the benefits and indications of sedation (see Box 19).

> *“Bloedafname heeft bij hem ook al een hele geschiedenis. Vroeger werd infuus in zijn handje geprikt, maar op den duur zaten we met 5 mensen op hem en dan lukte het nog niet. […] Terwijl je nu al met een beetje lachgas hem kalm krijgt. Nu hij volwassen is, dan leert hij het weer zonder lachgas.” (Parent 1)*

[zz] This cream contains local anaesthetics. It is used to numb the skin before a painful medical procedure (minor surgery, injections, blood tests, leg ulcer treatment, etc.)

[aaa] MEOPA (*Mélange Equimolaire Oxygène Protoxyde d’Azote* – Nitrous Oxide) : A colourless, odourless gas composed of a mixture of 50% oxygen and 50% nitrous oxide that acts by inhalation. This mixture is anxiolytic and provides surface analgesia.

Box 19 – Use of sedation techniques in dental care, Belgium

> *“Dental care for people with disabilities can be performed in a vigorous state, i.e. when the patient is fully conscious. However in case of limited collaboration, the dentist will opt for conscious sedation with MEOPA, a gaseous mixture which, when inhaled, has an anxiolytic and calming effect and suppresses the sensation of pain (surface analgesia). However, if the patient's cooperation is not possible, despite the doctors' gentle and reassuring approach, and/or the number of dental procedures to be performed is greater, general anaesthesia is considered. In this way, patients will receive the best care with maximum comfort”.*[112]

The last suggested change in attitude concerns people with ID and their supporters: **improving the recourse to the GP in case for acute and / or urgent but non-life-threatening emergency instead of going to the ED**. The planning of time slots reserved for emergencies is then seen as a necessity by participants to ensure the availability of the GP. In an institution, participants explained that a kind of protocol and hierarchy of professionals to be notified in case of acute medical problem was established: the educator notifies the nurse responsible for the beneficiary's health condition. This latter then contacts the GP who decides whether to go to the ED. For at home situation, it is suggested to encourage the development of better digital skills, better communication skills and better organisational skills of people with ID and their relatives, as the decision of going to ED could be guided by the lack of requirement for an appointment. The clear advantage is the already established relationship between the person with ID and the GP. The anxiety generated by the emergency is not compounded by the fear of the unknown.

Key messages

- HCP should involve more the patient and the supporters in the care decisions. The empowerment of people with ID is at the centre of the solution to counter attitudinal barriers, notably about care refusals and lack of compliance in case of chronic care. Tools exist to support people with ID to become actors of their health. The added value of the supporters is also crucial in the empowerment process.
- HCP need to improve their communication to control the anxiogenic factors related to care and to anticipate health consequences by prevention and early detection.
- Health-care institutions must implement adjustments allowing the supporters to always stay with the person with ID in all places, to make the appointment system more flexible and to encourage empathic and creative staff members initiatives.
- The supporters need to rely more on GP for acute and / or urgent but non-life-threatening emergency situations.

6.3.2 Possible solutions to counter knowledge and skill barriers

Awareness, training and practical or human supports are the main ways to counter knowledge barriers and lack of skills. They can be addressed to HCP, informal caregivers, people with ID, or professionals of the disability sector.

6.3.2.1 Health-care professionals

As previously identified, some HCP lack knowledge about intellectual disabilities and how to care for people with ID (see Chapter 5: Barriers to health care access in Belgium for people with intellectual disability).

Knowledge on ID

One solution suggested in the international literature to address knowledge and skills barriers concern the improvement of the collection of data on the specificity of health care of people with ID and on the health status of them. To optimise data collection, people with ID should be systematically included in national and regional public health surveys to allow comparison with people without ID. The priority should be put on the description of the unmet health care needs. Another focus should be on the monitoring and the evaluation of the new interventions.[31]. At the University Hospital of Geneva, the steering committee of the project on the pathway for people with ID suggested to add a flag in the hospital electronic health record of patient with ID in order to optimise the preventive aspect of the care. Thanks to this flag, the researchers can collect epidemiological data to evaluate efficiency of newly-implemented adjustments.[86]

During the nominal groups, it was also suggested to **raise awareness** among all staff to the specificities of people with ID. Not only hospital staff should be trained but also ambulatory HCP, such as home nurse and GP. Awareness raising can be done through information campaigns and workshops on demand. Launched together by *Inclusion asbl* and *Handicap & Santé*, the campaign *Dites aaa*[bbb] aiming at improving reception, support and accessibility for people with ID, (named "persons with specific needs" in the campaign) proposed those actions. A focus group organised by *Inclusion* with parents of persons with ID recommended in 2019 to train care staff and generalise awareness.[109] They proposed to give credits for disability-related courses in the standard curriculum and to involve associations such as *Inclusion asbl* to deliver continuous training, e.g. at the LOK-GLEM. In parallel, awareness can also be raised by interacting with persons with ID and listening carefully to the advice of their supporters. This can occur through volunteering with people with ID during basic cursus of HCP or as part of educational events (see Box 20). One example of optimal awareness is when the HCP knows very well his/her patients and can detect the symptoms behind the behavioural changes.

> *"Ook verwijderen van plakkers na onderzoek is een probleem en vaak staan de verpleegkundigen daar niet bij stil. Alles moet uitgelegd worden, verklaard worden, anders is dat een ramp. Oplossing zou zijn: begrip creëren bij mensen en uitleggen dat door uitleg, voorspelbaarheid te geven en ouders te betrekken hoe zij dat thuis zouden aanpakken. Anders ga je in de strijd met de patiënt" (Parent 1)*

Box 20 – Special Olympics Health Congress, Belgium and Netherlands

With Special Olympics Netherlands and Johnson & Johnson Families of Companies in Benelux, Special Olympics Belgium participated in the organisation of health-related conferences. During these congresses, various and current themes were adressed, allowing doctors and medical students to learn more about the needs and expectations of SO athletes. The aim is to make HCP feeling more comfortable when caring for people with ID. Collaboration with health care professionals from universities and colleges that have curricula corresponding to concern disciplines is very important for the healthy athletes programme. Many students participate as volunteers in the National Games, giving them the opportunity to carry out health check-ups while gaining experience with people with intellectual disabilities.

See more on:
https://www.medischcontact.nl/specialismen/specialisme/artsen-voor-verstandelijk-gehandicapten-avg.htm
https://www.knmg.nl/opleiding-herregistratie-carriere/geneeskundestudie/overzicht-opleidingen-1/arts-voor-verstandelijk-gehandicapten.htm

According to the international literature, the first step in the improvement of health care for people with ID is also to simply raise awareness amongst health care staff and managers of health care services and institutions on the barriers faced by people with ID and on the need for reasonable adjustments to overcome those barriers.[31,24] At the Geneva University

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[bbb] Discover more on the campaign *Dites aaa* (litt: Say aaa) (in French): http://ditesaaa.be/

Hospital, a video is available about people with ID health needs and legal rights to easily spread knowledge amongst staff.[86]

In parallel, specific training of HCP can lead to the development of positive attitudes, communications skills, awareness of legislation (informed consent), responsiveness to the additional needs of people with ID and awareness of the health problems more prevalent amongst people with ID.[31] Participant nurses in this study reported that contact with people with ID should be a priority.[8,123]

Box 21 – Training for HCP, *Hôpitaux Universitaires de Genève*, Switzerland

At the *Hôpitaux Universitaires de Genève*, the specific pathway project for people with ID included three types of training adressed (i) to in-hospital HCP, (ii) to students in nursing and (iii) to students in medical school. The innovative training programme for in-hospital HCP is implemented on three levels, involves a person with ID and uses a simulator of care situations for people with ID. First level, a flash training of 15 minutes targets every physician and every head nurse of the hospital and takes place during unit visits. It delivers only take-home-messages about four themes: "Careful! Vulnerable population"; "Specific health conditions"; "Atypical symptoms and pain expression"; "Call the ID physician or nurse if needed". The second level of training is a two-hour session for HCP of the emergency department and other sensitive sectors like neurology and intensive care units. And the third level is a five-day training to any interested HCP or staff or manager. This training includes the following topics: intellectual and developmental disability, autistic spectrum disorders, rights and consent, self-determination, communication and pain identification, behaviours viewed as challenging, specific health issues and dental care.[86]

Experts' opinion converge to the importance of hiring people with ID to provide input on and/or to conduct training.[24],[31] As explained by Northway, "*a key recommendation of the Michaels Report (2008)*[124] *was that […] people with intellectual disabilities should be involved in the provision of both undergraduate and postgraduate health professional education*". Similarly, Northway summarises the work of Pelleboer-Gunnick *et* al (2017)[125] which stresses that "*both 'contact and collaboration' are needed with 'experts-by-experience' in the education of health professionals*."

Another way to improve the knowledge and skills of HCP is to organise special days entirely for people with ID (see Box 22). The whole institution and its HCP are dedicated to people with ID. Indeed, these days have three objectives: to provide care, to raise awareness of HCP and to give the opportunity to people with ID to observe the functioning of the hospital and its services.

Box 22 – Down Syndrome days, The Netherlands

In the Netherlands and in some university hospitals in Belgium, an original way to raise awareness among all hospital staff is the organisation once a year of a full day of care dedicated to people with ID (mainly Down syndrome patients). It is an interesting initiative whichs allow all the professionals within a hospital to meet people with ID and to learn more about their needs.This kind of initiative is often organised by existing specialised teams

See more: https://www.antoniusziekenhuis.nl/down-team

An additional way to improve the quality of care for people with ID is to use or seek advice from **experienced HCP**. It is not necessary, according to the participants in the nominal groups that all HCP are trained in the specifics of the many syndromes that cause ID. What is important is that each HCP has access to a telephone number of an **expert in ID** which can give advice. It is also important that a trust person can help in the communication process. According to participants, being trained as a specialist in the care of people with ID is more about empathy, relational aspect and field experience than about biomedical and pathophysiological aspects. The training should preferably take place on an elective basis rather than as mandatory curriculum. As pointed out by participants, it seems not appropriate to increase the medical cursus by deep training on precise physiopathology of ID. The most important is to be confronted with people with ID patients during practical training (internship). However, it is interesting to note that in the Netherlands, a three-years training exists for medical doctors to specialise in disability care[ccc]. In Belgium, participants explained that HCP of the neuro-paediatric services are more aware of tools and methods of communication adapted to persons with ID and can manage all types of pathologies in children with ID.

Communication skills

Beyond the lack of knowledge, certain skills seem to be lacking, such as communication skills. However, the CSNPH - NHRPH insists that doctors should always be able to communicate with the patient, regardless of the degree of disability or illness and regardless of the patient's modes of communication (sign language, plain language, etc.).[119]

According to international literature, communication is crucial for high quality healthcare. In Israel, a quantitative study amongst GPs in Israel concluded that the increase of GPs' exposure to patients with ID within training improves effective communication with patients with ID.[126] It shows that the subjective report by GPs of having knowledge on ID issues increased utilisation of effective communication principles. Similarly, the fact that GPs having more patients with ID in their patient population also predicts an increased utilisation of effective communication principles. The results of the study also show that GPs provide clearer information that allows patients to make their own medical decisions when they see more patients with ID. In addition, they do not think that treatment of this population group is not desirable, they do not present negative affect facing people with ID and they perceive better that treatment of people with ID is part of their role. An effective preparation of ID patients for treatment was also predicted by a higher perception amongst GPs that treatment of people with ID is part of the GP's role, as well as higher perception that people with ID are unable to make their own choice.

Techniques exist for communicating effectively with people with ID. Training in plain language is reported as invaluable in improving care of people with ID (see Box 11).[127] Participants spoke of a greater importance of training nurses in Easy read communication methods and focusing on raising awareness about plain language among physicians. The 'know how to simplify' rules help to make information accessible.[128] They have been developed by *Inclusion Europe*. They are a guide to writing plain language texts. They should contain only the essential information, be written and presented in the most direct way possible and be understood by the widest possible audience.

Box 23 – *Wablieft*, Belgium

A Flemish organisation, *Wablieft*, promotes the use of an easily comprehensive language. Target population of this organization is not only focused on people with ID, but to all persons with comprehension difficulties. They offer a newspaper with easy accessible information about the daily news and a digital library of Easy Read books. Next to the offer of the newspaper and the books, the organization offers also training and advice on how to adapt texts from non-profit organisations or authorities to a Easy Read text. To increase the awareness about the need for easy read texts, a yearly price (*Wablieft-prijs*) is attributed to Belgian persons, organizations or projects which used easy read language to increase the accessibility of information for everybody.

See more on (in Dutch) : http://www.wablieft.be/nl

As one might expect, and as the participants confirmed, empathy is essential for the delivery of high-quality care to people with ID. Empathy is innate in some people and can be acquired by others. However, as it is not present in everyone, the opinion gathered from the participants is to favour an "on-demand" training offer such as continuing education or optional courses rather than a systematic training in the basic curriculum of the carers.

[ccc] See more on these training programs (In Dutch): https://www.medischcontact.nl/specialismen/specialisme/artsen-voor-verstandelijk-gehandicapten-avg.htm and https://www.knmg.nl/opleiding-herregistratie-carriere/geneeskundestudie/overzicht-opleidingen-1/arts-voor-verstandelijk-gehandicapten.htm

Management of anxiety and challenging behaviours

The management of anxiety and behaviours viewed as challenging also seems to be precarious. Some participants suggested the need improving ability of HCP to manage anxiety and those behaviours. A given option during the nominal groups is that HCP can be supported by the mobile psychiatric liaison team to help them to manage such anxiety and behaviours of people with ID. An illustration of the involvement of the psychiatric unit was suggested by a participant (see Box 31).

6.3.2.2 *Informal caregivers*

Informal caregivers may lack knowledge about health and have difficulties in understanding the problems of their relative with ID as shown in Chapter 5). However, it is important that people with ID can understand what is happening to them. The presence of a chronic illness can be a factor that increases the anxiety of people with ID, especially if they don't understand what is going on.

It is therefore suggested to optimise the training of informal carers on disability issues. One participant explained the major added value of a training proposed by Similes[ddd]. This training notably teaches parents to let their child with a mild disability manage his or her own treatment and medical appointments. Additional initiatives, often developed by parents or relatives of people with ID, also exist such as the website "*2 minutes pour mieux vivre l'autisme*" where advice, practical information and concrete solutions are given for the relatives[eee].

> *"Bij andere huisarts, zei ik hetzelfde "er is iets maar ik kan er geen vinger op leggen" en die reageerde "je bent ongerust hé. We gaan je ongerustheid wegnemen". Dat is een totaal andere manier. Zij nam mijn bezorgdheid als moeder au sérieux. Je wilt niet weten hoe lang het geduurd heeft voor ik aanvaardde dat mijn buikgevoel tov W juist was. Mensen hebben me moeten leren dat mijn buikgevoel wel juist was." (Parent 1)*

In parallel to a better understanding of the disability situation, health literacy of informal caregivers is also important to improve their health knowledge and thus compliance with care. GP have a role to play in guiding patients and their supporters to consult reliable sources of information.

> *"Je vindt veel op YouTube. Maar ook op tv-programma's. Er staat al veel op Internet. Ik zou dat wel interessant vinden om op 1 website alle informatie te vinden over wat dokters doen, ook met filmpjes. Die voorspelbaarheid is voor haar heel belangrijk. Op zich moet ik niet veel naar de dokter, maar als het zo is, dan vind ik dat wel fijn om dat op voorhand te weten wat er gaat gebeuren. Ze zouden beter een website maken waar alle informatie op staat, dan foute informatie. Een officiële website zou echt wel een meerwaarde zijn." (Participant 3)*

Caregivers should also be trained to the detection of pain and other symptoms which are not always expressed in a conventional way by people with ID.[86] The report of the Anesu on the somatic problems and pain of people with disability proposes tools to detect and evaluate change in the health situation of a person with ID as it is often of importance to report changes to HCP. Experts of the Anesm advise the supporters to use the tools, in particular the ones on pain assessment.[83]

According to participants, families and relatives do not seem to be well informed in identifying healthy food or using the internet. As more and more information are provided by digital tools, improving the digital skills of families and people with ID would improve their access to health care, especially when it comes to benefitting from financial and material supports to cope with ID and their consequences.

The presence of a multidisciplinary team around these families is an option that was expressed during the nominal groups. In addition to the support

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[ddd] Similes is a Belgian non-profit association supporting entourage of people living with psychic troubles: https://associationsimiles.org/proche-ou-familles/nos-formations-familles/

[eee] See more on the project « *2 minutes pour mieux vivre l'autisme* » (litt. 2 minutes to better live autism) (in French): https://deux-minutes-pour.org/

organised by sickness funds and municipalities, adapted work companies (*entreprises de travail adapté – maatwerkbedrijven*) also have a role to play when they can (see Box 24).

Box 24 – Adapted work companies, Belgium

The adapted work companies support workers with disabilities through supervision by monitors, and through follow-up by a social service. This social service is mainly made up of social workers. Their mission (the one for which these positions are subsidised) is to ensure the social follow-up in relation to the professional development of the worker. In the best of cases, the person with a disability is accompanied in his or her personal life project by a specific support service for people with ID: this support service advises and assists the person when he/she encounters difficulties in accessing health care.

Unfortunately, the support services are now overloaded and refuse many cases, with waiting times sometimes exceeding 6 months for cases in progress. We therefore note, both in the adapted work entreprise and in their related social services, that people with ID come with much broader needs than those linked to the primary missions of the company. As a consequence, the social services effectively provide support in health care matters (just as they manage files related to property rentals, mobile phone or energy subscriptions, property managers, etc.). This implies an overload of work for the social support services, who know, however, that the workers could not come to work serenely if their personal problems were not solved.

Some companies are lucky enough to work with a specific support service. This is the case of the ‘Ferme Nos Pilifs’ which collaborates with the ‘Maison des Pilifs’. As soon as a worker encounters a personal problem, the ‘Ferme’ orients the request to the’ Maison des Pilifs’. But this example appears to be the exception rather than the rule.[fff]

Non-profit organisations, such as STAN, which are dedicated to people with ID, also offer support to these families (see Box 25).

Box 25 – STAN, Belgium

Trefpunt STAN is an association for people or families who live with a *verSTANdelijke handicap* (intellectual disability). STAN provides clear information and helps to find the right support for both the person with a ID and the family. In addition, STAN organises (virtual) information sessions, adapted lectures and fun activities all over Flanders. Meeting Point STAN is both a safety net and a springboard. A safety net for people who are - for a while - struggling or who have noone to turn to with their questions. A springboard to a stronger and better-informed life.

See more on: https://www.trefpuntstan.be/

6.3.2.3 People with intellectual disability

According to the international literature quick scan, as some people with ID can experience difficulties to identify their health care needs, the setup of **regular health checks** for those, for example on an annual basis, is recommended as an important requirement for people with ID to access high quality health care.[24,33,31] The focus should be on the primary care in a spirit of inclusion in the community.[8,121] This requires that HCP are aware of the health problems more prevalent amongst people with ID so that a proactive approach can be taken. The monitoring of those potential health problems by HCP can lead to earlier detection and treatment.[31] Those checks represent a relevant anticipation which allows to proactively identify health needs that may previously have been unmet. They also can provide a baseline from which changes in individual health status can be measured. In the UK, such provision is not universal and variations exist between areas in relation to the uptake of annual health checks (Box 26).[31] As described in

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[fff] Adapted from a personal communication with Marie Dedobbelere, general secretary of the Fédération bruxelloise des entreprises de travail adapté

Chapter 1: Introduction, the Healthy Athletes Programme of SO is built to meet health needs of athletes with ID. It includes education to healthy lifestyle and detection of health problems.[18]

Box 26 – Learning Disability Annual Health Check, NHS England, United Kingdom

[…]"Evidence has emerged internationally about the largely unmet health needs of the specific population of people with ID. Health checks have been implemented in some countries to address those health inequalities. The checks provide targeted screening for health issues particular to people with intellectual disabilities. Questions about feeding, behaviour, continence and sensory problems (including, but not limited to, vision and hearing) are crucial to understanding how a person lives from day to day[117]. The checks offer a great opportunity for health promotion and can help people to take an active role in their own health and wellbeing. English GPs are paid to undertake annual health checks for people with ID.

The conditions to access this service is that the patient is aged 14 years or older and is registered on a specific register, the practice learning disability health checks register[129]. Also the GP has to follow a agreed protocol and had undertaken relevant training. A systematic review identified strong evidence suggesting that health checks have been effective in identifying a wide range of previously unidentified conditions including serious and life threatening conditions such as cancer, heart disease and dementia. More commonly, health checks have identified a substantial proportion of participants with what some may regarded as more minor health conditions, such as impacted ear wax and poor vision. But those less serious problems may impact negatively on the quality of life of people with intellectual disabilities[129].

However, Bauer *et al*. sought to explore the likely cost-effectiveness of annual health checks in England. They concluded that costs of annual health checks needed to reduce from £258 to under £100 per year in order for health checks to be cost-effective. In the same time, they suggest that the way health systems deliver care for vulnerable populations might need to be re-examined. For example, they pointed out that "*changing only one part of the system (here: the identification of health conditions in primary care) is not leading to health-related quality of life improvements or reductions in mortality if people are not able to access and benefit from effective treatment options provided in other parts of the system (in particular in secondary care*)", implying that improving quality of care needs an in-depth reform of the health care system as a whole.[130]

It is found from the nominal groups that some people with ID can benefit from initiatives for improving their health literacy. This could be developed by consulting websites or receiving training. Training is available and is often organised by non-profit organisations. This offer seems to be more than necessary, even for people without ID, in view of the results of the Belgian Health Interview Survey of 2018, which showed that one in three Belgians had difficulty understanding medical information.[131] The *'Begrijp je dokter'* initiative has made an online test available to citizens to assess their level of understanding of HCP[ggg]. From the literature, it is stated that disability-specific advocacy groups can serve as trusted information intermediaries. For example, in the context of prevention, they can distribute mammography materials and guidelines to enhance awareness and to promote regular mammograms.[132]

Non-profit associations provide educational tools adapted to people with ID. For example, the patient organisation for people with Down Syndrome, has elaborated several booklets for people and their supporters: e.g. a booklet ('*Dit doen dokters*') with Easy Read information on a visit to different types of care professionals (e.g. explanation on the different clinical examinations) and information for relatives with more specific information; a booklet ('*Downpas*') which can serve as a medical file and can be completed by the HCP, but also with a lot of health information adapted for people with Down

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[ggg] Literally "Understand your doctor", this is an initiative of the socialist sickness funds Solidaris to facilitate access to health services via the improvement of health literacy. See more on (in Dutch): https://www.begrijpjedokter.be/

Syndrome, more specific information for the supporters and a schematic overview of potential health problems related to the ID. In France, the website *Santé très facile*[hhh] , developed by associations of professionals and patients with Down Syndrome, provides advice on health promotion, health literacy and the possibility to create an account to enter one's medical follow-up. The platform also includes many health-related tools adapted to people with ID.

The time factor is involved in the stages of learning new concepts (illness, healing, prevention, etc.), new gestures (flossing, swallowing a pill, etc.), new attitudes (not moving, trusting, etc.) by the person with ID. It implies that HCP and supporters are in position to devote sufficient time to do so. Among other examples, a mother of a child with ID reported she decided not to work to have time to carry out a drill to learn daily habits such as teeth brushing to her child with the help of professionals such as speech therapists or specialised pedagogues. Similarly, an HCP developed on its own initiative workshops for people with ID in order to get to know their bodies better and to be able to express their symptoms.

According to the importance of the difficulty in expressing themself of the person with ID, the feedback that person can do to his/her supporters vary. A first solution, evoked in the nominal groups, is to help people with ID to improve their communication. They can benefit from training to learn to know themselves, to recognise their emotions and to express them in a way that is understandable for the supporters. This training can also help them to better manage their emotions and anxiety. The Institute for Psychological Disability at Niort hospital in France offers this type of training in its network called Rehab[iii].

When the person's abilities or state of health do not allow them to communicate with the supporters and the HCP, it was suggested that two types of liaison booklet can take over. First, a **liaison book** is proposed as a solution to inform the supporters. The book can be placed on the night table of the person with ID. Each person who visits can let a word on what is the situation during the visit and what was done etc… Second, a **health follow-up booklet**, which includes all the health information of the person, such as medical history and treatment, makes it possible to improve the continuity of care. This document must contain health information but also life habits (interests, autonomy, ADL, etc.). Participants highlighted that it is better that the health follow-up booklet was completed written by HCP as it is addressed to HCP.

> *"J'ai pris contact avec l'équipe médicale pour communiquer des informations utiles concernant le handicap intellectuel de cette personne mutique. J'ai insisté pour qu'il soit considéré toujours comme un adulte sans l'infantiliser. J'ai suggéré qu'un cahier de liaisons soit mis à la disposition des visiteurs pour y collationner des informations et surtout pour y mentionner leur nom. Cet outil a favorisé la communication et le dialogue avec la personne. On a pu notamment apprécier qu'en citant le nom de visiteurs, le visage de la personne hospitalisée s'éclairait. Tout ceci permettait également à la famille de constater qui entourait ce malade." (Retrieved from Altéo, 2019)*

6.3.2.4 Professionals in the disability sector

According to participants, professionals in the disability sector seem to have little training in the management of health problems. As explained by some participants, it seems that there is a political and professional will to make a clear distinction between HCP and educational staff. However, some participants suggested optimising the training of specialised educators in the field of health care.

[hhh] Literally "Health very easy". The website is accessible here (in French): http://www.santetresfacile.fr/

[iii] Learn more on the project (in French): https://www.ch-niort.fr/patients-visiteurs/nos-services/institut-du-handicap-psychique

6.3.2.5 The role of learning and supports in two situations

Prevention

As pointed out in Chapter 5, families and professionals in the disability sector, and even in healthcare, seem to give only a secondary place to prevention, notably because of a lack of foresight on the benefits of this type of care. People tend to focus on immediate health needs rather than on those whose benefits will only be visible in the long term. However, the difficulties that people with ID have in expressing their problems, added to the fact that therapeutic management is sometimes more complicated from an organisational point of view, should encourage health professionals to direct their follow-up of patients with ID towards prevention and screening. Indeed, some parents also plan regular check-ups with doctors to check eyesight, hearing or teeth because they know that their child will not complain if there is a problem. Moreover, it is considered important by participants that HCP explain the added value of screening to patients and their families, such as giving clear explanations about the actions needed to be and remain healthy. The *Centre Handicap & Santé* focuses its action on promotion and prevention (Box 27).

Box 27 – Centre Handicap & Santé, Belgium

In the field of health promotion, the *Centre Handicap & Santé*, part of the Belgian non-profit association *Association de Recherche et d'Action en faveur des Personnes Handicapées A.R.A.P.H.*, has chosen to promote access to health in general, and accessibility to health care in particular, for and with people with disabilities. Their objective is to find concrete solutions to raise awareness and train the different actors (beneficiaries, families, volunteers, professionals) in a perspective of prevention and health promotion. They provide awareness-raising and training tools and programmes to beneficiaries, as well as to reception staff and HCP.

See more here: http://www.handicap-et-sante.be/

Ways to improve prevention through knowledge and support exist. First, it is proposed that preventive care schedules be used in institutions or by informal carers, following a systematic organisation of screening and health check-ups. Again, routine and regularity are assets in the management.

Secondly, the analysis of the literature highlights the existence of targeted health education intervention programme to increase the participation rate to cancer screening programs. An example of such an educational programme is 'Women Be Healthy'.[93] This programme uses multimodal teaching strategies and experiential activities (e.g. hands-on breast models, games, colouring activities, video on the screening exam, field trip to a doctor's office) to teach the purpose and procedure of cancer screening programs and strategies for relaxing during these exams.

Finally, participants indicate that the results of preventive tests should be readily available and explained to people with ID and their supporters so that a link can be made between the test and its outcomes. For example, providing a pair of glasses to a person with ID who has had a vision test allows a link to be made between the test and the subsequent need for care. This is the technique adopted by the Special Olympics Healthy Athletes programme.

Symptom's expression

It is particularly a problem when people with ID are not able to express their symptoms. Participant's advice first to carefully observe the person. A systematic observation of clinical parameters and signs should be made by the supporters or the HCP. Secondly, they advise to use tools to facilitate communication like pictograms or SMOG (*Spreken Met Ondersteuning van Gebaren* - speaking with the aid of gestures) but a period of training is necessary before using the tools effectively (see Box 28).

For verbal people with ID, that is people able to express themselves with words, a drill of them to use a pain scale as a barometer is recommended by participants. Researchers of the Inserm highlighted that the recent explosion of knowledge, both on the causes of ID and on the underlying cognitive and adaptive processes, makes it possible to better understand the functioning of people with ID. This leads that new, better adapted learning, accompaniment and support strategies are proposed.[22] Another example of training for people with ID was delivered by *Inclusion asbl* during the sensitisation campaign "*Accueil… et moi !*". This training was entitled "*J'ai mal, comment le dire?*"[jjj] while the training for relatives and professionals was entitled *La douleur chez la personne en situation de handicap*[kkk]. In France, the Anesm (*Agence nationale de l'évaluation et de la qualité des établissements et services sociaux et médico-sociaux*) has developed a guide to help people with ID, their supporters and HCP to better manage somatic problems faced by people with ID, and particularly pain.[83]

> *"Ze gebruiken ook een systeem van pijnschaal (A tot D), gelijkaardig aan systeem op school. Schaal van 1 tot 10 zegt niks voor W. Veel geoefend thuis, zodat het in het ziekenhuis ook gebruikt kan worden" (Parent 1)*

Box 28 – Assessment of the expression of pain in multiply disabled adolescents and adults

The scale '*Evaluation de l'expression de la douleur chez l'adolescent ou adulte polyhandicapé' (*EDAAP scale) is an adaptation of the '*Douleur Enfant San Salvadour'* scale (DESS scale) for assessing pain among adults and adolescents with multiple disabilities. It can, more broadly, be adapted to a person whose oral communication is impaired. The scale consists of 11 categories to be assessed by observation. A final score between 0 and 41 can be established. This allows for a better assessment of the intensity of the pain based on observations. If the final score is equal to or higher than 7, there is a certainty of pain.

The scale makes it possible to have a more objective and reproducible analysis of the pain between the different actors working with people whose oral communication is impaired or absent. It is a good complement to spontaneous observations, which are often relevant, but which can sometimes lead to an underestimation of pain.

See more on: https://pediadol.org/wp-content/uploads/2022/03/EDAAP.pdf

Dutch researchers developed a pain observation scale (Pain Observation Scale for Adults with Intellectual Disabilities - POSAID) for adults with multiple and severe intellectual disability (defined here as having an IQ<25 points in combination with (very) severe physical impairments). This scale is based on the Rotterdam Elderly Pain Observation Scale (REPOS) and consists of 7 items, which are potential signs of pain: tense face, eyes (almost) shut, raise upper lip, grimace, freezing, moving more or less/change in movement activity, moving stiffly/tense. In the original pain scale (REPOS), a cut-off score of 3 positive items is considered that the person is in pain. However, these validation studies with the determination of the cut-off score is still ungoing for the POSAID[133].

Key messages

- HCP should be aware to needs and specificities of the health care to people with ID, notably on the management of anxiety and agitation. Training should be available for HCP who want to be trained to become experts in health care for people with ID. Communication tips are crucial.
- People with ID should have access to health information in Easy read versions.
- The supporters should be trained in detecting symptoms in people with ID who have difficulties to communicate. Tools are available.

6.3.3 Possible solutions to counter communication barriers – between protagonists involved in the health care

Coherence between the people involved in health situations is the key word underlying the solutions to counter many communication barriers. The transmission of information between HCP, but also with the supporters and the person with ID is essential for this coherence. As discussed by participants, the lack of coherence in care can lead to an unstable climate

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[jjj] Translation: I have pain, how to say it?

[kkk] Translation: Pain among persons with disabilities

around the person with ID, from which these latter may suffer. Inconsistency can even occur between different medical specialists on the same health problem, which complicates care due to lack of clarity on what to do. The more coherent the explanations are, the more the risk of refusing care decreases, explained some participants. As recommended by *Inclusion asbl* (2019), there is a need to ensure the coordination and the continuity of the health care pathway.[109] It also requires thinking the approach to care in its entirety and over the long term. However, data privacy protection may hamper contacts and exchanges.

The participants to the nominal groups have expressed the following solutions:

6.3.3.1 Coordination and collaboration

It is important that the discourse is consistent regardless of the source of information. Participants highlighted that a GP should monitor the situation regularly. Participants from institutions insist on a coherent discourse towards the residents notably concerning prevention and screening. The analysis of the literature shows that in the area of prevention there is a need to promote more interdisciplinary working and integration including, notably, GP and breast screening services, and linking with other support services.[92] Many professionals can play the role of coordinator, although currently GPs remain the central link in the coordination process.

> *"[…], maar ik ben blij dat onze huisarts hier een coördinerende rol inspeelt. Het is niet zo dat hij alles angstvallig bij zich houdt maar hij dient eerder als dispatching." (Parent 3)*

Participants pointed out that the coherence of the discourse is reinforced when there is a health care plan. This can be drawn up and discussed at multidisciplinary meetings involving the family and the patient. For primary care, it mainly depends on the impetus of the GP. It allows for a harmonisation of discourse and management through the constructive involvement of all the protagonists around the health care project. Some university hospitals also offer multidisciplinary consultations involving the families of children with genetic pathologies. They aim to detect early on any difficulties and health concerns that may arise during development. The health care plan involves specialist therapists (speech therapists, occupational therapists, physiotherapists, psychologists, etc.).

> *"Ik heb ook eens meegemaakt dat we bij een dokter na een uitgebreid onderzoek geen verslag kregen omdat de dokter ervan uitging dat ik de moeilijke woorden niet zou begrijpen of zou denken dat mijn zoon een of andere ernstige ziekte heeft. Pas na vermelden van de naam van mijn broer, kreeg ik pas het verslag. Snap je wat voor een strijd we moeten leveren en dat is dan alleen nog maar op medisch vlak." (Parent 1)"*

According to findings from the international literature, **care coordination** process is very important to improve quality of health care for people with ID. The WHO report on disability (2011) envisages the care coordination of people with disability as a collaborative and interdisciplinary approach which links the person with ID with appropriate services and resources. This coordination ensures a more efficient and equitable distribution of resources, reduces the use of residential care, improves the general health of people with ID and their participation in the community.[8]

For the WHO, two major actions have to be implemented.[8] First, to identify a care coordinator whose role can be assumed by a range of health personnel. Primary care structures are probably the most efficient for coordinating care throughout the health care system, and many people with disabilities see GPs as having the overall responsibility for their health care and being gatekeepers for the wide range of community-based services.[134] Sometimes, dedicated care coordination services and health facilitators can assist people to access primary health care services, as in the UK where clinical nurse specialists coordinate health care for people with ID.[135] Second, one should develop an individualised care plan for people with ID. A customised care plan is important to bridge current and past care and for arranging future needs. A plan should be flexible enough to accommodate changes in people's needs and circumstances. Enhanced Primary Care in Australia encourages general practitioners to carry out comprehensive health assessments, multidisciplinary care plans, and concertation meetings with people with ID.[135]

6.3.3.2 Organisational support and guidance

It is also important to implement the coordination necessary for improving compliance and planning follow-up. The GP can explain the steps to be taken to organize the follow-up. It is suggested that systematically giving the patient the next appointment helps to avoid a break in follow-up. Ideally, it is even suggested to ensure that the appointment has been entered into the person's calendar or that a reminder system takes place.

> *« Pour rebondir par rapport au psychiatre que je vois actuellement, là en fait je note dans la partie agenda de mon GSM comme ça, si je perds le petit papier, je me disais c'est pas grave. Au pire, je regarde dans la partie agenda ou alors calendrier de mon GSM mais je sais que parfois normalement, […] il y avait une sorte de petit rappel pour ne pas que j'oublie par rapport à ma prochaine consultation avec le psychiatre que je vois actuellement. » (Participant 4)*

Participants also pointed out that it is very difficult for people with ID and their supporters to identify competent HCP to take care of them when it comes to problems not related to their disability. By competent, it was meant HCP who can communicate with people with ID and who knows their health needs. Timely referral can facilitate access and decrease stress, frustration, and the development of secondary conditions. Inventories of relevant services and community resources also may be useful.[8] Some participants mentioned the existence of informal networks of people with ID (sort of parent/patient associations) where information about competent and appropriate HCP for people with ID is exchanged.

> *"Wij horen eerder bij de buurt voor de keuze van een dokter. We zitten ook in een netwerk van mensen die eerder alternatieve dokters zoeken." (Parent 3)*

> *"Door mijn zussen en broers die allemaal in de medische en paramedische wereld zitten en die raden me dan dokters aan. Dat is nu wel wat anders nu dat [] de volwassen wereld binnenstapt. En dat is nu wel weer wat zoeken, […]" (Parent 1)*

6.3.3.3 Transmission of information

Participants to the qualitative research explained that the file containing the health history and daily needs should always accompany the person with ID. This file should be easily accessible digitally by the HCP involved in the care. For example, participants explain that patient health record should be easily exportable from the institution's IT management program because there is no time to gather all the info when leaving to the hospital. Another participant explained that, in his institution, patient health records are always ready on USB sticks. At admission in the care unit, it is advisable to inform the staff of the ID situation and to quickly give the person's health record with the difficulties related to their disabilities and their specific needs. For information to flow properly about the health problems of people with ID, participants suggested many possibilities, including health passports and explanations from the supporters. Hospitalization passport already exist in Belgium for persons with multiple disabilities (see Box 29). But a direct exchange of information between HCP teams (primary care, hospital care, specialised follow-up) should also be encouraged, especially if a patient needs to be referred to a new HCP for follow-up.

Box 29 – Hospital passports in Belgium

Produced by WalloPoly, this booklet is a tool created to improve the reception of people with multiple disabilities in hospital. It includes administrative data, a section for emergencies, a section for hospitalisation and a section for well-being.

The booklet (in French) is available on http://wallopoly.be/wp-content/uploads/2017/02/Passeport%20Hospitalisation.pdf

The Flemish patient organisation, Gezin en Handicap, emphasizes on their website the added value of such a passport as a communication tool with the HCP in hospitals and refers to the Dutch medical passport, developed by the Dutch Association of Physicians for people with ID. It included information about the medical history of the person with ID, information about the functional status (e.g. dependency in ADL) but also information about preferences about reanimation and intensive care unit admission, and medication list.

The passport is available on https://nvavg.nl/wp-content/uploads/2020/04/V4-Medisch-paspoort-voor-mensen-met-een-beperking.pdf

Data from the literature confirm the participant's experience. The transmission of all relevant information on health topics and on psycho-social aspects including information about behaviour viewed as challenging is of utmost importance [31, 86] The information must circulate smoothly between providers from in- and out-hospital setting. All protagonists can participate to the best transmission of those information in a continued way: people with ID, supporters, GPs, etc. In addition to the usual completion of the electronic patients health records with data on the person with ID, the formalisation on an information transmission into a common system to people with ID, families and professionals is suggested.[31, 86]

One good example of optimal information transmission channel is the elaboration of personal passport which is a comprehensive document describing the specific care needs and usual health issues; the preferences and dislikes of the person with ID; the usual behaviour and how to interpret it; information on the person's abilities, challenges, and methods of learning or communicating, and the contact details of the available persons who know well the admitted patient with ID.[86] This type of document allows to ensure that key information is provided to support safe and person-centred care for people with ID who may not be able to communicate key information regarding their health and support needs to healthcare staff.[31] It can also support transition between child and adult services and between multiple health care practitioners.[136] Hospital passports have now been adopted in many healthcare settings in the UK but are not always accessed by health care staff even where they are available.[31]).

It is important that not only the nursing staff is informed about the ID situation but also the administrative staff. Indeed, as said by participants, hospital's organisation is not adapted to the situation of people with ID, for administrative procedures. It is therefore necessary to ensure from the outset that the right contact person is identified in the administrative record as to contact the supporters is often necessary for administrative documents. The ideal situation – as suggested in the nominal groups- is an administrative system in which the staff is sensitised to the specificities of people with ID, notably regarding the communication, the different types of living places and the role of administrators and supporters. It was suggested in the nominal groups that the health record of people with ID could contain a label so that all parties are aware of any difficulties in understanding. To add a specific label on the administrative folder of the persons with ID (who are under person's or goods' administration) could help particularly when the ID is not visible. It is useful especially if there are problems of compliances or collaboration in care. Adding a specific label in the administrative and health record will also allow for a cadastre. A specific label could at last trigger an information procedure in which a social assistant can give advice to informal caregivers living with a person with ID. However, there is a risk of stigmatisation in labelling people with ID.

> *"Nu heb ik een kaartje met disability op. Maar er staat niet op dat ik autisme heb. De mensen rondom mij die zien niet dat ik autisme heb. Ik heb wel een kortingskaart, maar dat is dezelfde voor mensen die bijvoorbeeld te weinig geld hebben" (participant 3)*

In order to ensure the best possible communication of information between all actors when accessing the hospital system, a single hospital contact point is proposed. This point of contact should offer a hotline for patients and relatives and be linked to the presence of an in-hospital liaison person specialised in the coordination and adapted approach of patients with ID. This liaison person would be a resource for relatives to organise grouped care in hospital. In addition, this person would be a reference for the nursing staff in case of difficulties in the care of a person with ID. This hospital referent could coordinate the care pathway and liaise after discharge (e.g., explanations to the patient, contact with the GP, post-operative appointment). Some participants suggested that a male and female doctor/nurse duo would be ideal: 1 medical doctor as medical adviser and 1 nurse as health-care adviser and coordinator. In-hospital liaison psychiatrists could fulfil the function of ID referent if they have undergone appropriate training. Two foreign initiatives illustrating ID referent in hospitals were identified in the literature analysis (Box 30 & Box 31). As recommended by Unia, « *look for a staff member who is open to the issue of disability and make him or her a reference person for the reception of different audiences. This person will gather and disseminate all useful information and will lead the implementation of reasonable accommodations. He or she can also raise awareness among colleagues and explain to them the different forms of disability, as well as the needs related to them".*[39]

Box 30 – In-hospital liaison persons specialised in ID, *Hôpitaux Universitaires de Genève*, Switzerland and NHS, North Bristol

A 60% full-time equivalent ID-physician and a full-time specialized ID-nurse positions were created at *Hôpitaux Universitaires de Genève*. The ID physician and ID-nurse play a key role in: adapting the various medical and care procedures to people with ID; coordinating the interventions, specific examinations and surgeries; training HCP and hospital staff members; facilitating and improving communication between persons with ID, supporters and HCP; collecting data, reviewing diagnostic codes and conducting researches on ID's health issues in the future.[86]

Learning disability and autism liaison nurses support anyone with diagnosed learning disabilities and/or autism over 16 years old at Southmead hospital with appointments, procedures and operations. The missions include to make sure that patients with ID and their supporters feel safe and supported at hospital; that adjustments are made. They help with the transmission of health informations and understanding of health conditions and treatments[lll].

Box 31 – HandiSanté initiative, Institute for Psychological Disability, France

The Institute for Psychological Disability is an initiative of the psychiatric department of the Niort hospital in France. The professionals of the *HandiSanté* service take care of patients with a disability, particularly intellectual disability, who present a dyscommunication with difficulties in accessing somatic care. The service organises the reception of patients in the form of day hospitalisation, half-day hospitalisation or outpatient consultation. A hyper-adaptation of the care context (clinical and somatic examinations, dental care, technical nursing acts, etc.) is put in place. Coordination with the technical platform appointment booking system and a system of support for specialised consultations, biological tests and imaging are also proposed.

The prevention axis is particularly addressed with work upstream of the services to identify, with the reception centres, the most vulnerable people who should regularly benefit from attention on the somatic level.

Discover more (in French): https://www.ch-niort.fr/patients-visiteurs/nos-services/handisante

At last, collaboration with professionals specialised in key issues like pain management is crucial in order to establish protocol to detection and management adapted to people with ID.[86]

[lll] https://www.nbt.nhs.uk/patients-carers/coming-hospital/learning-disability-nurses

Key points

Coherence requires both a coordinator and an up-to-date, easily exportable and comprehensive medical record. In primary care, GP can take the role of coordinator while a liaison person could take this role in the hospital sector.

6.3.4 Possible solutions to counter programmatic barriers

Programmatic barriers can induce missed care or denial of care. According to international literature, programmatic barriers to full access of people with ID to health care system led to the more numerous solutions suggested in the grey literature. Those programmatic solutions are often named the **reasonable adjustments** like flexibility in the appointment system, effective communication tips implementation or provision of accessible information (see 1.3.4 Reasonable adjustments). As in Belgium, foreign countries made reasonable adjustments a legal requirement (Box 32 and Table 41).

Box 32 – Legal requirements for reasonable adjustments, United Kingdom

"*Reasonable adjustments are a legal requirement in the UK under the 2010 Equality Act. Yet the provision of reasonable adjustments is not consistent with implementation often being dependent on the knowledge of individual staff and teams and their flexibility in terms of care provision. Making reasonable adjustments to care delivery therefore needs to become standard practice*" (Tuffrey-Wijne (2014) cited by Northway, 2017).

The reasonable adjustments are those that maximize efficiency while requiring a minimal financial and organisational effort.[86] Some reasonable adjustments do not cost anything.[137] Examples of implementation of reasonable adjustments are given in Box 33.

Box 33 – Implementation of reasonable adjustments, *Hôpitaux Universitaires de Genève*, Switzerland

At the *Hôpitaux Universitaires de Genève,* a specific emergency admission sheet was created as a reasonable adjustment to simplify admission procedure to the emergency department including a shortened waiting time (max. 2 hours) in a quiet and adapted waiting area. "*This document fits on a double-sided page and is quick to read. It includes important specific information such as: type of disability, description of behaviour viewed as challenging, other impairments, legal representation, capacity of consent, how the person communicates and expresses pain, comfort, discomfort and anger.*

This admission sheet is standardized in the electronic patient health record, so that the relevant information is readily available to every HCP when needed. This particular document relieves the parents and carers from repeating over again relevant information and helps the hospital staff quickly get the right information."[86]

Other adjustments are the creation of a central phone number for people with ID like a hospital hotline for them and an adaptation of care procedures (administration of anaesthesia (local or by gaz) to prevent pain induced by care. To highlight all those adaptations, a video available on the hospital website explains the reasonable adjustments.

Adaptations to the facilities and materials are part of the solution but some participants to the nominal groups said that it is so necessary to accept that one can do things differently for people with ID (priority ranking or separate waiting room) and to ensure that reasonable accommodation becomes structural: usable and understandable lifts; volunteers who accompany the person everywhere; grouping of appointments on the same day; answering the phone rather than a full online system.

6.3.4.1 Improving reachability

Physical reachability

Reasonable adjustments allow to overcome physical barriers. Although this type of barrier is not the main problem for people with ID in comparison with other types of disability, they should be considered mainly because people can cumulate intellectual and physical disabilities. Two types of solutions are given in the retrieved literature: the use of universal design for space and medical equipment, meaning a design usable by all without adaptations and the check that space and programmes follow laws on disability (Box 34). The main aspects are security, accessibility and comfort.[24]

Box 34 – Improving mobility, Hôpitaux Universitaires de Genève, Switzerland

At the *Hôpitaux Universitaires de Genève*, an inventory of the existing resources and equipment dedicated to the mobility of people with ID was made as well as a review of the access improvements to the facilities and buildings. As a result, tangible changes have been made. Several access ramps, handrails and doors were added in the psychiatric hospital department to allow easier access to wheelchairs to the buildings, and eight new dedicated parking spots have been created in the middle of the city hospital for large vehicles. Also, the revolving doors of the main entrance to the main hospital have been replaced: they were not easily accessible to electric wheel chairs.

Also, according to participants to the qualitative research, some people with ID also have motor limitations and therefore mobility limitations. The adaptation of ambulances to all wheelchair models or the adaptation of light medical vehicles to wheelchairs that do not fit in conventional ambulances was a first solution mentioned in the nominal groups. Some participants also suggested the creation of a cheap transport system to help with journeys (avoid blocking the institution's bus for one person).

However, people with ID without motor limitations can also have difficulties in moving around, particularly in relation to the fear of the unknown. Therefore, it is seen as important that people with ID borne by ambulance are referred to the hospital where they normally receive their care. Some participants regretted the underuse of home / institutions visits by HCP (and GP). It is a question of proposing a real paradigm shift in healthcare when it is impossible to move a person.

First, it is envisaged to bring specialists to the institution for medical visit on site. There is already an RIZIV – INAMI nomenclature allowing visits by specialists to patients' homes at the request of GP. Hosting consultations in institutions have pros and cons: on the one hand, medical visit on site allows to enrich the discussion with the institution staff (educators, doctor and nurses); on the other hand, there is a risk of conflict with the family if family's members are not present during the medical visit on site.

A second option for health care in the living place is based on ambulatory care teams travelling from place to place in a vehicle fitted out as a consulting room. Such an offer exists, for example, in the form of a MammoBus for breast cancer screening. This service is seen as a good solution for the lack of low threshold accessibility to prevention notably. Special Olympics has already exploited this option and presents the MammoBus as a place where there are fun events for people with ID. Other examples concern dentistry, such as the Dentalmobilis service and the mobile dentistry unit of the *Cliniques Universitaires Saint-Luc* (see Box 35 & Box 36).

Box 35 – Dentalmobilis, Belgium

Dentalmobilis is a non-profit association: it aims at improving oral health of the elderly and disabled through education, training and mobile dental care. Routine screening could lead to the development of personalised oral health care plan, including hygiene tips adapted to needs and abilities of the person with ID. Dentalmobilis applies the RIZIV – INAMI tariffication and the third payer. A supplementary payment of 25 EUR is requested per consultation to cover logistic fees: this supplementary payment is charged to the families or to the person.

See more here (in French): https://www.dentalmobilis.be/

Box 36 – Dentistry in the living place, *Cliniques Universitaires Saint-Luc*, Belgium

Since it is not easy for some patients to travel, the hospital has chosen to go and meet them where they live. "*Thanks to a small mobile unit, two members of the team travel to specialised institutions to carry out oral examinations, preventive care, but also some conservative care.*" […]"*The fact that the care takes place in their usual living environment simplifies things. Some institutions have even set up a dental practice, which makes it possible to carry out more complex treatments*".[112]

A third solution suggested in the nominal groups is the establishment of a medical office inside the institution. There, some participants consider the presence of specialists on site as a solution for prevention: a dentist who comes to do scaling for example, an orthopaedist who comes to prescribe orthopaedic shoes, adapted chairs etc. However, there are other voices against bringing medical sector actors into institutions for people with ID.

This solution is also identified in the international literature which suggest that programmatic solutions were developed in the living community of the people with ID with a year round access to high quality health care locally.[33, 84] Those resources and services should include curative as well as preventive care offers. The **building of partnership** with existing services, centres and programmes is recommended by the WHO and the CDC. The Healthy Community Program of the CDC is an example of programme aiming to connect local organisations of people with ID with HCP and wellness and fitness centres at the local level.[33]

Intellectual reachability

Findings from the international literature quick scan highlighted that reachability also includes that the health care materials and health information supports are adapted to the understanding of people with ID. In the Geneva University Hospital, medical procedures have been translated into Easy Read format and posted on the official website of the hospital.[86] And the Public Health England website provides a link to a suite of easy guides to help explain screening tests to people with ID.[85, 138] SO also explains that whenever forms need to be completed, an in-person assistance can be provided to ensure that the person understands materials.[24]

However, there is limited evidence evaluating the impact of accessible health information on the equal access to health and well-being for people with ID. Indeed, Chinn et al. (2017) review and synthesise evidence on this impact in the short available source of data. They conclude that individually tailored information is more likely to meet personalised health information needs for people with ID.[139]

According to the international literature, HCP must provide to people with ID all therapeutic options like to anyone in the same situation. Then people with ID will make the choice based on their needs and preferences.[110] To take decision, people with ID can require special support (e.g. a translation in Easy Read format) which is called a **targeted intervention** and can be assimilated to a reasonable adjustment.[24] Targeted interventions for specific subgroups of people with ID should be necessary particularly for those difficult to reach by health promotion programmes, those with higher risks of co-morbidities and those requiring close ongoing care.[8]

6.3.4.2 Improving orientation and navigation

During interviews, people with ID spoke of their difficulties in finding their way around large health-care institutions. Smaller centres are preferred because they are easier to find their way around. As stated by Unia, signage based on simple and universal pictograms makes information understandable to all.[39] Unapei also provide practical advice on signage.[42] Also in the nominal groups, it was mentioned to use orientation signs in the hospital in Easy Read format rather than numbers. *Inclusion asbl* cites the example of the nursing home "*Le Clairval*" as a good practice (see Box 37).

Box 37 – Adapted signage, *Le Clairval*, Namur, Belgium

The nursing home (MRS MRPA) Le Clairval worked on the accessibility of the structure and developed a an appropriate signage to make it easier for people to find their way around. It uses colour codes to identify the floor and the area where you are (coloured walls) but also to distinguish the different professionals (different coloured coats for the care assistants, the maintenance staff, etc.).[20]

The presence of people (professional or volunteer) available to help with orientation in care institutions is also requested by some of the interviewees. The "*Centre Handicap & Santé*" has developed a project to raise awareness of ID among volunteers posted at hospital entrances. In addition, a participant in the nominal groups explained the escort system developed in airports by airlines: *"In airports, everyone is made aware of the need to welcome people with disabilities and airport staff can call on the services of a specialised referent*" (see Box 38).

> *« Les volontaires qui mènent les patients qui sont déjà à l'hôpital ont un rôle très important, surtout pour les vieilles personnes qui vont à des examens. Souvent les bénévoles sont débordés. » (Participant 1)*

Box 38 – Special Service Request Codes – SSR

Airlines use international codes to indicate the type of assistance to be provided to passengers with specific needs. The following codes are used:

WCHR	Wheelchair assistance required; passenger can walk short distance up or down stairs.
WCHS	Wheelchair assistance required; passenger can walk short distance, but not up or down stairs.
WCHC	Wheelchair required; passenger cannot walk any distance and will require the aisle chair to board.
WCOB	On-board aisle wheelchair requested (for use during flight).
WCMP	Passenger is traveling with a manual wheelchair.
WCBD	Passenger is traveling with a dry cell battery-powered wheelchair.
WCBW	Passenger is traveling with a wet cell battery-powered wheelchair.
BLND	Passenger is blind or has reduced vision.
DEAF	Passenger is deaf or hard of hearing.
DPNA	Disabled Passenger with Intellectual or Developmental Disability Needing Assistance
ESAN	Passenger is traveling with an emotional support animal.
EXST	Passenger requires an extra seat due to body size.
MAAS	Meet-and-assist. Used by some airlines to identify passengers with intellectual disabilities.
MEDA	Medical case. Used by some airlines to identify passengers needing oxygen.
OXYG	Passenger will require oxygen.
PETC	Passenger is traveling with a pet in cabin.
PNUT	Passenger is allergic to peanut dust.
PPOC	Passenger is traveling with a portable oxygen concentrator.
STCR	Passenger is traveling on a stretcher.
SVAN	Passenger is traveling with a service animal.

See more on the website: https://wheelchairtravel.org/air-travel/special-service-request-codes/

6.3.4.3 The comfort of the specific pathway for people with ID

Some participants to the nominal groups also proposed the organisation of a specific pathway for people with ID, i.e., organisationally separate from other patients. It was suggested that these specific pathway for people with ID in hospitals should start at the ED. According to participants, the pathway could take the form of a service dedicated to people with ID, offering them holistic, integrated and centralised care in an environment adapted to their needs. This service would save the supporters multiple journeys. It would coordinate information between hospital HCP, external HCP and professional and informal carers, thus acting as a centralised contact point. In Belgium some hospitals have already developed clinics centralising all health care at a specific time, for example the Down clinic (see Box 39). Disability-related problems are dealt with and at the same time, a complete somatic and psychosocial check-up is carried out. Although this type of pathway would help to better target the needs of people with ID, it would not be a good idea, according to some participants, to create too distinct pathways because of the risk of losing the objective of inclusion. According to participants, a good trigger to identify people who should preferentially benefit from a specific pathway could be the presence of behaviours viewed as challenging (and not of a disability). Some suggests providing a separate and preferably closed waiting room for the peace and quiet of the person with ID and for the negative impact (fear, noise disturbance, …) that the disability has on other people in the waiting room.

> *"Ja, dan kijk ik wat rond [in the waiting room], of dan heb ik een boek of een gsm mee. Ik kijk heen graag rond als ik moet wachten. Nee, ik vind dat niet storend. Wel in een pretpark" (Participant 3)*

Box 39 – Multidisciplinary consultations, *Clinique CHC Mont Légia*, Liège, Belgium

Trisomy 21 is clinically translated by an intellectual disability but also by a whole series of associated pathologies: cardiac malformation, digestive, orthopaedic and ophthalmic disorders, ENT problems, endocrine or haematological complications. These different disorders make the follow-up of Down's syndrome children more specific and require regular screening throughout their growth. The paediatric service of the *Clinique CHC MontLégia* offers a meeting scheduled during the same afternoon - as required - with a cardiologist, a gastroenterologist, a neurologist, a dentist, an ENT specialist, an endocrinologist, a haematologist and an orthopaedist. Blood tests or imaging examinations can also be done during this afternoon. This multidisciplinary approach facilitates the care of patients with Down's syndrome and supports their parents through a global organisation.

See more on the website of the Clinique CHC MontLégia (in French): https://www.chc.be/Services/Suivi-des-enfants-et-adolescents-trisomiques

Access to the advice of a specialist in ID is crucial to a high-quality offer of health care. In the UK, many hospitals employ specialist learning disability liaison nurses who provide knowledge and expertise to support staff working in acute hospital settings. However, not all healthcare settings have such a function.[31] In addition, it is expected that specialised services and experts support primary care providers by providing comprehensive assessment and multidisciplinary feedback (see Box 40). In the Netherlands, a study involving GPs has shown that people with ID should be cared firstly in primary care if an easy access to specialist for health issues as behavioural, psychiatric or epileptic conditions exists.[8, 140]

Box 40 – Specialised services and expert's support

In the UK, learning disability teams are widely available for people with ID to provide specialist treatment where general services are unable to meet needs, support primary care services to identify and meet health needs, facilitate access to general services, and provide education and advice to individuals, families, and other professionals.[141]

6.3.4.4 *The added value of targeting people with specific needs*

In some Belgian hospitals, major changes have been already made to accommodate people with special needs, including people with ID, as the 'Welcome' project at the *CHR La Citadelle* in Liège and the project '*Unieke Mensen'* at the AZ Delta in Roeselare (see Box 41 & Box 42). These hospitals have developed a network of competent disability contact persons who work to support people with disabilities and their supporters. These professionals also have the task of making the hospital a friendly and welcoming place for people with special needs.

Box 41 – Welcome Plan, *Centre Hospitalier Régional de la Citadelle*, Liège, Belgium

The *Centre Hospitalier Régional (CHR) de la Citadelle* in Liège has set up a service specially dedicated to the reception of people with special needs. The overall objective of the project is to increase the quality of care and reception and thus improve the satisfaction of people with special needs. This service consists of personalising the reception of patients with special needs at each stage of their care in the hospital and assigning them an internal referent. Tailor-made adaptations can be put in place according to the needs expressed, and a document identifying these needs prior to admission or consultation is available online. The project also aims to minimise structural and architectural barriers.

See more (in French): https://www.citadelle.be/welcome

Box 42 – *Unieke Mensen*, AZ Delta, Roeselaere, Belgium

It is a project to adapt a hospital to people with disabilities. At present, people with disabilities usually have to adapt to the normal hospital routine, which is usually not geared to people with special needs. AZ Delta's '*Unieke Mensen*' project has been worked out as a first step with the paediatrics service because this is a discipline that looks at the patient as a whole. That is exactly what the target group needs. The project was therefore set up in cooperation with (head) nurses, doctors and paramedics from the paediatrics service. The input of experts by experience and the VAPH was also taken into account.

Before a patient comes to the hospital, AZ Delta, together with the parents or the VAPH centre, looks at what is important for the patient: nutritional requirements, recreational possibilities, etc. Everyone is also briefed internally from the reception to the surgical area. When the patient is consulted or admitted, he or she is welcomed personally from the entrance. This creates an atmosphere of privacy and trust. Parents or guardians can park their car in peace, knowing that their child or beneficiary is in good hands. The room reminds one as little as possible of a hospital. The care is also provided as much as possible in that room. Finally, the discharge is thoroughly prepared together with the parents or the VAPH centre. Attention is also paid to good communication with the family doctor. AZ Delta is also investigating whether the approach can be extended to people older than 25 year olds.

See more (in Dutch): https://www.azdelta.be/nl/prijs-voor-project-unieke-mensen

Key points

- Health care access should be improved by a change in the health care system paradigm: people difficult to move should beneficiate from visits in their living place by specialised HCP.
- Intra-hospital specific pathways should offer comfort to people with ID and their supporters.

6.3.5 *Possible solutions to counter policy and social barriers*

Participants to the nominal groups and interviews identified three main solutions which could solve policy and social barriers (defined in chapters 4 and 5): Improving equity, time and manpower availability, and better allocation of resources.

6.3.5.1 *Equal opportunities: a developing process*

The quick scan of the grey literature identified notably theoretical solutions reported by international experts and public health institutions to improve equality in the opportunities for people with ID in accessing health care. The word 'inclusion' sums up in itself the different suggested solutions identified. 'Inclusion' is the key concept underlying the objective of full respect of the human right charter of the United Nations (see also Chapter 1).[1] Indeed in the health care sector, inclusion allows for people with ID to take full advantage of the benefits of the same health programmes and services experienced by people without ID.[24] The path to inclusion leads to full access, without any exclusion criteria, of people with ID to all health programmes, services and activities.[24] To reach the objective of full access, change in attitude, organisational policies and practices within the whole health care sector should be adapted.

For example, in Australia, an initiative gives the opportunity to people with ID to an easier access to mental health care (Box 43).

Box 43 – Healthy Mind – Australia

Electronic mental health (e-mental health) programmes for people with ID are currently underexplored but may provide a way of mitigating some of the barriers that this population faces in accessing appropriate mental health services. The study conducted about such a programme in Australia, named Healthy Mind, shows that it is an excellent tool for people with ID and their carers. The research has pragmatic implications for the future development and implementation of this kind of programme, while contributing to knowledge in the broader fields of e-mental health and inclusive design for people with ID.[142]

Participants to the nominal groups report that the recent experience of the COVID-19 pandemic has highlighted the persistence of discriminatory behaviour in some health services. The issue of discrimination in the COVID crisis was also addressed during scoping interviews. Indeed, it would appear from the recent survey conducted by Unia in the context of hospital prioritisation in times of pandemic that prejudice and ignorance towards people with disabilities can lead to misinterpretation of medical criteria.[143] In addition, the obligations imposed by the anti-discrimination legislation and the UNCRPD seem to be ignored and/or poorly respected. And the refusal or the delay to make accommodations for people with disabilities prevents the reception and the adapted care of certain people with disabilities.

As consequence, Unia issued the following recommendations to the HCP and the authorities in charge of it:

- Respect the principles of non-discrimination in combination with ethical and medical criteria.
- Apply the obligation to provide reasonable accommodation, even in times of health crisis.
- Anticipate their implementation outside times of crisis.
- Include in hospital emergency plans a section devoted to the reception and care of people with disabilities
- Raise awareness and train practitioners in a de-medicalised approach to disability:
    - the situation of disability should not be confused with the state of health.
    - the notion of quality of life should not be based on a judgment of the value of life or of the person; the notion of quality of life should be limited to the evaluation of the expected benefit of the treatment
    - the notion of frailty is a geriatric concept and as such cannot be applied to non-elderly people with disabilities

Tools exist to help introducing and developing inclusive culture and practice; for example the booklet edited by Special Olympic and entitled “Inclusive health: principles and strategies”.[24] It gives practical information for organisations in the health sector based on equitable access and full participation.

An additional way to support inclusion is public financing to private inclusion initiatives and to awareness campaigns like the “Spread the word inclusion” campaign initiated by Special Olympics and aiming to increase respect and acceptance in school, organisations and communities (Box 44).[33, 86] Finally the ‘Centre for Inclusive Health’ supported by the CDC provides online resources, training and technical assistance to organisations developing inclusive health care[mmm].

[mmm] See more on the programme of Inclusive Health of Special Olympics (in English): https://inclusivehealth.specialolympics.org/

Box 44 – US State Disability and Health Programs, United States

Those programmes are supported by the CDC to improve the health and the quality of life of people with disabilities. It includes the adaptation and implementation of evidence-based strategies related to health in the local communities. It also develops useful and effective policies at the state level, and supports activities favouring inclusion, access and non-discrimination.

See more on https://www.cdc.gov/ncbddd/disabilityandhealth/programs.html

In order to overcome negative attitude and to optimise the choice in the panel of possible adaptations, **the input of people with ID** is highly recommended in the retrieved literature for all aspects of programmes' planning, development and implementation. Indeed, people with ID can express their needs and can provide input leading to progress in an organisation.[8, 24, 31, 124, 144, 145] People with ID can also help in the evaluation of programmes to support continuous improvement (Box 45).[24] It is advised to ask them which kind of barriers they faced and how the programme or service could work better for them.[24]

Box 45 – Empowerment of people with ID*, Hôpitaux Universitaires de Genève,* Switzerland

Some people with ID and their families were involved in the development and the evaluation of an implementation project of a specific ID pathway through notably their representation in the steering committee and through satisfaction questionnaires after any health care experience at the Geneva University Hospital. Once a year, the steering committee meets with all partners and families for feedback and continued improvement. The partnership includes out-hospitals HCP, city's politicians, families, professionals from the disability sector and people with ID.[86]

6.3.5.2 Allocating more time

Some participants in the nominal groups and interviews highlighted the pressure existing on HCP outside the disability sector. Some accommodations are theoretically envisaged by those HCP, but their implementation faces many obstacles, including lack of time. Training in communication techniques, re-explaining or illustrating one's words, involving the supporters, organising telephone hotlines, etc., all take time. It is in the hospital setting that this lack of time seems to be most obvious according to the participants: time to read the files, the transmission books, the documents listing the needs; time to discuss with the person, to question the family and friends, to find out about the person's specificities; time to write a report, to transmit the information to the patient, to the family and friends and to the other carers involved. In general practice, there is a lack of time to carry out preventive care. Participants reported that even the most committed doctors do not have enough time for quality care. It was pointed out that if they do take the necessary time, their visit or consultation is no longer sufficiently efficient, i.e., the time spent with the patient and the doctor's personal investment is no longer commensurate with the cost of a visit or consultation.

Time is needed to explain, listen and re-explain. This is what HCP lack most and what people with intellectual disabilities need most, to understand and to express themselves. The advice from *Inclusion asbl* to health professionals is: "*Take the time to listen to the person carefully. Ask the carer to translate if the person has difficulty speaking. Make sure you explain the diagnosis, the care, the treatment. Present things step by step, speak more slowly and clearly. Allow more time for consultation or examination.*"(Inclusion asbl 2019)

According to the literature, HCP should plan for additional time during examination as people with ID can present additional care needs. However, additional support should be implemented in avoiding positive discrimination and keeping extra cost reasonable.[86] On the Public Health England website, a guidance to decrease inequity in screening amongst people with ID pointed out that extra time for screening appointments should be planned.[85] The same guidance also highlighted the requirement of an extra appointment before the screening to discuss the necessary support and to explain the procedure and show the equipment.

Also in the nominal groups, some participants put forwards the idea of providing longer consultations when receiving a person with ID. This requires, according to other participants, better financing of long consultations so that they can really be implemented. Some participants also mentioned that a new nomenclature for these long consultations would be welcome. A nomenclature already exists for long consultations in geriatrics or psychiatry. This type of consultation could serve as a model for establishing reimbursement for consultations for people with special needs.

Time is also a key factor for the supporters of people with ID, both professional and informal. It is essential to prepare the person being cared for to their future experience in the health care system (consultation, diagnostic examination, new treatment, hospitalisation, etc.). For example, preparing a person who must undergo a complementary medical examination takes a lot of time but can avoid anaesthesia. Then the supporters must also free up a lot of time to accompany the person with ID during consultations or hospital stays. But this time is often lacking, making it impossible to have someone of an ID institution team or of the family 24/7 during hospital stay while their presence is essential to reassure and avoid challenging behaviours and to explain, listen and guide.

There are already some initiatives to provide some time for family carers, such as the leave for family carers, combined with a financial incentive in Flanders[nnn].

6.3.5.3 Improving manpower and clarification of missions

Participants to the nominal groups expressed that a necessary condition to the implementation of hospital care pathways for people with ID is creating a specific fee to increase attractivity for specialists and to make it profitable for the hospital management.

6.3.5.4 Other policy and social solutions from the international literature quick analyse

The policymakers should be made aware of all types of barriers faced by people with ID and this awareness should be reinforced by **formal acknowledgment** that people with ID experience health inequities. This was the aim of the US position paper entitled ‘US surveillance of health of people with ID’ published by the CDC, in the collaboration with the Association of University Centres on Disabilities (AUCD), representative of the federal government, advocacy communities and representatives of research [146]. Australia[147] and UK[124] have also published such acknowledgments under the form of a national agenda or position papers addressing the health problems of people with ID.[34]

The policy barriers can be overcome through the adaptation of **public health laws, policies, strategies, programming and funding**. First, solutions are that politics deliver inclusive messaging. Second, accessible communication materials should be available. Third, any further policy implementation should meet the health care needs of people with ID.[8] It is recommended by experts to involve HCP familiar with structural, institutional and professional challenges regarding people with ID quality care provision in the elaboration of health care system adaptations.[8] Also people with ID should be involved in the process.[8]

The creation of new policies is not seen as the most important step but well the **awareness’ improvement of the existing policies**, the monitoring of policies’ implementation, and the assessment of all policies in the health sector on their potential negative effect on the health access for people with ID. [31] While all those steps are realised, the creation of sustainable inclusive policies is the next step to envisage. For example, in England in 2014, the Department of Health gave the mission to NHS England to reduce premature death amongst people with ID under the age of 60.[31] This results notably in the publication of an overview on annual health check for people with ID.[148]

[nnn] More information on support for relatives in Flanders (in Dutch): https://www.trefpuntstan.be/vind-info/ondersteuning-voor-ouders-en-gezin/vinden-van-balans2/vinden-van-balans

Social barriers were rarely explored in the grey literature. Two solutions were however identified: having a health insurance and/or providing (extra) subventions in health-care coverage for people with ID. Having insurance improves the likelihood of receiving primary care, decreases the unmet needs and reduces delays. Insurance for a wide range of basic medical services can improve clinical outcomes, and can reduce the financial problems and the burden of out-of-pocket payments for families.[8] In Taiwan, health insurance scheme pays for part of the insurance premium for people with ID according to their level of disability.[8]

Key messages

- Unia and its expert committee make recommendations to the medical profession and the authorities to improve the implementation of the reasonable adjustments countering discrimination related to intellectual disability.
- Longer consultations when receiving a person with intellectual disabilities was suggested.

6.4 Conclusion

In the Chapter 5 on barriers, it was shown that communication deficits are the main stumbling block to better care for people with intellectual disabilities. In the current solution chapter, several suggestions for dealing with the different types of barriers are provided, the majority of which are aimed at improving communication.

First, changes in attitude of each protagonist involved in the care relationship could lead to better communication. Thus, empathy, trust in the supporters, mutual respect between health and disability professionals, demystification of health professionals and improved reception are among the attitudes that need to be changed to improve the care relationship. Atmosphere of care should be relaxed, and use of creative solutions would contribute to improving communication and access to care. All these attitudinal elements necessary for better communication imply an investment of time and include training of HCP to communicate in an appropriate way. Repeating information, avoiding medical jargon and illustrating explanations with comic books or videos are examples of communication techniques to be acquired in the health sector.

Secondly, a preventive and anticipatory view of care and the responsible involvement (empowerment) of patients would help to increase compliance and/or avoid missed care. Special Olympics has developed several strategies to raise health awareness and motivate people with intellectual disabilities to take care of themselves through prevention and screening. Health literacy plays an important role, with a particular need to improve the ability to express oneself and to detect symptoms. Digital skills and general knowledge about available aids are also to be considered. Numerous tools have been developed and listed, which, thanks to their adapted content, allow the maximum involvement of the person and their family. The non-profit organisations Inclusion asbl, Centre Santé & Handicap and STAN are working on the dissemination of these tools.

Better management of the anxiety of people with intellectual disabilities is also central to avoid refusal of care. The involvement of family and friends during check-ups and hospital stays is seen as essential to reassure the anxious person. The role of volunteers could be extended to include the reception of people with special needs, subject to targeted training. Preparing the person for care is an important step in avoiding refusals but this preparation requires time and didactic support. HCP should more often consider the benefits of sedation when the previous strategies failed.

A whole series of solutions proposed by the participants aim at structural or organisational changes. Those are usually viewed as reasonable adjustments. The appointment system would need to be made much more flexible. Respecting and establishing a routine allows people with intellectual disabilities to function better, appointment slots for emergencies in general medicine would avoid the need to go to an unknown emergency room, and telephone slots would strengthen communication, trust and coordination. Improving travel is also a key issue. The emergency referral system and the design of ambulances and waiting rooms are structural elements that need to be more inclusive. Finally, if it is impossible for a person with intellectual disabilities to travel, a paradigm shift in the way the health system works should be considered for these people, for example by moving specialist doctors or specialist paramedics to the place where they live, developing mobile health services in the form of buses, or setting up health office in institutions for people with disabilities.

Making reasonable adjustments is an obligation under Belgian anti-discrimination legislation and the UN Convention on the Rights of Persons with Disabilities. The implementation of reasonable adjustments allows improving the accessibility of health care for people with disabilities. Accommodation can be a technical or environmental adaptation, but also an adjustment of rules or organisation in order to allow the full participation of the disabled person in society. In the nominal groups, the importance of adopting a 'universal design' adapted to the needs of people with intellectual disabilities and improving comfort for all is mentioned many times. For example, Inclusion advises health professionals to provide an adapted waiting room: a specific space separate from the main traffic areas, enough seats, a toilet nearby, etc. The many reasonable accommodations mentioned in the Inclusion brochure are common to the results of the current study.[20] The analysis of the scientific literature also demonstrates the importance of an ID-friendly system. For example, Proulx et al (2012)[149] listed 25 proposals to increase participation to breast cancer screening program. These proposals reflect 5 major fields of actions: providing tools for the staff (e.g. checklists to facilitate the intake process, and guidelines and educational material for training); improving the screening programme invitation; making physical adaptations (of the centres, the mammography equipment) and disseminating information on centre accessibility); mobilizing key players (community resources and physician involvement); and identifying best practices (evaluation of effectiveness and quality of screening programme).

Raising awareness of intellectual disabilities among health care staff and the training and presence of ID-specialist liaison person in hospitals would facilitate the inclusion of people with intellectual disabilities in the health care system. A specific care pathway is also envisaged but is not unanimously supported due to the risk of stigmatisation and loss of contact with the general system.

In view of the difficulties of expression of people with disabilities, this research also highlights the importance of coordination and communication of information between the protagonists. The general practitioners play a key role in this coordination. They are expected to organise multidisciplinary consultations involving the patient and his family. Supports such as liaison books and shared files that include the needs, habits and abilities of the person with a disability are valuable tools in the care of people with difficulties of expression. The coherence of discourses also reveals its importance in this research. It is expected that specialists and general practitioners as well as nursing and paramedical staff coordinate the message delivered to the patient and the families. The organisation of a telephone line that centralises information about people with intellectual disabilities in hospital was mentioned.

7 CHAPTER 7: EXPERT CONSULTATIONS ON PROPOSAL OF SOLUTIONS

7.1 Introduction

During all the research process and as illustrated in Figure 1, a step-wise approach generated a set of solutions which was updated at each steps of the process in order to obtain the most relevant, feasible and acceptable solutions. This chapter presents the results of both the stakeholders and experts' consultation about the relevancy, the feasibility and the acceptability of those solutions in order to improve as best the access to health care for people with ID in Belgium.

7.2 Methodology

7.2.1 Selection of solutions

In a first step, 3 researchers compiled solutions emerging of the different steps of the research based on a common extraction framework. The extraction framework included the following categories: 1) solution; 2) source of the solution (where the solution was found in the project); 3) categories of solutions based on the categorisation used to analyse the qualitative data that is attitudinal / communication / competences / organisational / policy and social; 4) ranking (perceived priority when the solution is mentioned); 5) degree of implementation (must/should/could). The last 2 categories were not systematically fulfilled as the information was not available, supporting the need for the consultation of experts and stakeholders.

One researcher compiled solutions emerging from the interviews and nominal groups, one researcher compiled solutions identified in the grey and scientific literature and one researcher compiled solutions based on the description of the Belgian context. The solutions were either existing initiatives or projects developed by local actors, existing intervention inside the national health insurance / the health care system. Not all these solutions have been tested and evaluated, meaning that the impact of these solutions to improve access to health care is not yet documented and measured.

A total of 65 solutions were then retrieved: 33 from the qualitative research, 18 from the description of the Belgian context and 14 from literature (see Appendix 7).

In a second step, researchers discussed each solution taking into consideration the scope of the study as the selection thread: 1) focus on people with ID, 2) suitable for the Belgian context (i.e. existing initiative at local level in Belgium), 3) access to "routine care" and not to specialised care aiming at caring / curing the disability[ooo], 4) solutions promoting inclusive approach rather than specific pathways to be coherent with the social approach of disability (see Introduction). Redundant solutions were excluded. During team meetings, it was also possible to identify solutions for which there was not enough detail to implement or understand them: these solutions were excluded from the panel. This also allowed some solutions to be grouped together and a distinction to be made between solutions and actions (= implementation conditions).

In a third step, solutions were cross-referenced with the barriers previously identified. This corpus of solutions was then used as a basis for the consultation of stakeholders.

7.2.2 Consultation of stakeholders in the health care sector

Overall design and rationale

An online consultation via LimeSurvey was chosen to collect the opinions of the stakeholders in the health sector. It allows the involvement of a large sample of stakeholders representing the diversity of the health care sector. The online consultation was chosen because it allows respondents for an asynchronous participation and is more time-effective than individual interviews. It also prevents influence bias between respondents.

[ooo] For example, solutions to improve access to speech therapy or rehabilitation care were excluded.

Content of the questionnaire

To facilitate the handover of the questionnaire, barriers were grouped in 8 distinct categories, covering dimensions of access to health care (Box 46). These 8 categories were not based on an existing categorisation or on the categorisation used to analyse the qualitative data. They were selected for their capacity to be understood to all respondents with a reduced risk of misinterpretation as the questionnaire was aimed at a large and diverse panel. Table 53 presents the solutions and actions as submitted to stakeholders (in French and Dutch).

Box 46 – Categories of solutions as presented in the questionnaire for stakeholders

- Empowerment[ppp] of people with ID and their supporters – 1 global solution - 4 actions
- Coordination and integration of health information and health care by primary care – 1 global solution - 6 actions
- Reachability of health care and outreaching – 2 global solutions - 5 actions
- Availability of HCP during consultations and visits –1 global solution - 2 actions
- Coordination and accompaniment in hospital context – 2 global solutions - 13 actions
- Competences of the educational staff in the disability sector – 1 global solution - 3 actions
- Skills of HCP outside the disability sector – 1 global solution - 5 actions
- Monitoring and follow-up of the health care needs – 1 global solution - 5 actions

For each category of solutions, an overall solution was proposed in the form of an objective to be achieved (at the exception of the categories “Reachability of health care and outreaching” and “Coordination and accompaniment in hospital context” where two complementary solutions were proposed). This objective was accompanied by a series of actions, which contribute to its implementation. These actions aimed at addressing different problem elements and should be seen as complementary to each other. Although not always explicitly stated in the formulation of the actions, their implementation, when relevant, should consider the diversity of situations and the differences in abilities and resources between people living with ID.

In the online questionnaire, each category was introduced by its global solution followed by a summary of the related barriers[qqq]. To ensure the comprehensibility of the concepts, a lexicon introduced the questionnaire. For each barrier, several actions to attain the overall solution were listed. The possibility of asking a SMART[rrr] assessment of each action was considered by the research team. This was however perceived as complex to fulfil, time-consuming and likely to negatively impact the participation. It was then decided to opt for only 3 criteria for assessing the actions: 1) relevance defined as the capacity of action to solve the barrier(s); 2) feasibility defined as the degree to which one perceives it is possible to implement the action; 3) acceptability defined as the coherence of the action with the current practices and policies. Respondents could indicate if they

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[ppp] Empowerment is a process of personal transformation by which patients strengthen their ability to effectively take care of themselves and their health, not just their illness and treatment.[150]

[qqq] Questionnaires are available upon request to the research team.

[rrr] SMART Objectives are defined as a set of objectives and goals that are put in place by parameters, that bring structure and tractability together. SMART goal setting creates a verifiable trajectory towards a certain objective with clear milestones and an estimated timeline to attain the goals. SMART is an acronym that stands for: S – Specific, M – Measurable, A – Achievable, R – Relevant, T- Time-based. Source: https://www.questionpro.com/blog/smart-objectives-and-goals/

felt not competent enough to answer the question. At the end of the questionnaire, respondents had to choose their 3 priority solution categories.

Development of the questionnaire

The questionnaire was firstly developed in French then translated into Dutch, with reverse translation to ensure the correspondence of the versions. The questionnaire was integrated in the online survey tool LimeSurvey. Questions were close-ended questions, with binary response (yes / no). Respondents had the possibility of commenting each category in a text box. The online draft questionnaire was tested by KCE colleagues before launching.

Target population

This survey specifically targeted key stakeholders that are not currently involved or familiar with people with ID but are likely to influence the implementation of the suggested solutions because of their degree of interest and power. According to the multi-stakeholder partnerships terminology, this survey targeted the “context setters” and, in a lesser extent, the “crowd” rather than the “key players” or the “subjects”.[151] Stakeholders were categorised in “need to have” when identified as “context setters” and “nice to have” when assimilated to the “crowd”. Stakeholders had to provide a single response for the institution they represented. Responses could however be discussed by a team before being encoded in the questionnaire.

Based on these criteria, a defined list of stakeholders was established.

Table 12 – List of stakeholders invited for the LimeSurvey

Categories	Invited stakeholders
Public health administrations (n=7)	• FPS Public Health • National Institute for Health and Disability Insurance RIZIV – INAMI • FPS Interior General Directorate Civil Protection 112 department • *Agentschap Zorg en Gezondheid* (Flanders) • *Agence pour une Vie de Qualité* AVIQ (Wallonia) • Iriscare (Brussels region) • *Diensten van het Verenigd College van de GGC − Service des collèges réunis de la CoCom* (Brussels region) DVC – SCR
National sickness funds (n=5)	• *Landsbond der christelijke mutualiteiten − Alliance nationale des mutualités chrétiennes* • *Landsbond van de neutrale ziekenfondsen − Union nationale des mutualités neutres* • *Nationaal verbond van socialistische mutualiteiten − Union nationale des mutualités socialistes* • *Landsbond van Liberale Mutualiteiten − Union nationale des Mutualités Libérales* • *Landsbond van de onafhankelijke ziekenfondsen − Union nationale des mutualités libres*
Federation of hospitals and health institutions (n=5)	• Zorgnet ICURO • *Raad van Universitaire Ziekenhuizen RUZ − Conférence des Hôpitaux Académiques de Belgique* CHAB • Santhea • UNESSA • *Gezondheidsinstellingen Brussel − Bruxelles Institutions de Santé* GIBBIS
Patient platforms (n=4)	• *Vlaamse Patienten Plateform VPP* • *Ligue des Usagers des Services de Santé LUSS* • *Patienten Rat & Treff PRT* • *RaDiOrg- Rare Diseases Belgium*
Federation of integrated primary care services (n=2)	• *Fédération des maisons médicales* • *Vereniging van Wijkgezondheidscentra*
Professional associations of medical doctors (n=6)	• *Verbond der belgische beroepsverenigingen van artsen-specialisten VBS – Groupement des unions professionnelles belges de médecins spécialistes* GBS

	• *Vlaamse artsensyndicaat* BVAS − Association belge des syndicats médicaux ABSyM, • *Algemeen Syndicaat van Geneeskundigen ASGB − Groupement Belge des Omnipraticiens* GBO • *Monde Des Spécialistes MoDeS* • *Société Scientifique de Médecine Générale* SSMG • Domus Medica
Professional associations of physiotherapists (n=3)	• *Wetenschappelijke Vereniging voor Vlaamse Kinesitherapeuten* WVVK • Axxon Physical Therapy in Belgium, • *Union des Kinésithérapeutes de Belgique* UKB
Professional association of nurses (n=1)	• *Algemene Unie Verpleegkundigen België* AUVB − *Union générale des Infirmiers de Belgique* UGIB
Professional associations of dentists (n=5)	• *Vlaamse Beroepsvereniging van Tandartsen* VBT • *Verbond der Vlaamse Tandartsen* VVT • *Vlaamse Wetenschappelijk Vereniging voor Tandheelkunde* VWVT • *Société de Médecine Dentaire* SMD • *Chambres Syndicales Dentaires* CSD
Professional associations of psychologists and psychiatrists (n=4)	• *Union Professionnelle des Psychologues Cliniciens Francophones et Germanophones UPPCF* • *Vlaamse Vereniging Psychiatrie VVP* • *Vlaamse Vereniging Klinisch Psychologen VVKP,* • *Société Royale de Médecine Mentale de Belgique SRMMB*
Associations of public health information (n=2)	• *Centre Belge pour l'Evidence-Based Medicine / Belgisch Centrum voor Evidence-Based Medicine* CEBAM, • *Gezondheid en Wetenschap − Info. Santé*

Timing

The survey was opened from February 28, 2022, until March 13, 2022. A personal reminder was sent on March 7 to non-respondents. To increase the participation rate, invitations were personal and specifically indicated the reason for involving the stakeholder in the survey.

After March 13, the KCE researchers directly contacted the “context setters” who did not respond in order to fulfil the questionnaire with them during a phone call or a videoconference.

Data analysis

In total, 44 stakeholders were invited to participate to the online consultation. Two stakeholders explicitly declined participation as they felt not competent to participate. A total of 35 responses were received among which 2 responses were excluded as the respondents were not in the preestablished list of stakeholders. Thirty-three questionnaires (75%) were then considered as valid.

Detailed results of the online survey can be obtained upon request. Comments let by the respondents were qualitatively analysed and were used to nuance or precise some of the solutions and to identify additional actions to increase the feasibility of the solutions. Adaptations consisted in three adjustments: semantic (wording used), target population of action (e.g., physicians, also other care professionals) and description of action (more elaborated and/or linkage with existing initiatives). An updated version of the solutions was then compiled for the expert’s consultation. Besides, as some stakeholders expressed difficulties for understanding some aspects or pointed out the lack of details for other aspects, the updated version was adapted accordingly. Fourteen actions were added at the end of the stakeholder consultation.

7.2.3 Consultation of experts in the domain of ID

Overall design and rational

Experts in the field of the health of people with ID were invited to join an online stakeholder meeting. The meeting allows for exchanges and debates between participants. The online option was chosen for practical aspects and in accordance with the COVID19 regulations at the time.

Preparatory material

The invited experts received a preparatory document including the updated solutions and actions according to the stakeholder consultation, grouped according to the 8 categories as used with stakeholders (Box 47 – Categories of solutions as presented in the preparatory document for experts. Experts could complete a table indicating their opinion on the relevance, feasibility and acceptability of the different solutions. They could also comment on the solutions and suggest additional actions. The document was first drafted in French then translated in Dutch. Table 53 (Appendix 8) presents the solutions and actions as submitted to experts (in French and Dutch). Table 53 also indicates the actions added after the stakeholder consultation.

Box 47 – Categories of solutions as presented in the preparatory document for experts

- Empowerment of peo!ple with ID and their supporters – 1 global solution - 9 actions
- Coordination and integration of health information and health care by primary care – 1 global solution -9 actions
- Reachability of health care and outreaching – 2 global solutions - 8 actions
- Availability of HCP during consultations and visits –1 global solution - 2 actions

- Coordination and accompaniment in hospital context – 2 global solutions - 14 actions
- Competences of the educational staff in the disability sector – 1 global solution - 4 actions
- Skills of HCP outside the disability sector – 1 global solution - 5 actions
- Monitoring and follow-up of the health care needs – 1 global solution - 6 actions

Participants

Participants were academic experts and clinicians, representatives of people with ID and members of public authorities. They were identified in previous steps of the projects.

- **Representatives of people with ID / patients associations (n=6)**: CSNPH – NHRPH, *Down Syndrome Vlaanderen*, LUSS, RaDiOrg, *Participate,* VPP
- **Academic experts and clinicians (n=3)**: *Universitaire Ziekenhuis Antwerpen* (UZA), UCLouvain, *Universitaire Ziekenhuis Leuven* (UZLeuven)
- **Public authorities (n=7)**: AVIQ, Iriscare, *Service Personnes Handicapées Autonomie Recherchée Phare,* FPS Public Health, *Agentschap Zorg en Gezondheid*, SCR – DVC, VAPH
- **Non-profit expert associations (n=5)**: Special Olympics (SO), *Inclusion asbl*, *Association de Recherche-Action en faveur des Personnes Handicapées* (ARAPH), *Fondation SUSA*, *Altéo*.

Some of the participants in this expert meeting also participated in the online consultation via LimeSurvey because of their dual membership or, in the case of institutions, a portfolio of competences that straddles health and disability. Other participants had also participated in the scoping meeting of the project or in the qualitative data collection.

Thirty-three experts were invited (a same organisation could be represented by 2 persons): 19 have participated and 2 have declined participation because they felt not competent to participate to this meeting.

Timing

The meeting took place on April 28, 2022, via the Zoom online platform. The meeting was moderated by a duo of KCE experts in French and Dutch (CER & AND) as no translation was planned. Participants expressed themselves in their own language. Notes were taken directly during the meeting (JOG & CAD).

Progress

The meeting started by a presentation round and a short introduction to the KCE project. Each proposal of solution and the related actions were then presented: experts had the possibility of commenting and exchanging on the solutions. The order of the solutions was determined by decreasing order of range between relevance and feasibility as expressed by the stakeholders in the previous step (see Table 57). This order was consensually chosen by the research team for getting information about the more divergent actions. To determine this order of solutions, the gap between the feasibility and relevance of each solution was measured, i.e., the difference between the score for relevance and the score for feasibility. The higher the gap, the higher the priority of the solution to be discussed with the experts. Once the discussion was rounded on a solution, experts were invited to position themselves anonymously on the relevance and the feasibility of the solutions via the Zoom platform.

As acceptability of the decisions highly depends on political priorities and because of time constraints, the research team decided not to consult the experts on the acceptability of the solutions, that is the coherence of solutions with existing policies and practices. This was justified because the participating experts were selected for their academic, professional or experiential knowledge regarding health and ID and not for their political knowledge (this latter particularly applies for public authorities).[152] Moreover, as the solutions were based on the previous steps of the project, including the contributions of some experts (see Figure 1), the research team anticipated less discussion on the acceptability among experts of the health of people with ID than among stakeholders of the health sector.

At the end of the meeting, experts voted on the priority of the solutions.

Follow-up of the meeting

Experts had the possibility to share their comments on the solutions up to May 31, 2022, by email. Nine experts shared additional comments after the meeting.

Following the stakeholder meeting, the CSNPH – NHRPH invited the KCE research team to a presentation of the proposed solutions as they expressed their need to further discuss the solutions before positioning themselves. The meeting took place online on June 7, 2022, and written feedback was sent to the research team on June 21, 2022.

Data analysis

Based on an extensive notetaking, information and comments shared during the meeting were used to nuance or precise some of the solutions and to identify additional actions to increase the feasibility of the solutions. Similarly, to the process after the stakeholder consultation, adaptations consisted in three adjustments: semantic (wording used), target population of action (e.g., physicians, also other care professionals) and description of action (more elaborated and/or linkage with existing initiatives). Additional information and reflections shared during the meeting were integrated in the description of the solutions and were added, when relevant, as new actions to support the implementation of the proposed solutions. Written comments shared by the participants were also included. When needed, the KCE researchers conducted ad hoc search to bring additional information to the proposed solutions. The final version of the proposed solutions was then compiled.

Quotes are included in the text to illustrate the findings: these have been kept in original language but have been edited for length and clarity. Intermediary documents and research tools, developed in French and Dutch, are available upon request to the research team.

7.3 Results

7.3.1 *Stakeholder consultation*

7.3.1.1 Perception of the relevance of the actions

Table 54 (in Appendix 9) presents the relevance of actions by decreasing order of relevance as expressed by the stakeholders. No action was considered bas relevant by all stakeholders. The most relevant action was the planning by the RIZIV – INAMI of an additional budget for longer consultations and visits for people with specific needs, including people with ID (n=22/28). This action is part of the global solution aiming at improving the availability of HCP when caring for people with specific needs. Two participants declared they felt not competent to answer and 2 reported they don’t know. Diffusing tools for improving the participation of people with ID to the decisions about their health was considered as the second most relevant action (n=21/28). This action should be endorsed by the public authorities in collaboration with associations of the disability sector and aims at improving the empowerment of people with ID and their supporters. The third most relevant action is related to the first most relevant action as it concerns the development of longer consultations for people with comprehension needs (n=21/28).

The less relevant action (n=12/28), according to the stakeholders, was the development of performance indicators related to health monitoring and follow-up in institutions for people with ID. This action aims at improving the monitoring and the follow-up of the health care needs of people with ID. Two participants declared they felt not competent to answer and 4 participants reported they don’t know. The other less relevant action concerns giving the coordination of the interdisciplinary centre in the hospitals to a physician (n=12/28). This lack of perceived relevance could be explained by some comments let by respondents, namely that not only doctors could coordinate such centres but also other HCP. Moreover, this action could be considered by some respondents as implementation modality rather than an action that directly improves access.

7.3.1.2 Perception of the acceptability of the actions

Table 55 (in Appendix 10) presents the perceived acceptability of the solutions as expressed by the stakeholders.

Three actions emerged as the most acceptable: 1) diffusion of tools for improving the participation of people with ID to the decisions about their health (n=21/28); 2) selection, adaptation and diffusion of liaison tools for the GP by the scientific associations of GP with the support of associations of the disability sector (n=21/28); 3) development of longer consultations for people with comprehension problems (n=21/28).

The 3 actions perceived as less acceptable belong to the category Monitoring and follow-up of the health care needs: 1) creating indicators of follow-up of health of people with ID (n=12/28), 2) determining performance indicators in health for institutions (n=12/28) and 3) analysing data of home visits by specialists.

7.3.1.3 Perception of the feasibility of the actions

Table 56 (in Appendix 10) presents the perceived feasibility of actions to improve access to health care for people with ID as reported by stakeholders.

The most feasible action was raising awareness of people with ID and their supporters about the importance of having a referent GP and a centralised global medical record (*globaal medisch dossier - dossier médical global)* via an annual information campaign organised by public authorities in collaboration with the scientific societies of GP and the sickness funds (n=21/28). Three other actions were perceived as the most feasible. Two of these actions were related to the empowerment of people with ID and their supporters: 1) diffusing tools for empowerment (n=17/28); 2) developing Easy read version of the website *Gezondheid en Wetenschap – Infosanté.be* (n=17/28). The annual information of HCP about the tools for assessment of symptoms and needs by the public authorities in collaboration with associations of the disability was also identified as feasible action (n=17/28).

The least feasible action was the increase of the number of home visits by medical specialists (n=6/28), followed by the organisation of an annual interdisciplinary consultation by a GP (n=7/28) and the organisation of consultations inside the interdisciplinary centre (n=8/28).

7.3.1.4 Convergences and divergences between perceived feasibility and perceived relevance of actions

When comparing the perceived relevance of the actions with their perceived feasibility, it was possible to identify actions where the stakeholders perceived they were likely to improve access but will be difficult to put into practice.

This was particularly the case for the action consisting in increasing the number of home visits by specialists at the request of the GP in order to improve the reachability of health care, especially for people with ID whose transportation is difficult to organise. This action was perceived as relevant by 18 stakeholders out of 28 but only 6 stakeholders perceived it was feasible (Table 57 in Appendix 10).

Sixteen stakeholders out of 28 perceived that the organisation of an annual interdisciplinary consultation by the GP is relevant but only 7 perceived it as possible to be implemented.

Similarly, although identified as the most relevant action (n=22/28), the planning of a specific budget to cover the longer consultations was perceived as feasible by only 14 stakeholders.

At the opposite, 18 stakeholders (n=28) perceived that raising awareness about referent GP and patient health record is relevant but 21 perceived that it was feasible.

7.3.1.5 Perception of the competency to assess the actions

Stakeholders had the possibility to declare whether they felt competent to answer the question. Table 58 (in Appendix 10) presents the number of stakeholders who declared themselves not being competent to assess the relevance / the feasibility / the acceptability of the actions (the data do not allow to distinguish for which aspect the respondents felt not competent to assess the dimension). No stakeholder felt competent to assess feasibility, relevance or acceptability for all the 43 suggested actions.

Five stakeholders reported not being competent to assess the planning of a budget for the adaptation of hospitals to the needs of people with ID, the coordination of the interdisciplinary consultation and coordination centres by a medical doctor and the organisation of an annual interdisciplinary consultation by the GP.

7.3.1.6 Priority ranking of the global solutions

Stakeholders could choose up to 3 global solutions as priority to be followed (Table 13). The 3 priority categories of solutions were: 1) improving the empowerment of people with ID and their supporters by strengthening the ability of people with ID to take control of their health through improving their access to information and providing them with the necessary tools and resources. (n=16/28); 2) improving the training of HCP outside the disability sector (n=13/28); and 3) the implementation of a preferential status for people with special needs to ensure that they can benefit from a longer consultation or visit (n=12/28).

Table 13 – Priorities of global solutions according to stakeholders (n=28)

Categories	Global solutions	Priority 1	Priority 2	Priority 3	Total
Empowerment of people with ID and their supporters	The ability of people with ID to take control of their health should be strengthened by improving their access to information and providing them with the necessary tools and resources.	12	2	2	**16/28**
Skills of HCP outside the disability sector	HCP providers, especially GP, need to be better trained and prepared to support people with ID and their supporters.	8	2	3	**13/28**
Coordination and integration of health information and health care by the primary care	Each person with ID must have a GP in charge of multidisciplinary consultation and preventive follow-up, a global medical record and a follow-up booklet.	5	3	2	10/28
Reachability of health care and outreaching	People with ID must have the possibility of being cared for in their usual place of residence.	2	7	/	9/28
Coordination and accompaniment in hospital context	All hospitals and health services should provide an infrastructure that allows people with ID to be accompanied by a person of their choice at any time and any place.	/	2	3	5/28
Monitoring and follow-up of the health care needs	Opportunities for collecting data and statistics on the health of people with ID should be developed.	/	3	2	5/28

Availability of HCP during consultations and visits	The RIZIV – INAMI must introduce a preferential status for people with special needs, so that they can benefit from a longer consultation or visit.	/	4	8	**12/28**
Skills in health of professionals inside the disability sector	Professionals in the disability sector should be trained in the health of people with ID.	/	3	3	6/28
Coordination and accompaniment in hospital context	Hospitals with a centre for clinical genetics or a neuro-paediatric department should organise a multidisciplinary coordination and consultation centre for people with ID, regardless of age.	/	1	3	4/28
Reachability of health care and outreaching	People with ID must be accompanied by a person of their choice during transport in case of emergency, provided that the safety of that person is guaranteed.	/	/	1	1/28

7.3.1.7 Additional actions and conditions

Comments shared by stakeholders were categorised either as attention points or as additional actions. Attention points were used to nuance or precise the description of the actions while the additional actions were added to the list.

Empowerment of people with ID and their supporters

Attention points

- The target audience of people with ID is heterogeneous.
- The digital divide, low digital literacy and the lack of computer equipment, whether in institutions or in the homes of people with ID, are major barriers to access to information.
- These solutions require a lot of time from people around them. It is easier and/or quicker to decide for the person.
- Having the tools is not enough: those who must use them must be able to communicate adequately with people with ID and those around them, whether professional or not.
- There are other information sites that should be translated into Easy Read format or that could participate in the dissemination of validated information, such as the sites of public authorities.

Additional actions

- Supporting family and friends in their efforts to have the preferences of people with ID respected
- Organisation of annual information and dissemination campaigns on the use of tools to identify and correctly assess symptoms
- Training HCP in tools for detecting and assessing symptoms of people with ID
- Raising awareness and training people with ID to recognise their symptoms

Coordination and integration of health information and health care by the primary care

Attention points

- The GP is not the only person capable of organising and coordinating care for people with ID: other actors, such as (advanced practice) nurses, social workers or psychologists could play this role.
- Coordination and integration with existing structures such as the integrated home care services (*Eerstelijn Zones EZ - Services intégrés de Soins à Domicile SISD*) should be strengthened.

- Multidisciplinary consultation should be financed for all professionals involved, not just doctors.
- Therapeutic education and health education are not sufficiently valued in the current nomenclature.

Additional actions

- Establishment of financial incentives to increase the coverage of preventive care and screening among people with ID
- Establishment of (financial) incentives to support proactive approaches by GP to annual preventive monitoring of people with ID in their practice
- Provision of the necessary means for the implementation of a prevention and health promotion policy adapted to people with ID and their living environment(s)

Reachability of health care and outreaching

Attention points

- Some medical specialties require equipment that is difficult to transport and therefore cannot be consulted at home.
- Home consultations by specialists are not sufficiently funded and are difficult to organise.
- Non-emergency transport (medico-social transport), under the competence of the federated entities, should also be adapted, when circumstances allow, to the needs of people with ID.

Availability of health care professionals during consultations and visits

Attention points

- Other health professions, such as dentists and physiotherapists, would require longer consultation or visit times to take account of the specific needs of some of their patients.
- Having more time is not necessarily a guarantee of the quality of the exchange: it is therefore also necessary to think about the training of HCP.

Additional actions

- Adapting the infrastructure of institutions to allow for consultations, especially when they accommodate residents for whom travel is complicated or impossible
- Structural support and expansion of mobile care initiatives adapted to the needs of people with ID
- Coordination and organisation of participation in screening activities when a mobile screening device comes to the community

Coordination and accompaniment in hospital context

Attention points

- Not all patient platforms are familiar with disability issues: care should be taken to ensure that the most relevant interlocutor is involved and supported.
- The coordination of the centre could be ensured by a non-medical profile such as an advanced practice nurse.
- The creation of specialised centres attached to hospital institutions might create more barriers than solutions for people who already have difficulties in accessing health services.

Additional actions

- Creation of an interdisciplinary coordination and consultation centre

Skills in health of professionals inside the disability sector

Attention points

- Educational staff should not become health care staff: a good balance between the tasks of both should be ensured.
- Services for people with ID should not become health services.

Additional actions

- Consultation on the framework for the provision of care in institutions for people with ID.

Skills of health care professionals outside the disability sector

Attention points

- The development of guidelines may include other health professions than GP such as physiotherapists, dentists or nurses.

Additional actions

- Guidelines should be developed to support the work of other HCPs.

Monitoring and follow-up of the health care needs

Attention points

- Quality indicators should consider existing indicators and include Patient Reported Outcome Measures (PROM) and Patient Reported Experience Measures (PREM). They should also be qualitative and quantitative.
- General practice should not be the only area considered in terms of health system performance.
- Data collection and monitoring should be used to implement actions.
- Monitoring should not add to the administrative work of professionals.

Additional action

- Identification of unmet needs of people with ID via the methodology developed by the KCE.

7.3.2 Experts consultation

During the consultation, actions were presented to the experts according to the decreasing perceived difference between the relevance and the feasibility (see Table 57 in Appendix 10). This order was consensually chosen by the research team in order to get information about the more divergent actions.

Six global solutions were discussed with the experts.

At the beginning of the meeting, some experts pointed the lack of time to prepare the meeting and expressed feeling uncomfortable to express their opinions without being able to consult with others. Consequently, not all experts expressed themselves during the meeting and preferred giving their final appreciation after the meeting. Consequently, the research team suggested that extra comments and opinions could be sent by email after the meeting.

7.3.2.1 Perception of the relevance of the global solutions

Overall, global solutions were perceived as relevant although some experts declined expressing their opinion while others stated they felt not competent to assess the relevance of the solutions (Table 59 in Appendix 10). Some experts pointed out that some words used in French or in Dutch were not appropriate and could lead to misunderstandings.

7.3.2.2 Perceptions of the feasibility

From the discussion, it emerged that experts reported facing difficulties to assess the feasibility of global solutions (Table 60 in Appendix 10). For some experts, in the current context, it was not possible to express an opinion about the suggested solutions. As explained by some experts, the implementation of some solutions depends on political decisions or on major changes in the current health care system.

Regarding the skills in health issues of the educators, some experts in the meeting mentioned that it was a longstanding discussion without no clear decision. One could resent that this lack of progress in some cases, especially when there is a demand from the field, is likely to lead to a form of discouragement among experts and therefore to a more negative perception of the feasibility of the solutions.

7.3.2.3 Convergences and divergences between perceived feasibility and perceived relevance

When comparing the perceived relevance of the actions with their perceived feasibility, it was possible to identify actions where the experts perceived they were likely to improve access but will be difficult to put into practice (Table 61 in Appendix 10).

This was particularly the case for the action consisting in increasing the number of home visits by specialists at the request of the GP in order to improve the reachability of health care, especially for people with ID whose transportation is difficult to organise. This action was perceived as relevant by 12 experts out of 16 but only 2 experts perceived it was feasible.

Similarly, the development of a preferential status for people with special needs was perceived as relevant by 12 experts but only 5 estimated it is feasible to be put into practice (with 9 experts reporting they didn’t know whether it is feasible).

Regarding the solution suggesting the creation of an interdisciplinary consultation and coordination centre, some experts were concerned about the practical aspects such as the geographical distribution or the qualifications of those working in such centres.

7.3.2.4 Priority ranking of the global solutions

Ten experts expressed their priority global solution (Table 14). The three priority categories of solutions were: 1) improving the training of HCP outside the disability sector – equally with – improving the coordination and integration of the health information in the primary care; 2) improving the empowerment of people with ID and their supporters.

Table 14 – Priorities of global solutions according to experts (n=10)

Categories	Global solutions	Total (n=10)
Skills of HCP outside the disability sector	HCP providers, especially GP, need to be better trained and prepared to support people with ID and their supporters.	3
Coordination and integration of health information and health care by the primary care	Each person with ID must have a GP in charge of multidisciplinary consultation and preventive follow-up, a global medical record and a follow-up booklet.	3
Empowerment of people with ID and their supporters	The ability of people with ID to take control of their health should be strengthened by improving their access to information and providing them with the necessary tools and resources.	2
Coordination and accompaniment in hospital context	All hospitals and health services should provide an infrastructure that allows people with ID to be accompanied by a person of their choice at any time and any place.	1
Skills in health of professionals inside the disability sector	Professionals in the disability sector should be trained in the health of people with ID.	1
Reachability of health care and outreaching	People with ID must have the possibility of being cared for in their usual place of residence.	0
Monitoring and follow-up of the health care needs	Opportunities to collect data and statistics on the health of people with ID should be developed.	0

Availability of HCP during consultations and visits	The RIZIV – INAMI must introduce a preferential status for people with special needs, so that they can benefit from a longer consultation or visit.	0
Coordination and accompaniment in hospital context	Hospitals with a centre for clinical genetics or a neuro-paediatric department should organise a multidisciplinary coordination and consultation centre for people with ID, regardless of age.	0
Reachability of health care and outreaching	People with ID must be accompanied by a person of their choice during transport in case of emergency, provided that the safety of that person is guaranteed.	0

7.3.2.5 Additional actions and attention points

The RIZIV – INAMI must introduce a preferential status for people with special needs, so that they can benefit from a longer consultation or visit.

Attention points

- Other people than people with ID need longer consultation time
- GP are not the only professionals that are concerned: other health care professionals need longer consultation time.
- It is complex to discuss this solution as this mainly concerns the federal authorities and a political willingness
- It seems impossible to develop and implement a nomenclature for a specific target group: this action has a lot of practical objections
- If this action is chosen, it requires to test the concrete feasibility
- Vocabulary should be clarified.

Additional actions

- Provision of supporting tools and / or training for allowing HCPs to certify long-term services for patients with special needs

People with ID must have the possibility of being cared for in their usual place of residence.

Attention points

- There is a need for clarifying what is meant by “care” in terms of acuteness or chronicity of the situations, does the term “care” refers to health care in general or only acute care. It should be clarified whether it concerns primary care, secondary care or tertiary care (specialised care).
- When people with ID have a rare disease, not all health care professionals are able to manage the regular health care problems as the rare disease may impact the therapeutic options. Consequently, if there are consultation in specialized institutions for people with ID with a rare disease, the health care professionals should relate to a network of expertise centres for rare diseases.
- Not all health care could be provided at home, especially when it comes to diagnosis or rely on specific equipment
- Providing health care at home should not overlook a better organisation of transportation. Moreover, in some cases, the place of care has few or no importance if the people with ID can be accompanied by a member of their supporters.
- Caring for people in their environment is important: closer to home should be considered as a mantra. It therefore does not mean at home but rather in a place where the people with ID are familiar with. From the patient's point of view, the place is less important but the where, the

time and the guidance are important. If there is a trusted person from start to finish, health care will go smoothly. This is especially the case as there is a lot of informal care involved.

- Access to home care for people with ID need to be improved in general: the current offer is insufficient and financial issues appear to limit the access for some people with ID. The Flemish personal assistance budget (PAB) is mentioned as a solution to improve the coverage in home care for people with ID.
- The norms of infrastructure of the institutions include a consultation room but educational staff is reported as reluctant to make use of these rooms for consultations.
- Health care in institutions could be a solution if it allows for more flexibility of health care professionals and educational staff but should not tend to increase the medicalisation of people with ID.
- Attention should be paid to the different degrees of autonomy of the person and of the severity of the disability
- Outreach teams could be part of the solution but need funding.

Additional actions

- Adaptation of the institutions' infrastructure to allow the organisation of consultations, especially when they receive residents for whom travel is complicated or impossible
- Structural support and expansion of mobile care initiatives adapted to the needs of people with ID
- Coordination and organisation of participation in screening activities when a mobile screening device comes to the community

People with ID must be accompanied by a person of their choice during transport in case of emergency, provided that the safety of that person is guaranteed.

Attention points

- Dispatching 112 & 112 ambulance crew should be well informed.
- This will still depend on the capacity at the time of intervention.
- During transportation, extra attention should be paid to the accompanying persons to made them partners of the intervention.
- Not all hospitals feel ready or competent to care for people with ID.

All hospitals and health services should provide an infrastructure that allows people with ID to be accompanied by a person of their choice at any time and any place.

Attention points

- The term “infrastructure” is misleading: better use equipment and material as infrastructure concerns the building.
- Having single room should not be considered as a privilege but for accommodating people with behaviour viewed as challenging or needing an accompanier
- Initiatives and norms already exist for the reception of people with ID, but this should be made permanent.
- Follow-up needs to accompany the transition from paediatric care to adult care.
- Adaptation of material should not be limited to Easy Read format but also pay attention to other forms of impairments such as visual problems.

Additional actions

- Including the possibility of having a single room without supplements as part of the preferential status of people with special needs

Hospitals with a centre for clinical genetics or a neuro-paediatric department should organise a multidisciplinary coordination and consultation centre for people with ID, regardless of age.

Attention points

- There is a need to discuss the appropriate distribution of such centres: for some experts, this should be offered in all hospitals.
- Initiatives like the project Welcome in Liège should be sustained: alongside health care aspects, il also pays attention to the social needs and activities of the daily life.
- The neuro-paediatric department or centres for clinical genetics are perceived as vague.
- Not all hospitals have the necessary expertise: there may be more in hospitals with the neuro-paediatric department or centres for clinical genetics.
- There are challenges related to the geographical distribution.
- If the hospital networks are not yet stabilised, hospitals are not likely to invest in such project.
- Reception should be organised in all hospitals, but transfer should also be anticipated if there is a need for more specialised care
- Having list of “competent” professionals to care for people with ID is not a solution.
- Specialist doctors should be involved in the development of a preventive and curative health policy.
- An appropriate preventive policy could contribute to a decreasing in hospital costs.
- Connexions should be made with the existing network of services of the disability sector.
- Existing initiatives mostly exist because of the good will of the hospitals, which use their own funds or charity to support it.
- There is no nomenclature for such initiatives.
- The building of expertise requires funding.
- Existing initiatives should be compared to identify which one is the most suitable in the Belgian context.
- A pyramidal organisation with a progression in the level of expertise required from the health care settings could help to organise the health care.
- Regarding interdisciplinary collaboration, there is a need to prevent redundancy with existing initiatives.
- A focal contact point inside hospitals should be a minimum.

Additional actions

- Possibility of having a pyramidal organisation with a distinction between actions that could benefit to all patients and be implemented in all health care settings and actions that could be implemented in a limited number of hospitals

Professionals in the disability sector should be trained in the health of people with ID.

Attention points

- Delegation of nursing acts to non-health care professionals is a longstanding issue and no formal decisions have been made so far.
- Health care professionals also need better trained as part of their initial curriculum.
- Training should rely on patient partners and experts by experience to ensure the (future) professionals have a contact with people with ID.
- Difference should be made between basic training and specialized training.

Additional actions

- Enforcement of a memorandum of understanding for the provision of care in institutions for people with ID
- Enforcement of a memorandum of understanding for the provision of care for people with ID by their non-medical supporters

7.4 Conclusion

During this step of the project, 8 global solutions were submitted to a panel of stakeholders and experts in order to identify the feasibility, the acceptability and the relevance of actions. Overall, the proposed actions generated numerous reactions, especially when it comes to feasibility. This was, among others, illustrated in the difference in the perceived feasibility and the perceived relevance of the actions (see Table 57). As pointed, several actions depend on a political decision and on adequate financial means. Moreover, some actions are interrelated and need to be implemented together to be effective. It also appears from both the comments and discussions that both experts and stakeholders seem to share a common concern that some actions remain “too” theoretical and may not be realistic in the Belgian context.

Among the 43 actions, 41 were perceived as relevant to solve the barriers by at least 50% of the stakeholders from the health sector (n≥14/28). This result could be understood as a form of validation of the selected solutions. As they are not all familiar with people with ID, assessing the perceived acceptability was an important variable to predict a form of inclusion of the actions in the current practices. Thirty-six actions were perceived as acceptable by at least 50% of the stakeholders. Finally, assessing the feasibility helps to appreciate the potential for implementation: only 21 actions were perceived as feasible by at least 50% of the stakeholders. The actions with the highest feasibility score could be considered as “quick wins” as they require few investments or do not require legal changes in the current health care system. These are actions such as “raising awareness about referent GP and patient health record”, “diffusing tools for empowerment”, adaptation of the website “*Gezondheid en Wetenschap – Infosanté.be* “, “diffusing tools for assessment of symptoms and needs”. On the contrary, the actions with the lower feasibility score may require, among others, negotiations at strategic level, not only between the federal and federated entities but also with the professional associations, the sickness funds and the other social partners.

Another key result is the apparent divergence between stakeholders and experts. Stakeholders identified as priority the empowerment of people with ID and their supporters, defined as the ability of people with ID to take control of their health: this should be strengthened by improving their access to information and providing them with the necessary tools and resources. Experts identified the need for training of health care professionals as a priority. Experts had the possibility to discuss the solutions before proceeding to vote while the stakeholders were consulted individually.

Experts and stakeholders had also divergent views regarding the relevance and the feasibility of some actions. However, as not all actions were discussed with experts during the meeting, it was not possible to assess the difference between feasibility and relevance of all actions. Consequently, these apparent contradictions should be treated with caution as one could not exclude that longer discussions with experts could have led to different results. Experts had therefore the possibility to comment on the document after the meeting.

This research step has some limitations. Due to time constraints, three categories of solutions were not discussed during the expert meeting: empowerment of people with ID and their supporters, the coordination and integration of health information and health care by primary care and the monitoring and follow-up of the health care needs. This may imply that the actions proposed are not enough relevant or feasible. However, as participants had the possibility to comment the solutions after the meeting, they could still share their concerns about the solutions and actions. A discussion would have allowed for a clarification of some comments. There was no final meeting between stakeholders and experts to obtain a consensus about the priority solutions and actions. As some categories of solutions involved major changes outside the health care sector, there may be a bias towards quick wins solving only a part of the barriers.

8 CHAPTER 8: POSSIBLE OPTIONS FOR IMPROVING ACCESS TO HEALTH CARE FOR PEOPLE WITH ID

8.1 Introduction

This chapter presents the final overview of possible solutions to reduce or solve barriers to access to mainstream health care for people with ID in Belgium, based on stakeholders and experts' perspectives (See Chapter 7). Solutions are organised in 8 categories. For each category, a global solution (i.e., global objective) is proposed as well as implementation conditions and attention points. These conditions are not intended to be exhaustive: additional intermediary actions could be needed. Similarly, each implementation condition is assigned to a possible accountable actor, but alternative actors could also play a role in the implementation process.

It should be noted that a same solution could solve several barriers or pursue the same objective. Moreover, a solution proposed in a certain category of barriers could, if applied, contribute to solve a barrier in another category of barriers. Similarly, some actions are endorsed by multiple actors as their responsibilities overlap or as they contribute differently to the implementation of the actions. Across the different categories, several actions emerged under the form of future research: these actions are included in the section 8.9 Monitoring.

The solutions suggested below should be considered in the current policy context and be put into relation with existing collaborations.

The Federal Action Plan for Handicap (2021-2024) is currently in place. This plan aims at fulfilling the objectives of the (inter)federal strategy by providing recommendations to adapt the society to the needs of the persons rather than the other way round. Organised in 6 axis, the plan identifies actions and attributes it to the competent minister(s) and administration(s) (see Appendix 1 Federal ACTION PLAN HANDICAP 2021-2024). Unia is responsible for the monitoring of the implementation of these actions and for the respect of the UNCRPH.

Specifically for the health sector, the long-term objectives presented in the (inter)federal strategy 2021-2030 state that "*persons with disabilities should have access to the highest possible quality of health care without discrimination based on disability. This includes both access to mainstream care and access to specific care for people with disabilities*".[153, 154] There is therefore no specific timeline for expected changes in terms of policy change, possibly due to a lack of data on the health status of persons with ID[sss].

8.2 Empowerment of people with ID and their supporters

8.2.1.1 *Main barriers*

- Some people with ID are not sufficiently involved in decision making about their health by HCP and their supporters.
- Some people with ID and their families lack reliable and clear health information: this is explained, among others, by the multiplication of information sources, the lack of (digital) health literacy and the low availability of information in Easy Read language.
- Some people with ID need to be supported in expressing their preferences regarding their health and care. Like other patients, people with ID may have difficulty identifying their preferences and communicating them to their supporters, family, HCP (whether they are familiar with people with ID) or social and educational staff.
- Some people with ID have difficulties explaining their needs and symptoms, including pain, to their supporters and to HCP. These difficulties may be linked, among other things, to problems of verbal expression or difficulties in recognising what is causing them a problem.

[sss] Special Olympics Belgium: personal communication through the proposal at the KCE annual programme 2019 call.

- The expression of symptoms among people with ID may be hidden or may differ from the clinical picture that HCP who are not familiar with people with ID are used to: pain, for example, may be expressed through a change in behaviour and therefore not managed appropriately.

8.2.1.2 Global solution

- The capacity of people with ID to take responsibility for their health should be strengthened, by improving their access to clear, reliable and centralised information and by providing them with the tools and resources adapted to their level of understanding to appropriate this information.
- The family and friends of people with ID should be able to detect the symptoms and help them express their complaints.

8.2.1.3 Possible actions to reach the global solution

Providing accessible and comprehensible validated health information for people with ID and supporters

As stated in the Federal Action Plan for Handicap, there is a need for **providing accessible and comprehensible information** for people with ID and their supporters.[153, 154] (see Chapter 5: Barriers to health care access in Belgium for people with intellectual disability)

Among other examples, not all official websites have an Easy Read version. These official websites can also participate to the diffusion of validated information regarding health and health care such as the website *Gezondheid en Wetenschap – Infosanté.be* (Box 48).

Box 48 – *Gezondheid en Wetenschap – Infosanté.be, Belgium*

The Belgian Centre for Evidence-Based Medicine has been commissioned by the *Vlaamse Gemeenschap* to develop the independent website "*Infosanté.be – Gezondheidenwetenschap.be*". The initiators believe that there is a need for a reliable and accessible source of health information based on sound scientific research in Evidence-Based Medicine (EBM). Initially funded by the RIZIV – INAMI, the *Infosanté.be* site was later subsidised by the *Fédération Wallonie-Bruxelles*. The Flemish interface *Gezondheid en Wetenschap* is funded by the *Vlaamse Gemeenschap*, the *Rode Kruis Vlaanderen* and the *Universiteit Antwerpen*.

Initiatives such as the French website *SantéBD* are, among others, examples of good practice in the dissemination of health information adapted to people with comprehension problems (Box 15). Other information can be added to the *Gezondheid en Wetenschap – Infosanté.be* website, such as links to websites offering materials to help communicate with people with ID. These adaptations are in line with the recommendation on the **provision of official information in Easy Read language** as included in the Federal Action Plan for Handicap.[153, 154] It is therefore important that the FPS Public Health, the federated entities, the RIZIV – INAMI, the sickness funds, the patients' and disabled people's associations make the *Gezondheid en Wetenschap – Infosanté.be* website known to people with ID and their supporters.

Moreover, as reported in the KCE report 322, "*in Belgium, health literacy level appears problematic for 30 to 45% of the population*", meaning that efforts are still needed to improve the "*person's ability to understand health information so that they can maintain or improve their health and their quality of life*".[56]

Table 15 – Implementation conditions and institutions to be held accountable to provide accessible and comprehensible validated health information for people with ID and their supporters

WHAT?	WHO?
Development of an Easy Read version of the official websites of institutions concerned with health and health care of people with ID	• FPS Public Health • RIZIV – INAMI • Competent federated entities • Sickness funds
Development of an Easy Read version of the *Gezondheid en Wetenschap – Infosanté.be* websites	• Managers of the website Gezondheid en Wetenschap – Infosanté.be • Associations in the disability sector
Regular information in Easy Read format to people with ID and their relatives about the existence of the websites *Gezondheid en Wetenschap – Infosanté.be*	• FPS Public Health • RIZIV – INAMI • Competent federated entities • Sickness funds • Patients' associations • Associations of people with disabilities
Pilot-test of the adapted versions of the websites	• Experts in Easy Read language • People with ID

Improving digital (health) literacy

If the diffusion of information by Internet and online medias has become the mainstream communication channel, there is a need to reduce the growing digital divide, as also stated by the CSNPH – NHRPH.[155, 156] In the 2021 Statbel data[ttt], 46% of Belgians from 16 to 74 years reported none to low digital skills[uuu]. According to the State Secretary for Digitalisation, 49% of Belgians have no digital contact with public authorities. Because of their cognitive problems, people with ID are particularly at risk of being unable to search for and use (health) information on the Internet, preventing them from receiving appropriate care. Some have no access to IT equipment at home. Similarly, in some institutions of the disability sector, the IT equipment is still lacking or not powerful enough (e.g., for videocalls).

One of the ongoing projects to partially respond to the digital divide is the Connectoo project. Launched at the initiative of the State Secretary for Digitization, this project aims at training 5 000 federal and federated civil servants per year to reduce the digital divide. It can be an opportunity for raising awareness of civil servants to the specific needs of people with ID[vvv], especially as it involves supporting citizens in navigating across digital platforms such as *MijnGezondheid – MaSanté*. To ensure the coherence of the training, the CSNPH – NHRPH and other specialised associations of the disability sector should be involved.

The disappearance of counters and of the possibility of meeting a physical interlocutor has been pointed out as a factor reinforcing the digital divide and social exclusion[157 158]: while some people with ID appreciate the possibility of communicating online (for example when a physical or sensory disability complicates communication), it remains essential to **preserve the possibility of going to a physical space** to make an appointment, receive explanations or do any activity that the authorities encourage to do online, such as filling in a questionnaire or applying for social benefits.

[ttt] Statbel data concern a representative sample of the Belgian population based on criteria of age, gender, socioeconomic status and region. Disability is currently not a sampling variable.

[uuu] Data retrieved from https://statbel.fgov.be/fr/themes/menages/utilisation-des-tic-aupres-des-menages#news

[vvv] Connectoo project: https://bosa.belgium.be/fr/connectoo https://bosa.belgium.be/nl/connectoo

Table 16 – Implementation conditions and institutions to be held accountable to improve digital (health) literacy

WHAT?	WHO?
Integration of a training module focusing on the needs of people with ID in the Connectoo project	• *FOD Beleid en Ondersteuning – SPF Stratégie & Appui* • CSNPH – NHRPH
Development / update of the IT equipment of the disability sector	• Federated entities
Preservation of non-digital communication channels (i.e., counters, telephone appointments)	• Public authorities • Health care services & institutions

Supporting people with ID in expressing their preferences

The competent authorities, in collaboration with disability organisations such as *Inclusion asbl*, *Downsyndroom Vlaanderen*, *Handicap et Santé*, *Altéo*, ASPH, Dito and the patient umbrella organisations such as the *Ligue des Usagers des Services de Santé* (LUSS), the *Vlaams Patiëntenplatform* (VPP) and the *Patienten* and *Rad und Treff (*PRT) should organise **annual information campaigns** and disseminate supporting tools to enable people with ID to be involved in decisions concerning their health. These campaigns should be aimed at people with ID who are able to open a dialogue with their relatives. These campaigns should also raise awareness and stimulate supporters of people with ID to discuss their health and care preferences and needs with their loved ones, when the people with ID are able to do so, and to write down their choices in non-acute situations. The booklet Smile "*Ma santé*" developed by *Inclusion asbl* is an example of tool allowing the involvement of people with ID in decisions concerning their health[www]. This proposal should be linked to the recent FPS Public Health campaign "*Parlons de nos vieux jours / Praat over je oude dag*[xxx]" which, although focused on advanced care planning, encourages patients to open a dialogue with their relatives about their needs and preferences. The KCE report 349 also stresses the need to anticipate this dialogue.[55]

In the same vein, to ensure that the preferences and needs of people with ID are respected, **choosing a person of trust or a legal representative** could also be a solution.

Box 49 – Person of trust and legal representative

The person of trust (*personne de confiance – vertrouwenpersoon*) is designated by a person to assist her/him in the exercise of his rights as a "patient". This person does not have to make decisions for the patient but assists and advises her/him if necessary. This person may be a family member, a relative or any other person that the person chosen to help her/him, for example, to obtain information about his state of health, consult the patient file, etc. The patient remains the person who exercises the rights and the person of trust can support and advise her/him in the different steps.[159]

The mandatary/representative (*mandataire/ représentant – vertegenwoordiger*) is the person (one or more) who acts on behalf of patients when they are not able to express their will. If people are no longer able to decide on their own, their mandatary/representative makes the choices for the person.

Having a supporting tool to initiate dialogue is therefore not enough to ensure the expression of the preferences. Those using it should **be able to communicate adequately** with people with ID and their supporters (see also sections 8.7 Competences of the educational staff in the disability sector and 8.8 Skills of health care professionals outside the disability sector).

[www] The booklet Smile is available online: https://www.inclusion-asbl.be/wp-content/uploads/2018/10/Livret-Smile-4-Ma-sant%C3%A9.pdf

[xxx] The campaign can be found here: https://www.health.belgium.be/fr/news/parlons-de-nos-vieux-jours

These supports can be adapted to people with ID able to engage a dialogue with their supporters. However, it would be a mistake to consider that people with ID are a homogeneous group. For people whose cognitive condition hampers their expression and communication, the **supporters should also be supported** in all efforts to ensure that the needs and preferences of the people with ID are respected.[55] The competent authorities should **improve the living conditions of family carers and the working conditions of professionals** in the disability sector to allow them, among other things, to have quality time to discuss the preferences and needs of the people with ID.

Table 17 – Implementation conditions and institutions to be held accountable to support people with ID in expressing their preferences

WHAT?	WHO?
Information and annual dissemination of tools enabling people with ID to be involved in decisions concerning their health	• Competent authorities • Associations of people with disabilities
Launch of a continued policy of permanent development and improvement of tools	• Competent authorities • Associations of people with disabilities • CSNPH – NHRPH
Support of family and friends in their efforts to have the preferences of people with ID respected	• Competent authorities • HCP • Professionals of the disability sector
Encouraging the appointment of a trusted person	• Associations of the disability sector • FPS Public Health
Improvement of the living conditions of family carers and the working conditions of professionals in the disability sector	• Competent authorities

Detecting health problems

The competent authorities, with the support of disability and health associations, should organise **annual information and dissemination campaigns on the use of tools to correctly detect attention signs leading to health problems**. These campaigns should target people with ID, their supporters, the disability sector, including adapted work companies (*Entreprises de Travail Adapté ETA - Maatwerkbedrijven*). There are already many resources available, both those developed by the public authorities and those from more local and private initiatives, but these resources are not always known.

In addition to the dissemination of these tools, specific actions should be addressed to HCP less familiar with people with ID. They need **adapted assessment tools** but also a **proper training** to be able to use it. The professional associations can organise these trainings, possibly in partnership with continuing education institutes and specialised associations. In 2020, for example, Domus Medical organised an event for GP in collaboration with Special Olympics[yyy].

People with ID, according to their capacities, should be **made aware and trained to detect and express their symptoms**, for example, through group workshops on body expression or personalised coaching by their supporters. Such training and coaching could help to create automatisms that could be useful in case of problems.[160]

[yyy] See the event here: https://www.domusmedica.be/vorming/agenda/special-olympics-health-congres

Table 18 – Implementation conditions and institutions to be held accountable to better detect health problems

WHAT?	WHO?
Organisation of annual information and dissemination campaigns on the use of tools to identify attention signs leading to health problems	• Competent authorities • Associations of the disability sector • Associations of the health sector
Training of HCP in tools for the detection of health problems of people with ID	• Associations of the health sector • FPS Public Health • Federated entities
Raising awareness and training people with ID to recognise their symptoms	• Supporters of people with ID • Associations of the disability sector

Central repository of health care professionals and services

Not all HCP have the resources and the expertise to work with ID. A central repository of HCP qualified to work with people with ID can help to identify them. This can be inspired by the existing repositories of services such as the repository of *Sociaal Brussel – Bruxelles Social* or the *Sociale Kaart.* However, as the information already suffers from fragmentation, this repository should be centralised at federal level or, if not, regional level.

Similarly, some liberal health care professionals inform their patients about their expertise, i.e., physiotherapists informing they are specialised in paediatric care or dieticians with an expertise in the follow-up of alimentation disorders. This could therefore require a form of control from the professional associations to ensure the quality and the validity of the expertise (i.e., guarantying that the HCP are up to date regarding accreditations).

Table 19 – Implementation conditions and possible accountable actors for the creation of a central repository

WHAT?	WHO?
Creation of a central repository with information on HCP and services with expertise in ID	• FPS Public Health / Regions • Professional associations
Guarantying the quality and validity of the information / expertise of HCP	• Professional associations

8.3 Coordination and integration of health information and health care by primary care

8.3.1.1 Main barriers

- The health status of people with ID is worse than the health status of people without ID. Some disabilities require systematic screening for certain health problems. Type 2 diabetes and obesity are the two most epidemiologically frequent examples (see chapter 1 & Chapter 3: Quantitative analysis of health care use).
- Some people with ID lack access to different screening and preventive care: there is little or no adaptation of the preventive care offer for people with ID, messages and invitations are not understood, prevention is not considered a priority and resources to organise it are insufficient in the disability sector.
- Some people with ID live in families where no health care is provided for any of the family members because, among others, of low socio-economic status and low health literacy.
- Some people with ID are limited in their ability to pass on information about their health, such as their history or treatments, due to their comprehension problems.
- Health data, care and decisions about the health and health care of people with ID are not sufficiently coordinated, shared and integrated, either between the disability and health sectors or within the health sector itself (between specialists or between hospital and home). For

example, it appears that some specialists have difficulty coordinating the management of certain pathologies that overlap several specialities. As a result, some patients and/or their relatives receive contradictory instructions, which may increase the risk of non-adherence to the proposed care plan.

- The preferences of people with ID regarding their health are not considered, or only to a limited extent, which also increases the risk of non-adherence to care (see section 8.2. Empowerment of people with ID and their).

8.3.1.2 *Global solution*

- Everyone with ID should have a GP of reference (responsible for multidisciplinary consultation and preventive monitoring), a global medical record (GMD − DMG) and a liaison tool.

8.3.1.3 *Possible actions to reach the global solution*

Coordination, integration and transmission of health information

As the manager of the GMD − DMG, the **GP** has a role to play in the coordination of care and in the circulation of information. The **GMD − DMG** is one of the existing tools accessible to all patients. The opening of a GMD − DMG by the GP offers a better individual support for the patients and allows better circulation of information between doctors. Patients also benefit from a better reimbursement for a consultation or a visit of the GP.

In this sense, encouraging people with ID **to have a GMD − DMG** and therefore **a GP of reference** would contribute to a better quality of their care. It could therefore be interesting for the AVIQ, *Service PHARE*, *Brussels Aanmeldingspunt voor Personen met een Handicap* (BrAP – Brussels contact for people with disabilities) and VAPH, in collaboration with the SSMG, Domus Medica and the sickness funds, to organise an **awareness and information campaign** for people with ID and their supporters on the importance of having a GP and a GMD − DMG. If the GMD – DMG is personal, it is nevertheless possible for the patient to choose a trusted person who can consult the file (see section 8.2). It should be noted that the obligation of the GMD − DMG for the Belgian population has already been discussed but not decided so far.

If the GMD − DMG is a useful source of information, it however has some limitations. In that sense, **e-health** should be better invested to improve access to information for the patients and to ensure a better circulation of the information among HCP. Patients have access to the online portal *MijnGezondheid − Masanté* ("Personal Health Viewer"). This central access point allows to consult various personal health data and other health-related information in general. There is therefore a need to adapt the current services in Easy Read format.

For each person with an ID, the family paediatrician, the GP or a referent health care professional (e.g., a nurse) can organise an **annual multidisciplinary consultation**, preferably in the presence of the individual with ID, including the supporters and professionals. This consultation supports the coordination of care and the harmonisation of decisions based on the needs and preferences expressed by people with ID. Each consultation should be followed by a written report in Easy Read format transmitted to the people when they are able to understand it and included in the GMD − DMG. The resulting health care plan should be explained to and approved by the people with ID, where they have the capacity to do so. A specific funding needs to be planned for all HCP involved in the multidisciplinary consultation. When **transitioning from paediatric care to adult care**, a specific transition plan should be developed and a multidisciplinary consultation, including the paediatrician and the GP, should be organised. These annual multidisciplinary consultations can be inspired by the concertation for people with a decrease in autonomy in the framework of integrated health care.[161]

Liaison tools can solve the difficulties of expression and communication of people with ID regarding the transmission of health information such as the *Babbelgids* developed by Dito[zzz]. These tools exist in many formats. The format and use of this tool should be discussed and decided with the people with ID and their supporters. This should be one of the outcomes of the annual multidisciplinary consultation during which a referent person for the liaison tool can also be designated. This referent person can one of the supporters. As the designated manager of the GMD − DMG, the GP can also initiate the use of the liaison tool and ensure that it is kept up to date. This responsibility can also be endorsed by a referent HCP. HCP and especially the GP should also remind the supporters of the importance of this tool accompanying the people with ID when using the health care facilities.

In addition to medical information, the liaison tool should include a description of the needs and functioning of the person with ID. To ensure that they are practicable, the professional associations need to work together with the associations promoting these liaison tools to select, adapt, make them accessible and distribute them to primary care professionals.

Table 20 – Implementation conditions and possible accountable institutions

WHAT?	WHO?
Organisation of an annual campaign to raise awareness and inform people with ID and their families about the importance of having a GP of reference and a global medical file (GMD − DMG).	• Competent authorities • Sickness funds • *Société Scientifique de Médecine Générale* (SSMG) and Domus Medica
Development and testing of an Easy Read version of *MijnGezondheid − MaSanté*	• Competent authorities • Expert associations in Easy Read language
Setting up a physical and digital liaison tool for sharing needs, health information and preferences for each person with ID	• Referent GP OR • Referent member of the supporters
Selection, adaptation, provision and distribution of liaison tools to GP	• SSMG and Domus Medica • Associations developing and promoting liaison tools for people with ID and their supporters
Organisation of an annual multidisciplinary consultation for each person with an ID, and drafting of a report in Easy Read language transmitted to the person with an ID for approval / to a referent person	• Referent GP OR • Referent paediatrician OR • Referent nurse OR • EZL – SISD
Organisation of a multidisciplinary concertation for people with an ID with a transition plan from paediatric to adult care	• Referent GP OR • Referent paediatrician OR • Referent nurse

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[zzz] See the details here: https://www.ditovzw.be/actie/acties-projecten/nieuw-vfg-project-naar-de-dokter/

Improving access and coverage in screening and preventive care

Access to screening and preventive care for people with ID should be improved. Again, as manager of the GMD − DMG, the GP is one of the possible actors that can organise the preventive follow-up and screening of people with ID. Other HCP, such as (specialised) nurses, can also coordinate such follow-up, especially for people living in institutions. Social workers and psychologists can also coordinate the follow-up.

In order to ensure the implantation of a systematic follow-up, the RIZIV – INAMI should create a **nomenclature code for a minimum of 1 annual consultation of longer duration in general practice** aimed at carrying out a health check-up and organising preventive follow-up for people with ID. This check-up should be mentioned in the patient's GMD − DMG. The RIZIV – INAMI should provide the necessary budget to finance these consultations.

The RIZIV – INAMI, in collaboration with the federated entities and the sickness funds, should set up **financial incentives** to increase the coverage of preventive care and screening among people with ID, like what is done for dental care. (see Box 50)

Box 50 – Oral care path

To emphasise the importance of an annual dental visit among adults, oral care paths (*mondzorgtraject – trajet de soins bucco-dentaires*) have been introduced in July 2016 (in January 2017 for adults with preferential reimbursement). With this measure the amount of the reimbursement for some dental care is made conditional on a registered dental contact during the previous year. Those who skipped their dental visit in year x, are entitled a reduced reimbursement for e.g. restorative care, removable dentures and dental extractions in year x+1 (i.e. the patient’s co-payment is higher). For instance, if a patient had no reimbursed dental care in the previous year AND is not entitled to the preferential reimbursement scheme (cf. supra), the co-payment for fillings, root-canal treatments, extractions, emergency supplements and repair of prostheses (e.g. addition of a tooth or replacement of the base) will approximately double and the co-payment for X-rays images will be about one and a half times higher.

If a patient had no reimbursed dental care in the previous year AND is entitled to the preferential reimbursement scheme, the co-payment will increase with a maximum of € 2.00.

The reimbursement for preventive care, consultations, orthodontics and periodontal care are not affected by this measure.

The RIZIV – INAMI, in collaboration with the federated entities and the sickness funds, should set up **(financial) incentives to support the proactive steps of GP** in the annual preventive follow-up of people with ID in their patient base. Proactive approaches can consist, for example, in setting up a system of annual invitations to patients, like in some community health centres (*maisons médicales* or *wijkgezondheidscentra*). These structures are able, based on the GMD − DMG, to identify at-risk patients meeting the criteria for the seasonal flu immunisation and complete official information by local and adapted actions (e.g., directly calling the people, providing information in adapted language, or using pictograms).

Collaboration should also be reinforced with the *services intégrés de soins à domicile SISD* or the *eerstelijn zones EZL*. The SISD – ELZ promote the coordination of all the health actors, in the broadest sense of the term, who are called upon to intervene in the home of patients who have lost their physical or mental autonomy. They can also play a role in better coordinating the health care for people with ID.

The competent authorities need to provide the financial, human and material resources to implement a prevention and health promotion policy adapted to people with ID and their living environment(s), in consultation with the disability and health sectors. The preventive and health promotion vision of health (care) has an added value for all people and even more for people with ID. Competent authorities should initiate discussions on investing in prevention, as suggested by non-profit associations. This also requires a (financial) (re)valorisation of therapeutic education, health education, multidisciplinary consultations and other coordination activities.

Table 21 – Implementation conditions and institutions to be held accountable to improve access and coverage in screening and preventive care

WHAT?	WHO?
Creation of a nomenclature code for a long-term consultation in general medicine aimed at assessing the health and organising the preventive follow-up of people with ID, at least once a year	• RIZIV – INAMI
Establishing financial incentives to increase preventive care and screening coverage among people with ID	• RIZIV – INAMI • Federated entities • Sickness funds
Establishment of (financial) incentives to support proactive approaches by GP for the annual preventive monitoring of people with ID in their patient base	• RIZIV – INAMI • Federated entities • Sickness funds
Provision of the necessary means for the implementation of a prevention and health promotion policy adapted to people with ID and their living environment(s)	• Competent authorities • Health sector • Disability sector

Improving the follow-up of diabetes

For people in institutions, the RIZIV – INAMI should amend the **nursing nomenclature** to allow for the certification of diabetes therapy education in the home or community residence of people with disabilities, with additional training for nurses in plain language. Currently, diabetes education is the only reimbursed nursing service in health education as listed in Section 8 of the health care nomenclature.

Nurses can only bill these benefits if the benefits are delivered at the patient private home. Nurses cannot bill these benefits if the benefits are provided at the residence for people with disabilities (*tijdelijke of definitieve gemeenschappelijke woon- of verblijfplaats van mindervaliden – domicile ou à la résidence communautaires momentanés ou définitifs de personnes handicapées*) as these institutions are deemed to have trained staff for this, unlike the patient's home (this is like the situation in nursing homes).

Other activities related to patient therapeutic education, health education and health promotion are insufficiently valued in the current health care system, whether these activities are carried out by nurses or other health professionals.

Table 22 – Implementation conditions and institutions to be held accountable to improve the follow-up of diabetes

WHAT?	WHO?
Adaptation of the nursing nomenclature to allow the reimbursement of diabetes education sessions in the home or community residence of people with ID	• RIZIV – INAMI
Development of a training offer for nurses for health education of people with ID (including Easy Read format and plain language)	• Associations in charge of continuing education for nurses

8.4 Reachability of health care and outreaching

8.4.1.1 Main barriers

- Mobility for some people with ID can be complicated because of physical limitations and/or behaviours associated with ID viewed as challenging. For some people, the effort involved in organising transport is perceived as considerable compared to the potential benefit of the journey, such as participation in a screening test. Some vehicles are not suitable for transporting people with reduced mobility.
- Some people with ID are not able to stay alone, especially in unfamiliar places. The absence of a trusted supporter may aggravate their state of stress or anxiety, which is not always adequately managed or manageable by the reception staff and HCP. In some institutions and services in the disability sector, the lack of the staff does not allow people with ID to be accompanied when they travel to external health services.

8.4.1.2 Global solution

- Some people with ID should be able to be cared for in their usual place of residence (when relevant and appropriate).
- Some people with ID should be able to be accompanied by a supporter of their choice during (urgent) transport (provided that the safety of the supporter is ensured).

8.4.1.3 Possible actions to reach the global solution

Provision of care in the place of residence

The health care nomenclature provides the possibility of visits for advice by specialist doctors to the place of residence of patients (see section 2.4.7 Functionality). These visits can only be made at the request of a GP, the specialist is obligated to make a written report to the requesting GP. The complete provisions are to be found in Chapter II of the nomenclature relating to consultations, visits and advice, psychotherapy and other services. However, this possibility seems to be little used: it would therefore be important for the SSMG and Domus Medica, in collaboration with the RIZIV – INAMI and the sickness funds, to organise a campaign to raise awareness and inform GP about the possibility of requesting a specialist opinion at the family or community home of people with ID who have difficulty travelling (see also section 8.9).

Similarly, the professional associations of medical specialists, in collaboration with the CMG, Domus Medica, the RIZIV – INAMI and the sickness funds, should organise an awareness-raising campaign for medical specialists concerning the possibility of visiting the family home (benefit 103014) or community home (benefit 103073) of the people with ID at the request of the GP.

Some institutions for people with ID have an infrastructure that allows for regular and systematic consultations of some HCP such as GP, dentists, gynaecologists or internal medicine specialists to be organised on their premises. These on-site consultations make it possible to ensure the chronic follow-up and screening of the residents of the same institution over the same period, which reduces travel for the HCP and facilitates coordination for the institution. This type of system should be extended to institutions that do not yet have them, especially when they have residents for whom travel is complicated or impossible. This requires therefore that they have a dedicated space where this could be organised in an efficient and caring way. Besides, there may be reluctance of institutions to reserve a space for medical purposes.

This system of consultations can also be opened to other people who are not residents of these institutions, but for whom travel is difficult, such as the elderly, people with physical disabilities or people in areas where geographical access to health care is complicated.

Mobile surgeries and other mobile screening devices offer the possibility to provide certain specialised and technical care or to carry out preventive examinations in an environment close to where people live, be it an institution, their workplace (i.e., in adapted work enterprises) or their home. This is for example what the Dentalmobilis project is doing with a mobile dental practice that can carry out dental examinations and care in institutions for people with disabilities or in nursing homes (Box 35). This type of initiative should be financially supported by the competent authorities in order to increase accessibility. Currently, the health care delivered is covered by the national health insurance, but additional fees are charged to cover the costs of travel and organisation. In addition, there is a need to expand this type of scheme to promote greater coverage of dental care, especially in regions where there is little or no dental provision for people with ID. Screening for breast cancer and tuberculosis, and more recently vaccination against Covid-19, are also the subject of initiatives where professionals go into the patient's living environment. For this reason, the competent authorities, eventually with the support of the municipalities and other local services, should consult with the facilities for people with ID on their territory to coordinate and organise participation in prevention and screening activities.

However, some screening or diagnosis tests as well as some treatments require a specific infrastructure. Not all health care can be provided at home and not all institutions can host HCP. In these circumstances, transport to a health care facility should be organised: the transportation and the health care facilities need then to be adapted to provide a caring and comforting environment.

Table 23 – Implementation conditions and institutions to be held accountable for the implementation of care provision in the place of residence

WHAT?	WHO?
Increased specialist visits to the family or community home of the people with ID at the request of the GP for advice, as listed in Chapter II of the nomenclature.	• Professional associations of medical specialists
Annual information to GP about the possibility of asking a specialist doctor to visit the family or community home of the people with ID for an opinion.	• SSMG & Domus Medica • RIZIV – INAMI • Sickness funds
Annual information to specialists about the possibility of visiting the family or community home of the people with ID at the request of a GP for an opinion.	• Professional associations of medical specialists • SSMG & Domus Medica • RIZIV – INAMI • Sickness funds
Adaptation of the institutions' infrastructure to allow the organisation of consultations, especially when they receive residents for whom travel is complicated or impossible	• Competent authorities
Structural support and expansion of mobile care initiatives adapted to the needs of people with ID	• Competent authorities
Coordination and organisation of participation in screening activities when a mobile screening device comes to the community	• Competent authorities • Municipalities • Institutions for people with ID

Assistance during urgent transport

At present, the **presence of an accompanying person** in the case of emergency transport is not always guaranteed (except for minors). However, for some people with ID, the presence of an accompanying person would help to calm them down and thus facilitate the work of the crews responsible for emergency transport. Therefore, it would be important for the FPS Interior and the FPS Public Health to organise an information campaign for the emergency zones and services concerning the care of people with ID in emergency situations[aaaa], including transport, by insisting on the possibility of always having a supporter, provided that the person's safety is guaranteed. For example, the member of the supporters should have a seat at the back of the vehicle, close to the person with ID.

Familiarity with the place and the people involved in the health care provision is important for people with ID. Where circumstances permit, emergency transport crews should seek agreement from the 112 regulators in the emergency area to **transfer the people with ID to their usual place** of care if that place is appropriate for the acute problem. While the generic rule is to take the person to the nearest hospital, it is indeed possible to take patients with complex health problems to their referral hospital, with the agreement of the 112 regulators. The liaison tool (see section 8.3) could serve as a source of information also for 112 crew.

Table 24 – Implementation conditions and possible accountable institutions for improving urgent transport

WHAT?	WHO?
Development and dissemination of good practice for the care of people with ID in emergency situations, including transport, with emphasis on the possibility of always having a relative if their safety is assured.	• FPS Public health • *Nationale Raad voor Dringende Geneeskundige Hulpverlening – Conseil National des Secours Médicaux d'Urgence* (National Council of Emergency Medical Care) • CNSPH – NHRPH
Requesting agreement from the 112 regulators of the emergency zone to transfer the people with ID to their usual place of care	• 112 crew
Development and dissemination of good practice for the care of people with ID in emergency situations, including transport, with emphasis on the possibility of always having a relative if their safety is assured.	• FPS Public health • *Nationale Raad voor Dringende Geneeskundige Hulpverlening – Conseil National des Secours Médicaux d'Urgence* (National Council of Emergency Medical Care) • CNSPH – NHRPH

Assistance during non-urgent transport

The **current offer of non-emergency patient transport services** to external health services **should also be improved** to facilitate the access to health services, especially for those living in poorly deserved areas qua public transportation. The offer can be improved in several aspects: financial accessibility, number of vehicles available, simplification of the reservation procedures, development of vehicles to be suitable for wheelchairs, additional staff in institutions for people with ID to accompany them, training of the crew…The non-urgent transport sector depends on public and private

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[aaaa] To date, the last manual of medical regulation does not include instructions for the 112 call takers in presence of people with ID https://www.health.belgium.be/sites/default/files/uploads/fields/fpshealth_theme_file/2022_protocoles_112_fr.pdf

funding: the adaptation of vehicles to all types of wheelchairs needs to be included in the budget of this sector.

Table 25 – Implementation conditions and possible accountable institutions for improving assistance during non-urgent transport

WHAT?	WHO?
Increasing the current offer of the non-emergency patient transport services by devolving extra financial resources	• Federated entities

8.5 Availability of health care professionals during consultations and visits

8.5.1.1 *Main barriers*

- The length of consultations does not allow HCP to create a bond of trust allowing good collaboration in care.
- The length of consultations does not allow HCP, in particular doctors, to provide comprehensible and clear explanations to people with ID and their supporters.

8.5.1.2 *Global solution*

- The RIZIV – INAMI should implement a preferential status for people with special needs so that they can enjoy longer benefits with HCPs. In this study, people with special needs are those whose understanding and expression are limited because they have cognitive impairments, sensory impairments, are intellectually disabled, do not speak the usual language of professionals, have low health literacy...

8.5.1.3 *Possible actions to reach the global solution*

There is a need to **create an insurance status "people with special needs**": this status goes beyond living with ID and includes various complex medical and social situations where there is a need for a longer benefit. Using the concept of people with specific needs is in line with a 2022 Belgian study focusing on "child with special health needs" in order to shift from an exclusive focus on the disease or deficit to a focus on supporting all the persons involved in the health of the child with special health needs in the case of an established disability or chronic pathology.[162] This status is linked to the patients on the model of the chronic disease status: it does not mean that only specialised HCP can care for people with ID.

For HCP, these patients require **more time**, particularly to pass on information and ensure that they understand. Similarly, having more time allows for a better climate of trust and listening between the professionals and the patients, and between the professionals and the supporters. This allows time to provide appropriate information and to check that the patients and their supporters understand it. It also makes it possible to prepare the patients adequately for technical procedures that may give rise to reactions of fear, rejection or aggression if these procedures are not explained to the patients, or are not explained at all, due to lack of time.

The nomenclature does not set a maximum duration for consultations with doctors. In some cases, it is a minimum duration that a specific consultation must take (e.g., minimum one hour). The duration of consultations is therefore dependent on the demand and needs of the patients. Long consultations limit the number of patients seen per day and, in some circumstances, are considered "unprofitable" by the institutions or the HCP. The current tariff for consultations is not sufficiently remunerative for the HCP if they have many "long" consultations. Offering a financial incentive, for example in the form of a specific nomenclature code, cand be a determining factor in the willingness of some HCP to care for this type of patients.

In the context of the ongoing reform of the nomenclature, it would therefore be interesting for the *Nationale commissie artsen-ziekenfondsen − Commission nationale médico-mutualiste*[bbbb] to examine the possibility of creating **nomenclature codes for longer benefits related to the complexity of the patient**, such as the specific needs of people with ID in terms of communication and understanding. However, the definition of the target group must be clear, especially because of the different possible interpretations of what a specific need is. Monitoring of the needs for such adapted consultations could be supported by the upcoming Patient Forum and/or the Observatory of the Chronic Diseases (see section 8.9).

This possibility of longer benefits should be available to all HCP, not just medical doctors. Among others, dentists, physiotherapists and nurses could benefit from this measure.

This adaptation of the nomenclature should be accompanied by the **provision of a budget by the RIZIV – INAMI** to finance these longer consultations and visits, as is already the case for consultations in internal medicine for complex pathology without diagnosis. While the provision of an additional budget may be seen as a hindrance to the introduction of this measure, these adaptations can lead to long-term savings by improving the early detection and treatment of preventable health problems.

The HCPs who certify these longer health benefits need therefore to have **supporting tools and/or be trained** to be able to communicate appropriately with people falling under the specific needs' status. Training under the form of a certification may ensure that the benefits are performed by qualified HCP. Therefore, attention should be paid to ensure the accessibility and the availability of those HCP to people with ID to prevent increasing inequalities among people with ID. This certification should not be required to work with people with ID but only to obtain the benefits covered by the specific needs' status.

Table 26 – Implementation conditions and possible accountable institutions for improving the availability of HCP for consultations and visits

WHAT?	•	WHO?
Creation of an "individual with special needs" status in the health and disability insurance	•	RIZIV – INAMI
Initiation of a reflection on the creation of nomenclature codes for longer services due to the complexity of the patient for all HCPs	•	*Nationale commissie artsen-ziekenfondsen − Commission nationale médico-mutualiste*
Budgeting for the financing of longer health care benefits	•	RIZIV – INAMI
Provision of supporting tools and/or training for allowing HCP to certify long-term services for patients with special needs	• •	Professional associations Health services

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[bbbb] The *Nationale commissie artsen-ziekenfondsen − Commission nationale médico-mutualiste* (National commission of agreement between medical doctors and sickness funds) is in charge of establishing the National Agreement laying down the agreements on tariffs between the doctors and the sickness funds. It is concluded for one or two years and determines the rates that participating doctors may charge. It thus offers knowledge on expected fees to the patient and provides stability to the health care system. The agreement also contains concrete agreements to improve the quality and organisation of health care. See more on: https://www.riziv.fgov.be/nl/professionals/individuelezorgverleners/artsen/verzorging/Paginas/nationaal-akkoord-artsen-ziekenfondsen.aspx

8.6 Coordination and accompaniment in hospital context

8.6.1.1 Main barriers

- Hospital and health service infrastructures are not sufficiently adapted to the reception of people with ID. The following points are highlighted: hospital signage, the layout of waiting rooms, the lack of flexibility regarding the supporters, the limitation of visiting hours, the lack of furniture for the accompanier (such as an extra bed in hospital room or extra chair in surgeries), etc.
- Professionals in hospitals lack availability to support supporters and do not always know how to respond to needs not directly related to the reason for admission. They do not always know which network and resources to mobilise to meet the needs of people with ID. This lack of resources is particularly present when HCP are rarely confronted with people with ID.
- There is a lack of coordination and communication between hospitals and supporters. The transmission of information is not adequate, there is a lack of structured exchanges, such as a systematic phone call or a follow-up file transmitted to supporters. The health and disability sectors are not familiar with each other's working methods, which can lead to misunderstandings.
- Some hospital HCP confuse the capacities in terms of care provision of institutions for people with ID with those in nursing homes.
- The transition from paediatric age to adulthood of people with ID is not coordinated. This can occur when a specialised paediatric centre has overseen the follow-up since birth: in these situations, the GP has not always been able to follow up and establish a progressive contact with the individual with ID. Some initiatives and services are no longer accessible to people with ID once they reach adulthood.
- Some people with ID do not find HCP who can follow up on their health, such as dentists, gynaecologists or other medical and paramedical specialities.

8.6.1.2 Global solution

- All hospitals should provide an adapted physical and social environment to people with ID. Adapted physical and social environment consists of an environment that allows people with ID to be always accompanied and in all places by the person of their choice, provided that this accompaniment respects the person's wishes and privacy and is safe for the person accompanying them.
- The competent authorities should organise interdisciplinary coordination and consultation centres for people with ID, regardless of their age.

8.6.1.3 Possible actions to reach the global solution

Centralised point of contact inside hospitals

In each hospital (network), there is a need for a centralised point of contact to which people with ID and their supporters could turn to in order to facilitate exchanges of information with primary care and to coordinate outpatient and residential hospital care. This mission could be devoted, for example, to a health care coordinator, a community health nurse or a social worker.

Table 27 – Implementation conditions and possible accountable actors for the creation of a central contact point

WHAT?	WHO?
Creation of a central contact point inside the hospital	• Hospital direction

Provision of information in Easy Read format

Hospitals (and health care services) need to translate the information available into Easy Read format through its different media, such as the website, explanatory or orientation panels, leaflets, with the support of associations specialised in Easy Read and plain language. This can be helped by the associations of people with (intellectual) disabilities or the patient platforms but also by the hospital social service, the intercultural mediators, the patient partners or the experts by experience (when available). Moreover, hospital networks tend to invest in professional communication services that can also participate to the adaptation of the information. Similarly, to other actions, this also supports access to information to people whose personal competences limit their ability to read and understand (health) information.

By improving the quality of the communication, hospitals and health care services fulfil their legal obligation of providing information in a clear language, as stated by the Art. 7 of the Law on Patient Rights (*Wet van 22 Augustus 2002 betreffende de rechten van de patient – Loi du 22 août 2002 relative aux droits du patient*).

Table 28 – Implementation conditions and possible accountable actors for adapting information to people with ID

WHAT?	WHO?
Adaptation of information available in the hospital network into Easy Read format (website, explanatory or orientation panels, etc.) or other adapted supports (e.g., pictograms)	• Specialised associations in Easy Read format • Social service • When available: communication service, intercultural mediation service, patient partners, experts by experience

Accompaniment by a referent person from the supporters

Even in pandemic context, people with ID **should be accompanied** by a supporter of their choice when they express their wish to be accompanied. When people with ID are not able to express their preferences, a **referent person** of their daily supporters should be allowed to permanently accompany the people, unless their personal safety is compromised. As an illustration, this referent person should be allowed to accompany the person with ID right up to the doors of the operative quarter / until asleep and be present in the post-operative recovery room. This should be made clear when appointments are made by the administrative staff or the HCP.

Table 29 – Implementation conditions and possible accountable actors for guarantying accompaniment

WHAT?	WHO?
Publication of a doctrine authorising the presence of a referent person as accompanier of the person with ID	• *Federale raad voor ziekenhuisvoorzieningen – Conseil fédéral des établissements hospitaliers*

Training of reception staff and volunteers in health care settings

Volunteers and receptionists in hospitals play an essential role in supporting people with ID and their families. Their presence, when desired and accepted by the people with ID and their supporters, can bring relief and comfort. In a very pragmatic way, it can also allow the supporters to take a breather, to go for refreshments or any other activity. However, the reception of people with ID requires communication skills. Therefore, it is important for hospitals to organise **training on the specific needs of people with ID for volunteers and staff** who welcome and accompany patients. These trainings could be inspired by the project led by the *AZ Delta* in Roeselaere (Box 42) or the CHR *La Citadelle* in Liège (Box 41).

Table 30 – Implementation conditions and possible accountable actors for training staff & volunteers

WHAT?	WHO?
Organisation of training for volunteers and reception staff	• Hospital management • Associations of the disability sector

Accompaniment by a patient navigator provided by the hospital

For isolated people, or when a supporter cannot attend, the health service should first ask the people with ID whether they want to be accompanied. In the affirmative, the hospital should provide a **patient navigator,** that is a *trained person who individually assists patients, families and caregivers navigate the healthcare system barriers efficiently and effectively at any point along the care continuum, improving patient care at all levels of an organization.*[163] Moreover, the patient navigator can also accompany the people with ID and their supporters (if they so wish) to the various appointments in the hospital. Contrary to the reception staff or the volunteers, the patient navigator is only devoted to personal accompaniment while volunteers and reception staff have other duties.

Table 31 – Implementation conditions and possible accountable actors for developing patient navigators

WHAT?	WHO?
Development of the function of patient navigators	• Hospital directions

Adaptation of the conditions of hospitalisation and of the physical environment

Hospital environment should be adapted to make it more accessible and qualitative for patients with special needs. This **adapted environment** can, for example, be inspired by the rules of good practice for children, such as the rights reported in the European Association for Children in Hospital Charter, and palliative patients: possibility to sleep in the room, 24-hour visits, reception services for families attached to the hospitals. Particularly of interest is the Article 2 of the stating that "*children in hospital shall have the right to have their parents or parent substitute with them at all times*". In the Art. 6, the Charter further states that "*admitting adult patients with the mental abilities of a child to a children's ward could be upsetting for children and is disrespectful to the adult patient*".[164]

There are already recommendations and advice, especially at the level of the federated entities[cccc][dddd][eeee], for the accessibility and adaptation of services[ffff]. The CNSPH – NHRPH also made recommendations for adapting hospitals.[165] However, it is necessary for the competent authorities to provide the necessary financial means to support hospitals and health services in the adaptation of the environment to allow the accompaniment of people with ID.

To ensure the adequacy of the adaptations, it is important that hospitals and health services work together with the CSNPH – NHRP, the associations of people with (intellectual) disabilities or the patient platforms **to adapt their physical environment** to the needs of people with (intellectual) disabilities, including documentation in Easy Read format, lifts adapted to large wheelchairs and hospital signage. However, this major task requires resources to enable the associations concerned to participate fully.

Unia, Inclusion asbl, Handicap et Santé, *Kennis Centrum vzw* edit support documents on reasonable adjustments in health care settings. This concerns both independent (solo) HCP and larger institutions such as hospitals. For example, Unia recommends organising **test visits** with groups of people with different disabilities. This allows a better understanding of the most appropriate adjustments for each type of public. Non-profit associations representing people with disabilities can usefully guide and advise in the organisation of such visits.

[cccc] Recommendations of the VAPH: https://www.vaph.be/documenten/checklist-omgevingsbediening-voor-personen-met-een-motorische-handicap

[dddd] Recommendations of Flemish Authorities: https://www.inter.vlaanderen/sites/default/files/Checklist_toegankelijkheid_vaccinatiecentra_COVID19_inrichting%20en%20communicatie_def1.pdf

[eeee] Recommendations of AVIQ: https://www.aviq.be/handicap/telechargement/logement-accessible.pdf

[ffff] Recommendations of UNIA: https://www.unia.be/files/Documenten/Aanbevelingen-advies/unia-recommandation_SNCB_(2021).pdf

Table 32 – Implementation conditions to be undertaken and institutions to be held accountable for the implementation of better reception and accompaniment in health care facilities and hospitals

WHAT?	WHO?
Adaptation of the adult wards to allow the presence of a member of the supporters for people with special needs such as people with ID (e.g., possibility of sleeping)	• Hospitals
Adaptation of the visit rules to allow the presence of a member of the supporters for people with special needs such as people with ID (e.g., possibility of sleeping)	• Hospitals
Development and diffusion of rules of good practices for the hospitalisation of people with ID	• Associations of the disability sector • CSNPH – NHRPH • LUSS, VPP & PRT • *Federale raad voor ziekenhuisvoorzieningen / Conseil fédéral des établissements hospitaliers*
Provision of financial means for the adaptation of the hospitals / health services	• Competent authorities • Hospital charity funds
Adaptation of hospital signage to people with ID and other impairments	• Hospital management • Communication service of hospitals • Associations of the disability sector
Implementation of existing recommendations on reasonable adjustments	• Hospital management
Organising test visits	• Associations of the disability sector • CSNPH – NHRPH • Hospital management • Communication service of hospitals

Possibility of having a single room

For some people with ID, having a **single room** for medical reasons is important. The decision of “medical reason” is so far left to the discretion of the doctor in charge. This may create inequities among people with ID as the extra costs related to such accommodation are not supported by the regular health insurance scheme, which constitutes a financial barrier. This can be solved by a formalisation by the RIZIV – INAMI of the acknowledgement of intellectual disability as a medical reason to benefit from a single room without extra costs.

Another option can be to consider that the status “people with special needs” is a reason to benefit from a single room for medical reasons (when the people express their preference to be alone) (see section 8.5). This status would therefore need to be created.

Table 33 – Implementation conditions and possible accountable actors for improving access to single room

WHAT?	WHO?
Issuing an information circular to sickness funds and hospital managements concerning the recognition of intellectual disability as a medical reason for a single room without supplements	• RIZIV – INAMI
Linking the possibility of having a single room to the status “people with special needs”	• RIZIV – INAMI

Liaison team to support the HCP

Another form of support consists in creating a **function of liaison** to support the hospital professionals caring for people with ID, based on the model of the model of the geriatric liaison during hospitalisations.[166] The liaison function is endorsed by trained professionals in the specificities and needs of people with ID. This interdisciplinary team organises the reception of the people with ID, advises the hospital professionals on appropriate care and informs the people with ID and their supporters in Easy Read format about the progress of the appointments. The liaison team also supports hospital teams during hospitalisations, including via training and *ad hoc* education for other HCP.

Table 34 – Implementation conditions and possible accountable actors for implementing a liaison team

WHAT?	WHO?
Development of liaison teams for other hospital professionals	FPS Public Health

Integrating patient expertise in the hospitals

To date, ID is not included as part of the experts by experience programme. Experts by experience in the health care sector are people who have experienced difficulties in accessing health care services and who work with the RIZIV – INAMI to improve accessibility to care. The RIZIV – INAMI and the PPS Social Integration should therefore **extend the experts by experience programme to people with ID**. This implies that the PPS Social Integration provides an additional budget for the hiring and training of these experts by experience. This is in line with the recommendations of the Federal Action Plan for Handicap.

Table 35 – Implementation condition and possible accountable institutions for adapting the environment

WHAT?	WHO?
Provision of the necessary financial means to support hospitals and health services to provide an adapted human and physical environment	Competent authorities
Provision of the necessary financial means to support associations of people with (intellectual) disabilities and/or patient platforms	Competent authorities
Integration and funding of people with ID in the experts by experience programme	• PPS Social Integration • INAMI – RIZIV

Reference centres

(A limited number of) hospitals can organise an **interdisciplinary coordination and consultation centre** for people with ID, regardless of their age. A distribution key should be therefore determined to ensure these centres reach their objective of accessibility. A first possible key concerns the geographical distribution, that is ensuring that a centre is available and reachable in each region / province / hospital network. A second possible distribution key implies building on existing expertise, that is identifying and sustaining projects developed by hospitals and health care services that pursue the objectives of interdisciplinarity and coordination. A third possible key is integrating such centres in hospitals with a clinical genetics centre or a neuro-paediatric service. The presence of the clinical genetics centre or a neuro-paediatric service can be seen as a "guarantee" of having the expertise to support people with ID. An inappropriate distribution key can reinforce the gap between those already experiencing difficulties to access mainstream health care and those who already benefit from the existing services because they and / or their supporters are able to use it.

Whatever the distribution key, the team of this centre should be multidisciplinary, including medical specialists, nurses, allied HCPs, etc. with a recognised expertise in caring for people with ID. The centre should include a disability expert by experience. This centre would preferably be coordinated by a GP, a specialist with recognised expertise in supporting people with ID or an advanced practice nurse. The centre and the patient's GP would exchange information on the health check-ups carried out, whether in the context of the annual first-line check-up (check-ups and prevention) or the specialised check-ups carried out in hospital, whether related to the disability. The GP would ensure that this information is included in the patient's overall medical file.

The centre can host the specialists and other service providers carrying out the assessments and follow-ups in its own premises, when possible, in order to provide a reassuring and calm environment for people with ID. In this organisation, the HCP go the patient rather than the other way round, to limit the number of trips to the hospital and the repeated changes of environment.

This centre can offer a biopsychosocial assessment, including non-medical determinants of health, and participate in activities related to health education, therapeutic education and health promotion for people with ID and their relatives in partnership with local and regional experts. The centre can also help to connect people with ID with patient and disability support associations and other competent actors in the field of health and disability

Table 36 – Implementation conditions and possible accountable actors for the creation of an interdisciplinary centre

WHAT?	WHO?
Creation of an interdisciplinary coordination and consultation centre, including a discussion of an appropriate distribution key across Belgium, the conditions of access, the funding mechanisms and the human resources	• INAMI – RIZIV • FPS Public Health • Competent federated entities • *Federale raad voor ziekenhuisvoorzieningen – Conseil fédéral des établissements hospitaliers* • Hospital federations

8.7 Competences of the educational staff in the disability sector

8.7.1.1 *Main barriers*

- Some professionals in the disability sector, who are not HCP, don't know how to use the tools to correctly identify the complaints and health problems expressed by people with ID, such as pain. While some, through practice and experience, become able to identify these needs, for others it remains a challenge. Some educational staff lack opportunity to meet HCP, apart from their colleagues in the institutions, and thus to learn about the health sector and its functioning. Moreover, the lack of time and staff in some facilities implies that educational staff are not always present during consultations or hospitalisations of people with ID. Consequently, the educational staff doesn't receive directly information from HCP. Educational staff misses support that can contribute to their literacy and skills in understanding health needs and providing appropriate responses in case of health problems.
- HCP are unevenly distributed across services and institutions in the disability sector. The standards of some services include time for allied health care professionals in the broadest sense, but their recruitment will depend on the institutional project: for example, some services will hire speech therapists while others will prefer physiotherapists (see Chapter 1). The presence of nurses, trained to dispense medication and nursing care, is not guaranteed in all institutions.
- The tasks of educational staff in the disability sector are not clearly (legally) defined in terms of their roles and responsibilities regarding health monitoring and the provision of (nursing) care to beneficiaries (see Chapter 1). It is not clear whether care can be delivered by educational staff as parents would do for their own children (e.g., for an antibiotic treatment) or whether everything that is a care act, as listed in the nomenclature, should be entrusted to the health professional who has the required title to carry out this act (e.g., a nurse to administer the medication). This lack of clarity also raises questions about the level of training expected of educational staff, particularly educators, in relation to the health monitoring of people with ID and the provision of care.
- Some professionals in the disability sector, who are not HCP, do not have the knowledge and skills to take care of the health of people with ID, especially regarding health promotion and prevention. Some experts expressed the concern that this lack of knowledge leads to inappropriate use of emergency services or to an underestimation of the seriousness of the situation.

8.7.1.2 *Global solution*

- Educational staff in the disability sector should have the opportunity to be better informed and trained about health and care for people with ID.
- Educational staff in the disability sector should have the opportunity to be better trained in the use of tools to correctly identify health complaints and problems expressed by people with ID, such as pain.

8.7.1.3 Possible actions to reach the global solution

There are already **tools** that can help to decode complaints, recognise symptoms and identify health problems requiring intervention. The disability sector, with the financial and logistical support of the competent authorities and in collaboration with the health sector, should organise **continuous training for educational staff** on the health of people with ID, including the recognition of symptoms and health needs, the decoding of complaints and the use of tools to assess symptoms and pain.

Given the lack of clarity regarding the legal framework for the provision of care by non-nursing staff in institutions for people with ID, the competent authorities should consult with the relevant professional associations **to define a framework that respects the titles and qualifications of the different caregivers** and, where necessary, provide the human and financial resources to make it possible. Educational staff should not become health care staff: a good balance between the tasks of both should be ensured.

Three memoranda of understanding regarding nursing acts were signed on February 24, 2014, on which the CSNPH – NHRPH.[167, 168] They concerned respectively the areas of home care, care in institutions for people with disabilities and child care in licensed childcare facilities, covering care dispensed by the supporters, either professionals or informal carers. In 2017, these memoranda of understanding were replaced by a unique memorandum covering all areas. This updated memorandum was negatively appreciated by the CSNPH – NHRPH.[169] To date, the current memorandum is not yet in force. Besides, as mentioned by the CSNPH – NHRPH on their website, there has been no evaluation of the previous protocols (see also Chapter 1 and section 8.9).

While many professionals engage in continuing education programmes on a voluntary basis, **incorporating training into accreditation standards** could encourage adherence to and implementation of such measures. For this reason, participation in continuing education should be included as a quality indicator in the standards of the services concerned, with a minimum threshold of trained staff per institution.

Table 37 – Implementation conditions and possible accountable for developing the training of the educational staff in the disability sector

WHAT?	WHO?
Organisation of continuous training for professionals concerning the health of people with ID, including the recognition of symptoms and health needs, the decoding of complaints and the use of assessment tools for symptoms and pain.	• Disability sector • Health sector
Annual dissemination of tools to correctly identify symptoms and health needs to professionals in the disability sector	• Competent authorities • Associations of the disability sector
Enforcement of a memorandum of understanding for the provision of care in institutions for people with ID	• Competent authorities • Professional associations in the health sector • Professional associations in the disability sector
Enforcement of a memorandum of understanding for the provision of care for people with ID by their non-medical supporters	• Competent authorities • Professional associations in the health sector • Professional associations in the disability sector
Inclusion of participation in in-service training as a quality indicator in the reference systems of the services concerned, with a minimum threshold of people trained per institution	• Authorities responsible for the accreditation and quality of services for people with disabilities

8.8 Skills of health care professionals outside the disability sector

8.8.1.1 *Main barriers*

- Outside the disability sector, HCP are not sufficiently trained and prepared to communicate with people with ID (and their relatives), to identify their needs, to decode their symptoms and complaints, and to collect their preferences. This lack of training concerns, among other things, the ability to assess the feasibility and relevance of carrying out preventive and diagnostic examinations, knowledge about co-morbidities associated with disability and skills to communicate and interact with people with ID. Moreover, it was pointed out that HCP outside the disability sector lack relational and communicational skills towards the supporters of people with ID.
- The expression of symptoms by some people with ID may be hidden or differ from the clinical picture that HCP are used to, which requires a different clinical judgement.
- HCP lack opportunity to develop sufficient skills, nor the time to use the tools to manage pain and anxiety in people with ID when providing care or performing technical and medical imaging procedures. As they are not very familiar with people with ID, some HCP tend to be reluctant to welcome them into their practice for fear of not knowing how to manage the reactions and behaviours they anticipate negatively.

8.8.1.2 *Global solution*

- HCP should be better trained and prepared to support people with ID and their supporters.

8.8.1.3 *Possible actions to reach the global solution*

Ebpracticenet is a digital database of all evidence-based clinical practice guidelines and other information materials for Belgian HCP. This mission makes it a suitable interlocutor for the dissemination of good practice for HCP. Therefore ebpracticenet, in partnership with the SSMG and Domus Medica, should **develop and disseminate a guideline for the follow-up of people with ID** by GP, including screening and preventive examinations. The guidelines should include symptom assessment tools adapted to people with ID. Additionally, other HCP can benefit of such guidelines such as nurses, physiotherapists or dentists.

Reducing anxiety and distress requires techniques and skills that not all HCPs have mastered.[170] This is why somatic and mental HCP, in partnership with associations of people with ID, should develop and disseminate good practice **recommendations for the appropriate management of anxiety and agitation** in people with ID during care. These calming techniques should include a wide range of practices (music, use of a mixture of equimolar oxygen-nitrous oxide mixture such as MEOPA or Nitronox©…).[171, 172, 173, 174, 175] In addition to training, it is essential that hospital managements provide HCP with the necessary equipment to reduce the anxiety and agitation of people with ID such as installation for playing music or the installation for using medical analgesic gas.

The RIZIV – INAMI already offers training for HCP in the form of e-learning. Therefore, it can be interesting for the FPS Public Health and the RIZIV – INAMI to develop an e-learning training module for HCP concerning the approach and support of people with ID. This training should be adapted to the different HCP and not only to GP. This **training module** can be inspired by existing projects and include the expertise developed by disability associations such as *Inclusion asbl*. For example, as part of their "*Dites aaa*" campaign, *Inclusion asbl* and *Handicap & Santé* have identified different tools to help HCP assessing pain. This training should include a module on tools for communicating with people with ID in general, identifying symptoms and pain, managing anxiety and coping with ID in care. Additionally, institutions of continuous and initial training must offer (future) professionals the opportunity to be in direct contact with people with ID, whether during teaching activities, one-off events or their internships.

HCP need to be **better informed about existing support associations** for people with ID: for accessing information useful for their practices, for orienting people directly to these associations.

Table 38 – Implementation conditions and possible accountable institutions to better train and prepare HCP

WHAT?	WHO?
Development and dissemination of a guideline for the follow-up of people with ID by GP, including screening and preventive examinations	• Ebpracticenet • SSMG • Domus Medica
Development and dissemination of guidelines for the follow-up of people with ID by HCP, including pain and stress management	• Ebpracticenet • Professional and / or scientific associations of HCPs
Development and dissemination of good practice recommendations for the appropriate management of anxiety and agitation in people with ID during care and technical procedures	• Professional and scientific associations in the fields of somatic and mental health • Associations in the disability sector
Provision of the necessary equipment for HCPs to reduce the anxiety and agitation of people with ID	• Hospital management
Development, dissemination and perpetuation of an accredited e-learning course for HCPs on the approach and support of people with ID, in collaboration with professional associations and associations in the disability sector.	• FPS Public Health • INAMI – RIZIV • Professional and scientific associations in the health sector • Associations in the disability sector
Annual information to HCP on the existence of tools to identify the symptoms and health needs of people with ID	• Competent authorities • Associations of the disability sector
Development and dissemination of a guideline for the follow-up of people with ID by GP, including screening and preventive examinations	• Ebpracticenet • SSMG • Domus Medica
Development and dissemination of guidelines for the follow-up of people with ID by HCP, including pain and stress management	• Ebpracticenet • Professional and / or scientific associations of HCPs

8.9 Monitoring and follow-up of the health care needs

8.9.1.1 *Main barriers*

- The health needs of people with ID in Belgium are not known. The data collected now is mainly the result of one-off and/or local projects.
- The current system of data collection does not allow the identification of people with ID in Belgium. The definition of an individual with ID is not uniform.

8.9.1.2 *Global solution*

- Opportunities for data collection and statistics on the health of people with ID should be developed to better apprehend their needs and monitor their health status in order to support health policies, starting by the development of an identification system of people with ID in databases.

8.9.1.3 Possible actions to reach the global solution and research perspectives

This global solution is in line with the Flagship measure 130 "Establish a working group to identify the needs and possibilities for data collection and statistics on people with disabilities (taking into account other criteria such as gender, age, etc.)" of the Federal Disability Action Plan 2021-2024.[153, 154]

In this context, it could be interesting, through the creation of an identification system in accordance with ethical regulations and the General Data Protection Regulation (GDPR), to evaluate the **performance of the health system** in terms of its performance to take into account the health needs of people with (intellectual) disabilities.[176 177 71 178 179] Specifically, it can be relevant to determine monitoring indicators for the care of people with ID in the health care system, especially for primary care.

Quality indicators should take into account existing indicators and include PROMs and PREMs.[180] The experiences and needs of people with ID should be collected both qualitatively and quantitatively. For example, a joint project between AVIQ and UMons is planned on the representations of people with intellectual disabilities among primary care health professionals and to qualitatively analyse the needs of people with ID about the conduct of medical consultations.

The KCE report 348 on unmet patient needs focuses on the development of a method to identify the most important **unmet patient needs** in a scientific and structural way.[181] This method can be used in the INAMI – RIZIV's reimbursement decisions, but it can also be used to better inform HCP about the real needs of patients and to determine the research priorities to be set in the agendas of industry and public research funding bodies. It can be relevant to use this tool for the identification and monitoring of the needs of people with ID by public authorities and health institutions.

The National Health Interview Survey (HIS) is a powerful tool for epidemiological monitoring of the Belgian population: it can be interesting for Sciensano to include an **additional sample of people with ID**[gggg]. The survey instruments and the training of interviewers must consider the capacity of people with ID or the possibility of conducting the interview with a supporter.

There are already specific provisions in the health care nomenclature, such as the possibility of visits to the family or community home of people with ID by medical specialists. In order to facilitate and adapt this measure, it can be interesting for the RIZIV – INAMI to carry out an annual analysis of the data on visits made to the family or community homes of people with ID by medical specialists and to investigate the obstacles and incentives involved.

In order to promote health monitoring, the competent authorities and institutions in the disability sector can set **annual targets for the health monitoring of people with ID**. This allows institutions to develop health-related projects, in partnership with local private and public actors, which consider their reality and the needs of their public. For example, an institution that only accommodates women can choose to organise an annual gynaecological examination for each of its residents, while an institution where many people have an obesity problem can prioritise dietetic follow-up.

In order to be supported by HCP and staff, data collection and monitoring should be used to implement actions, and not only for administrative purpose. Developing a monitoring should not add to the administrative work of professionals and, on the contrary, be implemented as much as possible in existing monitoring systems.

Data collection and monitoring should therefore be accompanied by **ethical precautions**. This specific monitoring should **avoid stigmatisation** and prejudices against people with ID but rather serve the objectives of inclusion and equity. Alongside precautions regarding the data collection, there is a need for appropriate communication of such data to public authorities and the society.

[gggg] Methodology of HIS can be found here: https://www.sciensano.be/en/projects/health-interview-survey#method-and-sample

Table 39 – Implementation conditions to be undertaken and institutions to be held accountable to better train and prepare HCP to support people with ID and their supporters

WHAT?	WHO?
Creation of an identification system of people with ID in accordance with ethical regulations and the GDPR	• Competent authorities • CSNPH – NHRPH
Creation of a set of indicators to assess the performance of the health system in relation to the health needs of people with ID	• Competent authorities • Sickness funds • KCE • Services and institutions of the disability and health sectors
Identification of the unmet needs of people with ID using the methodology developed by the KCE	• INAMI – RIZIV • Sickness funds • Competent authorities • Research centres • Services and institutions of the disability and health sectors
Inclusion of a representative sample of people with ID in the national health interview survey (HIS)	• Sciensano
Annual analysis of data on visits made to the family or community homes of people with ID by medical specialists and investigation of the obstacles and incentives involved	• INAMI – RIZIV
Development of monitoring indicators for the care of people with ID in general practice	• Competent authorities • CMG • Domus Medica • Sickness funds
Annual determination of the objectives to be reached in the field of health monitoring of people with ID by and with the institutions of the disability sector	• Competent authorities • Institutions of the disability sector
Implementation of a monitoring of needs that can be addressed through the patients' associations in the future Patients' Forum and/or the Observatory on Chronic Diseases, which can feed back these needs to the competent councils	• *Patiënten Forum* and/or Observatory of the Chronic Diseases
Evaluation of the current practices related to the provision of care in institutions or at home for people with ID	• Academic research centres • KCE

8.10 Conclusion

Emerging solutions presented in this chapter have the potential to solve partly the barriers related to access for people with ID. These solutions can be combined as barriers to access are also a combination of interacting factors.

Among the solutions and actions, it is worth noting that several of them are not specific to people with ID but to other categories of people with specific needs within the health care system. Not only people with ID face difficulties when it comes to access to preventive care and dental care but, because of their vulnerabilities, people with ID mirror the difficulties experienced by a larger group of **people with specific needs**. Consequently, improving access to health for people with ID needs to be considered in a larger context than “just” the people with ID.

Similarly, implementation of the solutions should prevent the reinforcement of the gap between those already experiencing difficulties to access mainstream health care and those already benefiting from the existing services. In that sense, the concepts of **reasonable adjustment and universal design** can be used as a template to further develop the solutions. These approaches are not based on the “average Joe” but on the needs of the most vulnerable groups, making adaptations useful and practicable for all.

To be implemented, some of the solutions need **major changes inside and outside the health system**. Among other examples, the shortage of HCP, especially nurses and GP, the lack of support for the supporters, the inadequacy of the fee-for-service scheme for complex situations, the turnover of educational staff in institutions are issues that may need to be solved. Moreover, the solutions were not investigated regarding their costs or their efficiency: for some to be effective, additional financial resources are needed. Additionally, some solutions are not yet existing or funded: some – as the reference centres – require major investments that may not be supportable now, notably by hospitals. This need for extra investments can also be jeopardised because of the different funding mechanisms and governance levels between the health care sector and the disability. Some solutions rely on the non-profit associations to share their knowledge and expertise with professionals: this may require additional human and financial resources that are not available or, when available, are not sustained over time. The funding by non-permanent subsidies is not a guarantee of sustainability over time and can create uncertainties about the future of the project among professionals.

9 DISCUSSION

9.1 General reflexions on main findings

As previously mentioned, the final solutions concern people with ID and their supporters, HCP and educational staff and the health care system as a whole: this reflects the complex interactions between the different barriers. Access to health care is not only an individual problem requiring thus solutions at different levels, including the system level.

In that context, it is worth noting that the 3 emerging priority solutions (training HCP, empowering people with ID and improving coordination in primary care) lie into these 3 categories although no information about the level of action was provided to the participants. It seems that, implicitly, both experts and stakeholders value a multilevel action framework, coherent with the reduction of health inequities and the current integrated care approach. This could also be perceived as an implicit cautioning of a more inclusive and social approach of disability than a medical and specific one. This finding is in line with the report on "Child with special health needs" arguing for an integrated accompaniment based on social determinants of health rather than on a pathology-based management.[162] These 3 priorities also somehow reflect different temporalities: from short-term, almost quick wins solutions to long term action, requiring a political consensus and the allocation of specific resources. Actions targeting empowerment of people with ID mainly consist in informing and disseminating existing resources: one cannot have to wait for political decisions to start diffusing such material. On the contrary, improving coordination in primary care requires more investment at political level as pointed out in the recent KCE report on integrated care.[161] If the need for a more coordinated and integrated approach in primary care, including prevention, is acknowledged, field actors still wait for a clear political framework in which all governance levels define and coordinate their actions[hhhh]. Again, one may question whether unconsciously experts and stakeholders were considering these different temporalities.

Training professionals to provide (better) care is one of the solutions that was praised by the participants: however, there are still unknowns about the real effect of training on the accessibility of services for people with ID and the relevance of making these training schemes compulsory and/or part of initial training. Training implies acquiring new knowledge (*savoir – kennis*), new skills (*savoir-faire – kunnen*) and new attitudes (*savoir-être – houding*). While the acquisition of new knowledge may seem easy to achieve, for example through a lecture, the acquisition of new skills requires the learner to put them into practice, whether through simulation, an internship or practical work. This passage through the "field" is essential for the consolidation of skills, as a significant part of professionals' skills are achieved through social learning.[182, 183] Soft skills, on the other hand, are more closely linked to personality and values: they reflect the way in which the professionals interact with their social environment. It cannot be learned: it is developed through social relationships and life experiences but does not guarantee an intrinsic change in personality. By extension, some HCP may therefore have a great deal of knowledge and skills but lack the life skills that enable them to put that knowledge and skill to work. This observation should not lead to a shortcut according to which training has no interest but rather to a reasoned approach to training. Making training compulsory for all professionals, some of whom will have little or no opportunity to use it, is likely to be irrelevant and even counterproductive. On the other hand, developing a continuous training offer and ensuring the presence of relay professionals trained in knowledge, skills and attitudes seems more relevant.

Empowering people with ID and their supporters was also favoured as a solution by both experts and stakeholders. One may hypothesise that this reflects a willingness for improving the social participation of people with ID by giving them the resources to exert their rights as patients and, to a larger extent, as citizens. This should therefore not occult that people with ID, as

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[hhhh] The interfederal plan on integrated care should be published in 2024.

mentioned repeatedly, is not a homogeneous community. Reinforcing empowerment needs to consider the large diversity of people with ID, including their preferences, needs and resources. This also applies for all solutions directly aiming at people with ID but also to other solutions suggested in this report. Improving access to health care should be rooted in proportionate universalism, that is the resourcing and delivering of universal services at a scale and intensity proportionate to the degree of need, and operationalised, as stated above, via universal design and reasonable adjustments.[184] As an illustration, increasing health literacy requires a diverse range of approaches in order to meet the diversity of the needs and preferences of people with ID: one should not consider that "just" providing a brochure in Easy read format helps all people with ID. Moreover, reinforcing empowerment of people with ID should therefore not lead to a form of disempowerment of the HCP and the policymakers: they also must pursue their efforts for achieving a more equitable access to health care for people with ID.

Beyond creating specific centres or expanding the coverage for some health care benefits, for some people with ID, as pointed by a stakeholder, *"begeleider is belangrijker dan plek waar het gebeurt"* (litt: being accompanied is more important than the place where it happens). In other words, above all solutions, more attention should be paid to the role devoted to the supporters of people with ID. Supporters encompass all those who provide daily support to people with ID and are the most knowledgeable, beside the people themselves, about the needs and preferences of the people with ID. For some people with ID, accessing health care could be "simply" improved if they can be accompanied any time any place by someone they know and trust. The current study pointed out that a lot of the supporters are highly motivated to give the best life to their loved one, but not only, also a lot of good will from the educational staff was noticed, for example, by visiting their beneficiaries at the hospital after their working hours.

Indeed, some of the suggested solutions highly rely on the involvement and the availability of the supporters. The time that informal caregivers need to support the inclusion and participation in people with ID's health care depends on the collective recognition of the major role that informal carers play and the lack of support they receive. It is only possible to adequately prepare a person to take a medical examination if there is time and energy to do so. It could be easier or faster to decide on behalf of the people with ID rather than taking the time to invest in exploring the needs and preferences of those people. This is why improving access to health care is not only a question of HCP's behaviour or knowledge improvement, but is also a need to improve the daily living conditions of the supporters. Moreover, the degree of involvement as informal caregiver for a person with ID should remain a personal choice and consider the situation of the supporters: solutions should consider the decisions and capacities of the relatives alongside the preferences of the people with ID.

In this report, the research team adopted the principle of inclusion, promoting the integration of people with ID in the mainstream health care system rather than in a specific health care trajectory. This principle of inclusion yet enshrined in the UNCRPD and in the Federal Action Plan Handicap is however not consensual. On the one hand, those supporting the principle of full inclusion promote the full access to all benefits of the health care system, with the risk of unmet needs. As an illustration, not all HCP are knowledgeable about the specificity of clinical presentations and adaptation of treatments when the underlying cause is a rare disease. This may complexify the delivery of "regular" care, for example because of interaction of medications or of the different physiological response to a treatment. Consequently, promoting full inclusion could then become hazardous for people with ID if the HCP are not sufficiently aware of their clinical specificity. On the other hand, those who support specific pathways promote a focus on the specific needs but with a risk of stigmatisation and delays related to the shortage of HCP involved. In this approach, HCP caring for the people with ID are highly specialised but may not be able to consider the diversity of the people with ID. Specific approaches usually require the definition of inclusion and exclusion criteria, leading to situations where the patients fall between "categories" as they cumulate multiple vulnerabilities. This was, among others, mentioned for the youths cumulating a psychiatric problem and an ID.[60] One may thus deplore that this report does not assess the balance between horizontal equity (same response for same needs) and vertical equity (specific responses for specific needs). However, despite a positioning on the principle of inclusion, the emerging solutions tend to proportionate universalism. It proposes solutions accessible in the mainstream health care system, without a specific trajectory (horizontal equity) while acknowledging the need for specific responses for specific needs (vertical equity).

9.2 Limitations

In addition to limitations mentioned in each chapter, some transversal points must be mentioned.

Before this study, none of the researchers had an experience in conducting research with people with ID. Interviews were conducted by AND, trained as physiotherapist, and CER, trained as geriatrician: both of them have an experience of interviews with patients as part of their practice as health care professionals. Therefore, they both attended a training in Easy read language to be able to communicate adequately with people with ID. The alternative would have consisted in hiring researchers trained in Easy Read language. Another option could have been hiring educators as they are familiar with this public and train them to qualitative research interviews. It is not usual for researchers to be trained to be able to access their target audience. In a scoping review, Copeland et al. pointed that in only 6 researches out of 29 studies the researchers were trained before collecting data during interviews with people with ID.[106] Some may question whether getting more familiar with the target audience may have influenced the attitudes of the researchers in analysing and interpreting the data. To counterbalance a possible “empathy” bias, the researchers conducting the interviews had the possibility of sharing their experiences with the qualitative group of the KCE as part of a supervision. Moreover, analysis was discussed with the whole research team: this helped the researchers to be aware of the social setting of the research and of the socioeconomic context, as part of their reflexive posture.[185]

The international literature search was limited to practical search targeting general information on definitions, inequity, barriers to health care access and good practices when Belgian initiatives were not identified. The choice was indeed made to focus the time and human resources at KCE to focus on the collection of data from Belgium. The quick scan led on the different topics results, with a good overview on the different topics as numerous reports and summaries of evidence from trustable sources were available in the literature.

There was no final meeting between experts and stakeholders about the suggested solutions. This meeting could have helped to obtain a consensus on the priority actions to be developed and better identify critical points that may need further discussion between experts and stakeholders. It could also have helped to identify more detailed and practical implementation conditions and propose a planification of the solutions (short, middle or long term). The priority of the solutions and the recommendations were nonetheless based on the views of both experts and stakeholders. The priorities were almost the same, although the research design did not allow for a clear identification of differences in views between those participants with a background in general health care and those with a background in disability services. Moreover, one cannot exclude internal variation of perspectives and priorities inside both groups: as previously mentioned, people with ID constitute a heterogenous group and, as consequence, one may also expect heterogeneity in the perspectives and views of those inside the “disability sector”. Further research may investigate the likely differences between those participants with a background in general health care and those with a background in disability services in order to better support implementation of solutions.

This report does not question any of the ethical issues arising when considering access to health care for people with ID such as the provision of health care without obtaining an informed consent, the forced health care such as the forced sterilisation, or the triage based on validist arguments preventing people with ID from accessing (intensive) treatments. A focus on these issues could have been of added value to better understand under which circumstances some people with ID and their supporters are confronted with health care professionals and how these influence the relationships between them.

9.3 Further research

As mentioned above, this report did not investigate efficiency and efficacy of the solutions or the economic dimensions. Some of the solutions were perceived as poor or not feasible by experts and stakeholders although they are likely to improve access to health care as shown by international experiences or with other patients. Other solutions, as the adaptation of the emergency procedures, may be the topic of guidelines for practice. Moreover, some situations or some more vulnerable groups among people with ID were not considered in this report. This is, among others, the case for the management of sexual violence or the health care of asylum seekers with ID, that are both mentioned in the Federal Action Plan Handicap. These topics may require additional research.

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APPENDICES

APPENDIX 1. FEDERAL ACTION PLAN HANDICAP 2021-2024

Table 40 – Selection of measures related to the access and quality of care for the persons with disabilities in the Federal Action Plan Handicap Plan 2021-2024

Subtopic	Actions	Ministers	Administrations
Axe 1: Solidarity			
Management of sanitary crisis	Updating crisis plans with the inclusion of the needs of persons with handicap	Annelies Verlinden Minister of Interior Zakia Khattabi, Minister of environment Frank Vandenbroucke, minister of public health	FPS Interior FPS Public Health
Management of sanitary crisis	Ensuring the availability of the crisis communication in tailored and available format	Annelies Verlinden, Minister of Interior Frank Vandenbroucke, Minister of Public Health	FPS Interior FPS Public Health
Healthcare	Defining, in collaboration with the federated entities, the thresholds of access to healthcare aimed at persons with disability, particularly for health care at the border of the distribution of the competences in public health and wellbeing (e.g., speech therapy nomenclature, physiotherapy related to rehabilitation centres).		
Healthcare	Examining the respect of the rights of persons with sensorial disability regarding interpretation in sign languages within the healthcare system.	Frank Vandenbroucke, Minister of Public Health	FPS Public Health

Subtopic	Actions	Ministers	Administrations
Healthcare	Guaranteeing access of persons with disability to the national health insurance and other funds related to the health insurance, on the grounds of the equality with the others: discussing the issues of the pre-existing conditions	Frank Vandenbroucke, Ministre of Social Affairs and Public Health	RIZIV – INAMI
Healthcare	Reforming the law of June 26, 1990, related to the protection of the person of mentally ills in the respect of the rights of the persons with disability	Vincent Van Quickenborne, Minister of Justice	FPS Justice
Healthcare	Supporting innovative initiatives in mental health services of hospitals to deliver more human healthcare and to reduce the use of coercive measures	Frank Vandenbroucke, Minister of Public Health	FPS Public Health
Government & public services	Developing a network of experts by experience in the disability to support federal administration in the development of more inclusive services.	Karine Lalieux, Minister for the persons living with disabilities Petra De Sutter, Minister of the public function	
Guaranteeing right to access information	Generalisation of the use of "easy to read" format of important official documents for citizens	All the members of the government	All the administrations
Guaranteeing right to access information	Publishing and vulgarising the information related to the United Nations Convention related to the rights of persons with disability, including the general observations of the Committee of the United Nations to make them accessible, in the three national languages in « easy to read » format and in sign languages.	Karine Lalieux, Minister for the persons living with disabilities	FPS Social Welfare
Axe 2 Prosperity			
	Assessment of the practice for persons with disability related to the extension of the right to be forgotten regarding insurance (e.g., for some diabetes)	Pierre-Yves Dermagne, Minister of Economy Eva De Bleeker,	FPS Economy

Subtopic	Actions	Ministers	Administrations
		State Secretary for the protection of consumers	
Axe 4 Safety			
	Raise the awareness of the emergency services to the European Disability Card.	Annelies Verlinden, Minister of Interior	FPS Interior Federal police for the integrated police
Situation of persons with disability in the penitentiary system	To invest in healthcare team able to care for persons with disability in prisons	Vincent Van Quickenborne, Minister of Justice	SPF Justice
Persons with disability victims of familial / sexual / sexist violence	Highlighting the disability in the framework of the action plan against gender violence	Sarah Schlitz, State Secretary for gender equality, equal opportunities and diversity	Institute for equality between women and men
Persons with disability victims of familial / sexual / sexist violence	Assessing the accessibility of Centres for the Management of Sexual Violence for persons with disability	Sarah Schlitz, State Secretary for gender equality, equal opportunities and diversity	Institute for equality between women and men
Axe 5 Cooperation & respect			
	Prolonging the project « Improving Equality Data Collection in Belgium[iiii]» to enlarge it to other criteria of discrimination such as disability.	Sarah Schlitz, State Secretary for gender equality, equal opportunities and diversity	Equal Opportunities Cell
	Creating a working group in charge of identifying needs and opportunities in data collection and statistics related to persons with disability (including other criteria such as gender, age, etc.).	Karine Lalieux, Minister for the persons living with disabilities Frank Vandenbroucke, Minister of Social Afffairs Pierre-Yves Dermagne, Minister of Economy and Labour	FPS Social Welfare Statbel FPS Employment, Labour and Social Dialogue
Axis 6 – European & international participation			
Asylum & migration	Ensuring an appropriate evaluation to quickly and correctly identify the specific	Sammy Mahdi, State Secretary for Asylum & Migration	Fedasil

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[iiii] The project “Improving Equality Data Collection” could be found here: https://www.unia.be/fr/publications-et-statistiques/publications/donnees-sur-linegalite-la-discrimination-en-belgique

Subtopic	Actions	Ministers	Administrations
	needs of asylum seekers with disability living in the reception network and ensuring the follow-up.		
Asylum & migration	Promoting the mobility and an appropriate communication for asylum seekers with disability in the reception network	Sammy Mahdi, State Secretary for Asylum & Migration	Fedasil

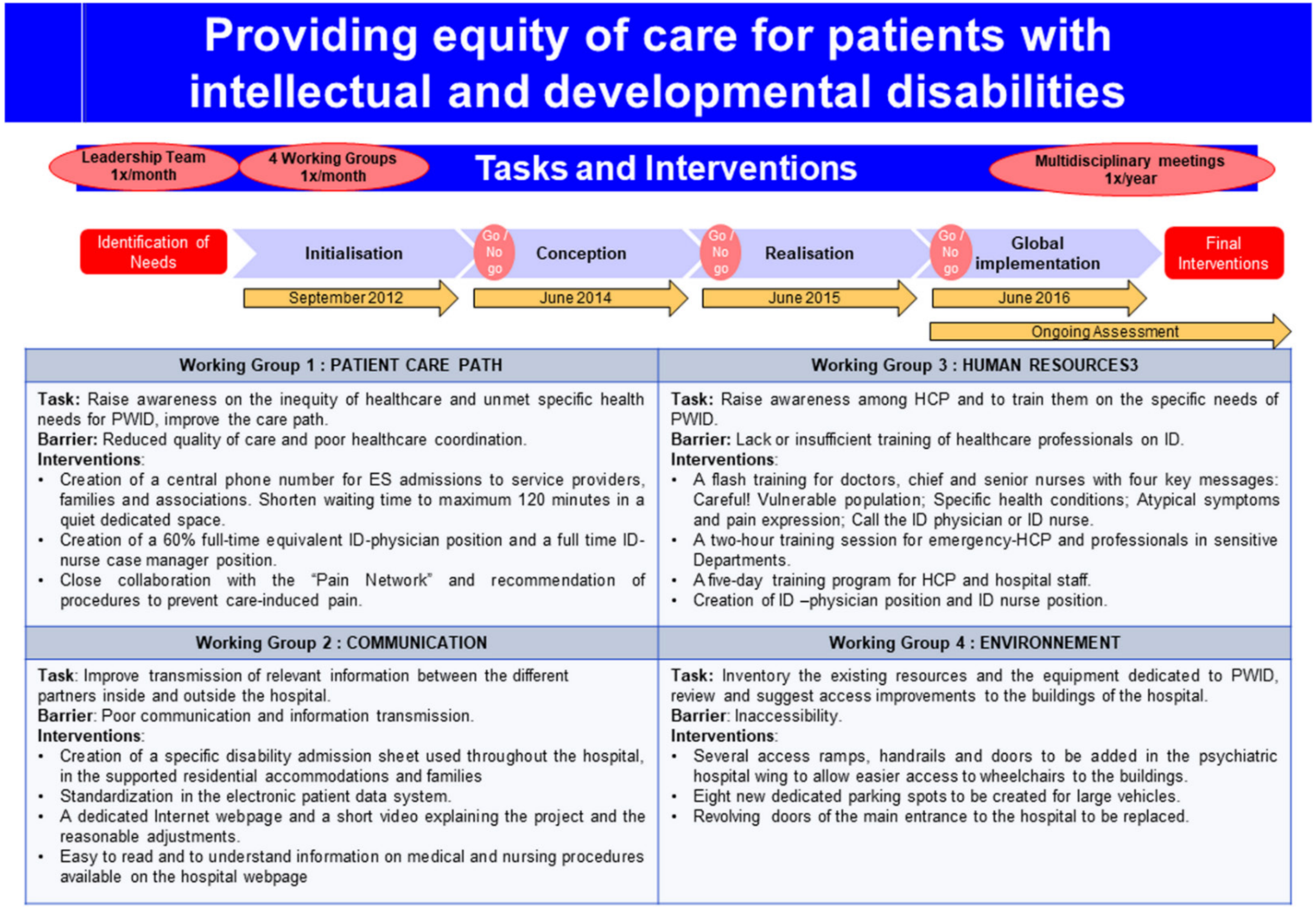
APPENDIX 2. EXAMPLES OF REASONABLE ADJUSTMENTS

Table 41 – Examples of reasonable adjustments according to Special Olympics

Creating welcoming spaces	Ensuring accessible communication	Awareness and training	Sustainable and intentional inclusion
Incorporate disability etiquette into internal staff training	Use accessible language	Train staff and leaders on the barriers faced by people with ID and methods for how to overcome those barriers	Embed inclusion into your organisational culture
Explore how using Universal Design (the design of services or physical environments to be useable by all without adaptation) may be applied to your services or organisation	Provide in-person assistance to ensure individuals understand materials and can complete forms	Hire people with ID to provide input on and/or conduct the training	Partner with local disability organisations to learn how you can improve your inclusive practices
Ensure your space or programmes follow the law on disabled people. Where possible, ask people with ID if there is a particular accommodation that might help them better use or benefit from your services.	Include images of people with ID in your promotional materials		Include people with ID in the planning, implementation, and evaluation of programmes, services, or activities
	Materials should also be available in other accessible formats like braille and large type		Hire people with ID to work at your organisation in a meaningful capacity, both as a way of promoting a culture of diversity and inclusion and as an effective way to increase awareness of the need for inclusive practices

Adapted from Special Olympics[24]

Figure 21 – Summary of the interventions and reasonable adjustments achieved throughout the Disability Project of the *Hôpitaux Universitaires de Genève*, Switzerland



Providing equity of care for patients with intellectual and developmental disabilities

Leadership Team 1x/month

4 Working Groups 1x/month

Tasks and Interventions

Multidisciplinary meetings 1x/year

Identification of Needs → Initialisation → Go / No go → Conception → Go / No go → Realisation → Go / No go → Global implementation → Final Interventions

September 2012 – June 2014 – June 2015 – June 2016 – Ongoing Assessment

Working Group 1 : PATIENT CARE PATH

Task: Raise awareness on the inequity of healthcare and unmet specific health needs for PWID, improve the care path.
Barrier: Reduced quality of care and poor healthcare coordination.
Interventions:

- Creation of a central phone number for ES admissions to service providers, families and associations. Shorten waiting time to maximum 120 minutes in a quiet dedicated space.
- Creation of a 60% full-time equivalent ID-physician position and a full time ID-nurse case manager position.
- Close collaboration with the "Pain Network" and recommendation of procedures to prevent care-induced pain.

Working Group 3 : HUMAN RESOURCES3

Task: Raise awareness among HCP and to train them on the specific needs of PWID.
Barrier: Lack or insufficient training of healthcare professionals on ID.
Interventions:

- A flash training for doctors, chief and senior nurses with four key messages: Careful! Vulnerable population; Specific health conditions; Atypical symptoms and pain expression; Call the ID physician or ID nurse.
- A two-hour training session for emergency-HCP and professionals in sensitive Departments.
- A five-day training program for HCP and hospital staff.
- Creation of ID –physician position and ID nurse position.

Working Group 2 : COMMUNICATION

Task: Improve transmission of relevant information between the different partners inside and outside the hospital.
Barrier: Poor communication and information transmission.
Interventions:

- Creation of a specific disability admission sheet used throughout the hospital, in the supported residential accommodations and families
- Standardization in the electronic patient data system.
- A dedicated Internet webpage and a short video explaining the project and the reasonable adjustments.
- Easy to read and to understand information on medical and nursing procedures available on the hospital webpage

Working Group 4 : ENVIRONNEMENT

Task: Inventory the existing resources and the equipment dedicated to PWID, review and suggest access improvements to the buildings of the hospital.
Barrier: Inaccessibility.
Interventions:

- Several access ramps, handrails and doors to be added in the psychiatric hospital wing to allow easier access to wheelchairs to the buildings.
- Eight new dedicated parking spots to be created for large vehicles.
- Revolving doors of the main entrance to the hospital to be replaced.

Extracted from the publication of Lalive et al.[86]

APPENDIX 3. BARRIERS IDENTIFIED IN THE LITERATURE

The following tables summarises the barriers identified in the literature, give some examples of the barriers, some consequences, the protagonist concerned by a change which can solve the barrier and the findings identified by the current qualitative approach in the Belgian context and which are in common with the literature findings (see Chapter 4: International Literature scan on barriers and facilitators).

Table 42 – Cross-comparison of attitudinal barriers retrieved from the literature scan and the qualitative data collection

Barriers retrieved from literature	Examples	Consequences	Protagonists concerned by a change/solution	Similar findings in Belgium by the qualitative data collection
Misconceptions (unconsciously, related to fear)	People with ID are psychiatric patients People with ID do not understand anything People with ID cannot improve their health Assuming that women with an intellectual disability are not sexually active	Missed diagnostic or treatment (physical problems viewed as a part of the intellectual impairment, or certain treatment options not offered Poor listening to people with ID Denied healthcare admission/admission in psychiatry instead of somatic wards/criteria for choosing a hospital service differ when it comes to a people with ID	HCP and staff	Admission refusal in psychiatric ward or intensive care ward Choice of referral to a hospital ward based on the person's mental age rather than their chronological age
Negative attitude of the HCP towards the person with an intellectual disability	Dentist were reluctant to treat their child, and this was more common in children with severe and profound and moderate disability	This reluctancy could be due to a lack of knowledge and skills, and communication barriers in relation to people with an intellectual disability	HCP	Reluctance to care for people with ID
Experienced previously lack of respect	Previous experience rape of molestation	Avoidance or reluctance to healthcare, notably pelvic exams	People with ID	
Previous negative medical experiences = Experienced previously pain related to healthcare or bad treatment	Experiences of pain during and after screening	Avoidance or reluctance to healthcare Feel uncomfortable during the procedure	People with ID and supporters	Great impact of a previous negative experience in healthcare

Experience anxiety about receiving exams				
Beliefs about vulnerability	Seeing oneself in a weak position when encountering the health care system	Felt uncomfortable with exams	People with ID	
Caregiver concerns and beliefs	Fear for aggressive behaviour of the person with an intellectual disability as reaction on unwillingness, or worries to hurt the person		Supporters or HCP	Reluctant to attend screening appointments, believing that the health gain is less than the effort required to carry out the test
Fear of the unknown	Lack of familiarity with the doctor Lack of familiarity of the caregiver	Felt uncomfortable with exams Some people with id will only accept supervision during daily oral routine by staff to whom he is familiar to and like	People with ID	Being frightened by unfamiliar person or place
Avoidance to use anti-anxiety medications or sedatives to tolerate an exam			HCP	
lack of a positive and encouraging environment for screening	Using appropriate language and attitude (mannerism and demeanour) and encouragement by the staff	Hamper the participation to a screening program	HCP and staff	
Behavioural factors	Obstructive or behaviour viewed as challenging		People with ID	Care refusal/behaviours viewed as challenging
affective factors	Mood and motivation, fear and distress, and dislike oral care and toothbrushing	Impede daily oral care	People with ID	Frequent high intensity reaction and anxiety related to pain
Unhealthy lifestyle	Smoking, sugary food and medication use		People with ID	
Lack of direct support by carrying out some or all the cleaning of the teeth			Supporters	

Table 43 – Cross-comparison of communication barriers retrieved from the literature scan and the qualitative data collection

Barriers	Examples	Consequences	Protagonists concerned by a change/solution	Similar findings in Belgium by the qualitative data collection
Lack of communication skills with patients	Medical jargon Complicated language Lack of active listening Lack of explanation of the procedure	People with ID not aware of certain treatment options because explanation not understood Accompaniers must repeat over again the same info Patient felt uncomfortable with exams	HCP	Not always listen to and hear the supporters: both family members and professional caregivers information must be repeated and illustrated
Lack of informing PEOPLE WITH ID on the procedure and the understanding of cancer screening			Supporters	Neglect of the stage of explanation by the supporters due to lack of time or energy
Not adapted medical communication materials	Folder, poster		system	
Limited available time		Lack of discharge instructions about treatment and diagnostic	HCP and system	See barrier attitudinal and organisational
Weak info transmission between HCP		Repetition Time waste Inappropriate behaviour	HCP	Incoherence between different HCP
Caregiver’s belief that exams are unnecessary			Supporters	See barrier knowledge
Lack of network of dentists specialised in care of people with ID	Lack of information where the person with a disability can be treated by a dentist, also info on location of the dental office (and its related transportation issues)			

Table 44 – Cross-comparison of skills and knowledge barriers retrieved from the literature scan and the qualitative data collection

Barriers	Examples	Consequences	Protagonists concerned by a change/solution	Similar findings in Belgium by the qualitative data collection
Lack of awareness on ID and needs of people with ID **Lack of training or knowledge related to intellectual disabilities**		Feeling of helplessness Could even lead to pejorative attitudes about people with intellectual disabilities	HCP and staff	very little knowledge about intellectual disabilities
Lack of knowledge about clinical signs specific to people with ID, their specific healthcare needs and what disability is and means and leads to		Avoid examining clinically a person with ID by fear or by powerless feeling Interpreting those behaviours like symptoms of psychiatric disease instead of somatic disease signs and pain Insufficient somatic diagnostic, insufficient pain medications, and inadequate dispatching of care like asking to carers to remove stitches or to perform all the basic care (feeding, bathing etc…	HCP	Misinterpret clinical symptoms as consequences of intellectual disability
Lack of skills to care people with ID with behaviour viewed as challenging		Avoid examining clinically a person with ID by fear or by powerless feeling	HCP	
Lack of knowledge about supports and services specialised in ID issues			HCP	
Not always know where to go to find help and care			People with ID and supporters	Not well informed about existing financial and logistical support
Lack of knowledge about legal requirements on consent		How do professionals advise someone with intellectual disability to consent and if they can't, who will consent for them	HCP	
Inability to give consent for procedure/treatment			people with ID	

Insufficient research on and involving people with ID		Nonexistence of specific data and the weakness of the knowledge	System and researcher in social or health sectors	
Poor health literacy skills **Lack of health promotion and education**	Lack of skill and knowledge to recognise the health problems and to communicate it to HCP Lack of knowledge of needed health screenings	Limited knowledge about (breast) cancer and the need for regularly undertaking self-examinations and going for breast screening	People with ID and supporters	lack knowledge (health literacy) about common chronic diseases: better knowledge leads to better involvement and therefore better compliance Lack knowledge (health literacy) about common chronic diseases: the knowledge deficit is even more pronounced in prevention care (lack knowledge about healthy behaviours)
Limited communication skills and level of understanding	Individual invitation letters to screening requires the ability to read and understand the information		People with id	See communication barrier
Difficulties using an appointment system			People with ID	Do not always know how to use the Internet
Insufficient reminder system			HCP and system and supporters and people with ID	See organisational barriers
Reliance on caregivers	People with ID often rely on family caregivers to schedule, coordinate, and accompany them to the medical appointments	Women who live with family caregivers are much less likely to receive recommended screenings as compared with women who live independently or in residential care facilities	people with id	
Lack of awareness about the importance of oral health + Lack of training of the caregiver	Caregivers failing to see oral health as a health priority not to know how to support carrying out oral care routine		supporters	difficulty in using existing scales by non-healthcare workers
unawareness of disability-related dental problems		hamper the timely provision of dental care	HCP	

Table 45 – Cross-comparison of programmatic barriers retrieved from the literature scan and the qualitative data collection

Barriers	Examples	Consequences	Protagonists concerned by a change/solution	Similar findings in Belgium by the qualitative data collection
Inflexible appointment scheduling system		Insufficient time for good care delivery	System and HCP	not usual to provide longer and more frequent consultations
Absence of pathway adapted to people with ID		Not enough time to read the large medical files Discharge during night with no organisational anticipation adapted to the living situation	System and HCP and PEOPLE WITH ID and supporters	ethical questionability of a system of identification of people with behaviours viewed as challenging to enable them to avoid (or reduce) this waiting time
Lack of time for clinical activities		Nonunderstanding or coping with the complex situation of people with ID	System and HCP	even the most committed doctors do not have enough time for quality care
Scarcity of specialised services or professionals specialised in ID issues			System and HCP	
Lack of time for training activities		lack of knowledge and skills of HCP about ID	System	
physical access	Transport not available to healthcare services Not adapted orientation signage in doorways		System and transport companies	internal signage (as mentioned above) not adapted to people with ID
People with severe and profound intellectual disability have often physical impairments	related mobility problems (e.g., wheelchair) and not adapted dental office and equipment			
Unpreparedness for exams	Lack of familiarity of the person with an intellectual disability with the screening procedure		System and HCP and supporters	
GP as gatekeeper		GP and he/she can make comments and decide if the women with an intellectual disability should be invited for screening or not.	System	Specific to UK

		In the UK, not registered with a GP, not invited to a screening programme (women living in a residential setting which has a unit doctor, so there is no need for registration with a local GP)		
Presence of family caregivers not allowed during the exam		Participant is not calm	HCP	
Lack of time	Not enough support strategies such as prompting and reminding, reassurance and encouragement, watching and monitoring, persuasion, coaxing, rewards and distraction		supporters	
long waiting time to secure an appointment			System or HCP	Specific to UK
long waiting time in the waiting rooms of dental clinics			System or HCP	consultations organisation not adapted: frequent delays, crowded and noisy waiting rooms, long delays in receiving results
inconvenient opening hours of the dental office			System or HCP	
architectural obstacles	physical access to the dental office, parking facilities No environmental adaptations for a wheelchair user		System or HCP	
lengthy appointments and appointment schedules which do not fit with their family routines			Supporters	family and friends also struggle to cope with the many trips to the HC centre too long consultations or full days of several consultations: loss of effectiveness in understanding

Non-adapted equipment for daily oral care routine	preference for a specific type of toothbrush or toothpaste use of dental suction tool in people with dysphagia		HCP or system	
Lack of continuity of care	less than half of the dentists made an appointment for the next visit the timing of the subsequent visit was often not fixed			lack of coordination of care: absence of an in-hospital reference person

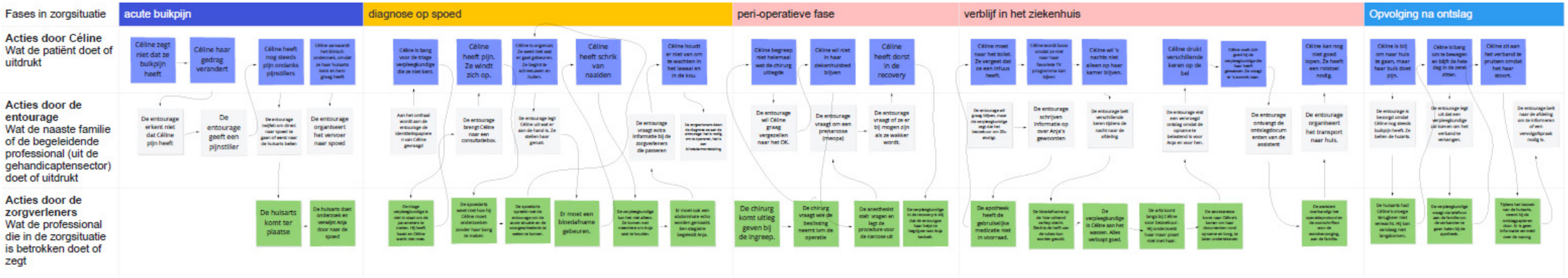
Table 46 – Cross-comparison of policy and social barriers retrieved from the literature scan and the qualitative data collection

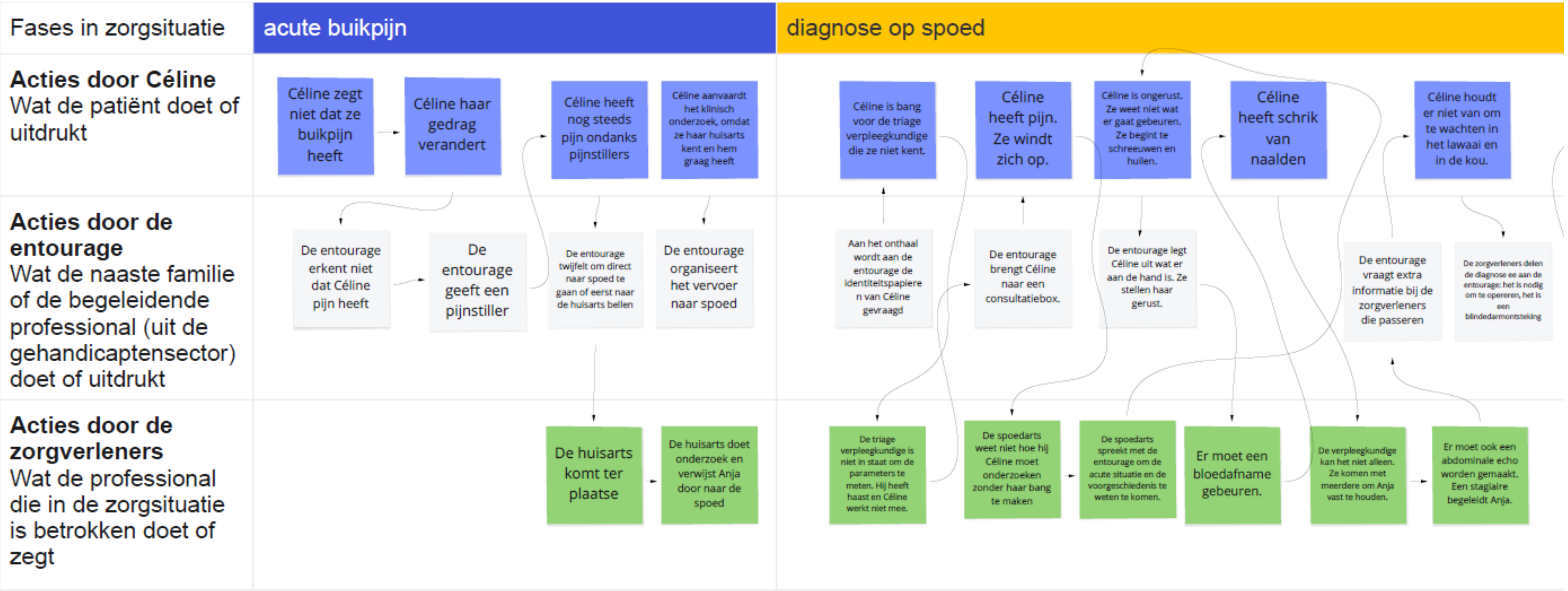
Barriers	Examples	Consequences	Protagonists concerned by a change/solution	Similar findings in Belgium by the qualitative data collection
Lack of laws and regulations requiring equitable access	absence of financing for extra-time required during medical appointment		System	
Lack of enforcement of existing laws or official documents	deny by organisations to set up reasonable accommodations		System	
Lack of financial resources	no money to afford the transport to come to the visit No access to non-reimbursed extra-time appointment for comprehensive healthcare		people with ID	problem of resources can also affect people with ID and their supporters Neither family carers nor professionals from institutions have the resources and support to provide 24/7 care for hospitalised people with intellectual disabilities lack of care staff and of specific means to finance them problem of financial resources that prevent hospitals from financing an in-hospital reference person *and initiatives in agreement with the RIZIV – INAMI*
Supporters could not easily take time-off	People with ID are often reliant to upon a third party both to recognise signs of ill health and to go to visit		Supporters	lack the time to organise and accompany people to preventive appointments

High costs / non reimburses benefits		restricted access to some speech therapy or psychological services mobile palliative care teams at home cannot always intervene in residential institutions

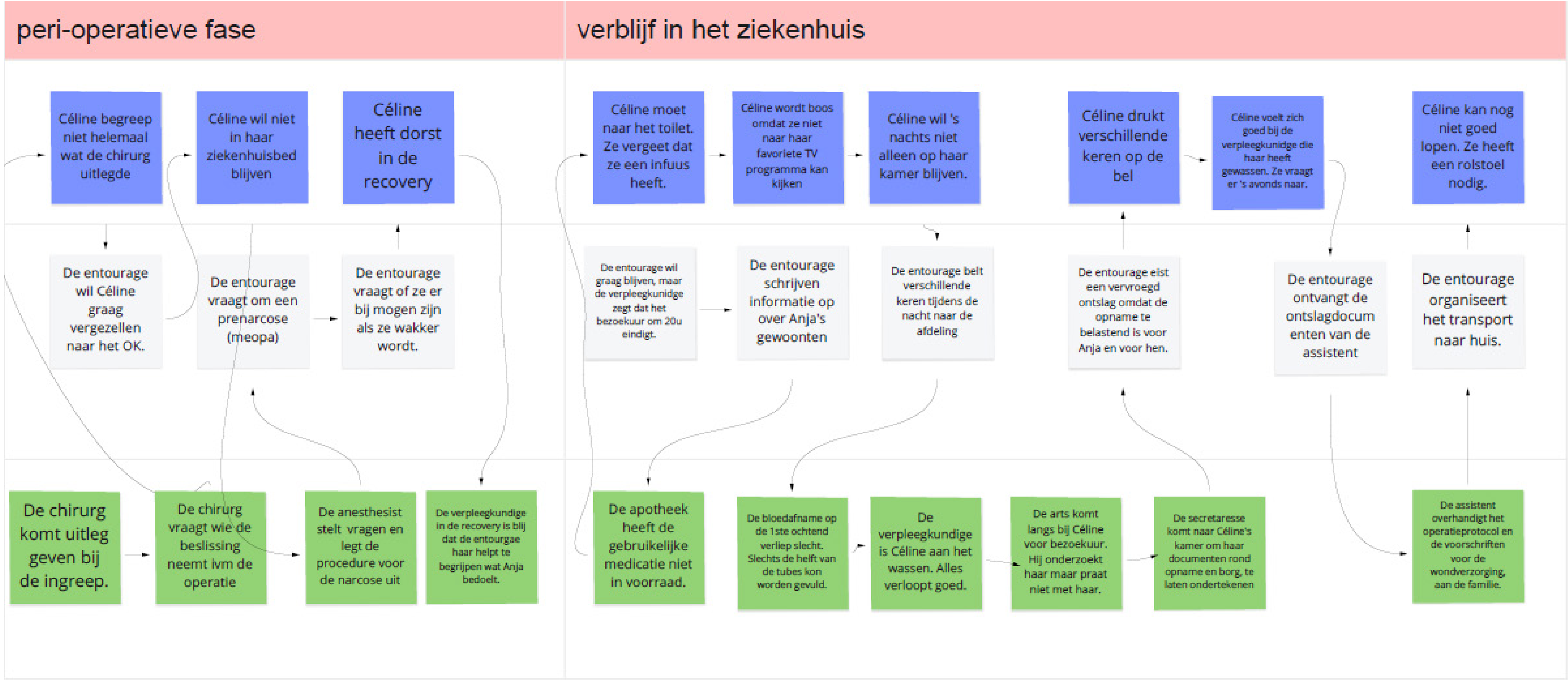
APPENDIX 4. PATIENT JOURNEYS USED IN NOMINAL GROUPS

Acute patient journey (Dutch version)





Fases in zorgsituatie	acute buikpijn	diagnose op spoed
Acties door Céline Wat de patiënt doet of uitdrukt	Céline zegt niet dat ze buikpijn heeft Céline haar gedrag verandert Céline heeft nog steeds pijn ondanks pijnstillers Céline aanvaardt het klinisch onderzoek, omdat ze haar huisarts kent en hem graag heeft	Céline is bang voor de triage verpleegkundige die ze niet kent. Céline heeft pijn. Ze windt zich op. Céline is ongerust. Ze weet niet wat er gaat gebeuren. Ze begint te schreeuwen en huilen. Céline heeft schrik van naalden Céline houdt er niet van om te wachten in het lawaai en in de kou.
Acties door de entourage Wat de naaste familie of de begeleidende professional (uit de gehandicaptensector) doet of uitdrukt	De entourage erkent niet dat Céline pijn heeft De entourage geeft een pijnstiller De entourage twijfelt om direct naar spoed te gaan of eerst naar de huisarts bellen De entourage organiseert het vervoer naar spoed	Aan het onthaal wordt aan de entourage de identiteitspapieren van Céline gevraagd De entourage brengt Céline naar een consultatiebox. De entourage legt Céline uit wat er aan de hand is. Ze stellen haar gerust. De entourage vraagt extra informatie bij de zorgverleners die passeren De zorgverleners delen de diagnose ee aan de entourage: het is nodig om te opereren, het is een blindedarmontsteking
Acties door de zorgverleners Wat de professional die in de zorgsituatie is betrokken doet of zegt	De huisarts komt ter plaatse De huisarts doet onderzoek en verwijst Anja door naar de spoed	De triage verpleegkundige is niet in staat om de parameters te meten. Hij heeft haast en Céline werkt niet mee. De spoedarts weet niet hoe hij Céline moet onderzoeken zonder haar bang te maken De spoedarts spreekt met de entourage om de acute situatie en de voorgeschiedenis te weten te komen. Er moet een bloedafname gebeuren. De verpleegkundige kan het niet alleen. Ze komen met meerdere om Anja vast te houden. Er moet ook een abdominale echo worden gemaakt. Een stagiaire begeleidt Anja.



peri-operatieve fase

Céline begreep niet helemaal wat de chirurg uitlegde

Céline wil niet in haar ziekenhuisbed blijven

Céline heeft dorst in de recovery

De entourage wil Céline graag vergezellen naar het OK.

De entourage vraagt om een prenarcose (meopa)

De entourage vraagt of ze er bij mogen zijn als ze wakker wordt.

De chirurg komt uitleg geven bij de ingreep.

De chirurg vraagt wie de beslissing neemt ivm de operatie

De anesthesist stelt vragen en legt de procedure voor de narcose uit

De verpleegkundige in de recovery is blij dat de entourgae haar helpt te begrijpen wat Anja bedoelt.

verblijf in het ziekenhuis

Céline moet naar het toilet. Ze vergeet dat ze een infuus heeft.

Céline wordt boos omdat ze niet naar haar favoriete TV programma kan kijken

Céline wil 's nachts niet alleen op haar kamer blijven.

Céline drukt verschillende keren op de bel

Céline voelt zich goed bij de verpleegkunidge die haar heeft gewassen. Ze vraagt er 's avonds naar.

Céline kan nog niet goed lopen. Ze heeft een rolstoel nodig.

De entourage wil graag blijven, maar de verpleegkunidge zegt dat het bezoekuur om 20u eindigt.

De entourage schrijven informatie op over Anja's gewoonten

De entourage belt verschillende keren tijdens de nacht naar de afdeling

De entourage eist een vervroegd ontslag omdat de opname te belastend is voor Anja en voor hen.

De entourage ontvangt de ontslagdocumenten van de assistent

De entourage organiseert het transport naar huis.

De apotheek heeft de gebruikelijke medicatie niet in voorraad.

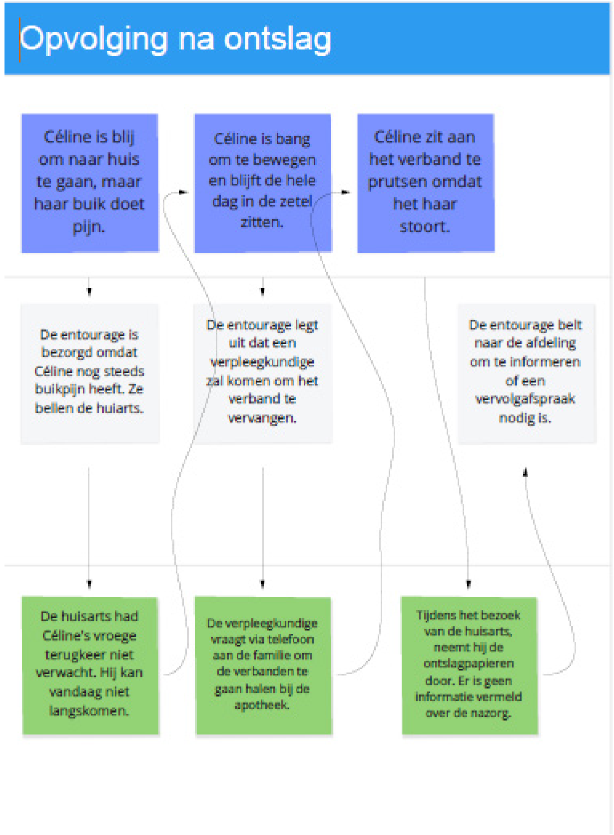
De bloedafname op de 1ste ochtend verliep slecht. Slechts de helft van de tubes kon worden gevuld.

De verpleegkundige is Céline aan het wassen. Alles verloopt goed.

De arts komt langs bij Céline voor bezoekuur. Hij onderzoekt haar maar praat niet met haar.

De secretaresse komt naar Céline's kamer om haar documenten rond opname en borg, te laten ondertekenen

De assistent overhandigt het operatieprotocol en de voorschriften voor de wondverzorging, aan de familie.



Opvolging na ontslag

Céline is blij om naar huis te gaan, maar haar buik doet pijn.

Céline is bang om te bewegen en blijft de hele dag in de zetel zitten.

Céline zit aan het verband te prutsen omdat het haar stoort.

De entourage is bezorgd omdat Céline nog steeds buikpijn heeft. Ze bellen de huiarts.

De entourage legt uit dat een verpleegkundige zal komen om het verband te vervangen.

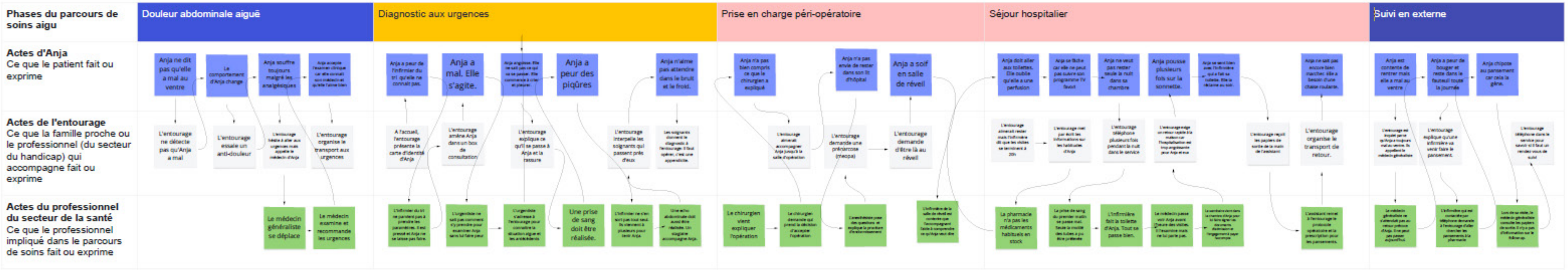
De entourage belt naar de afdeling om te informeren of een vervolgafspraak nodig is.

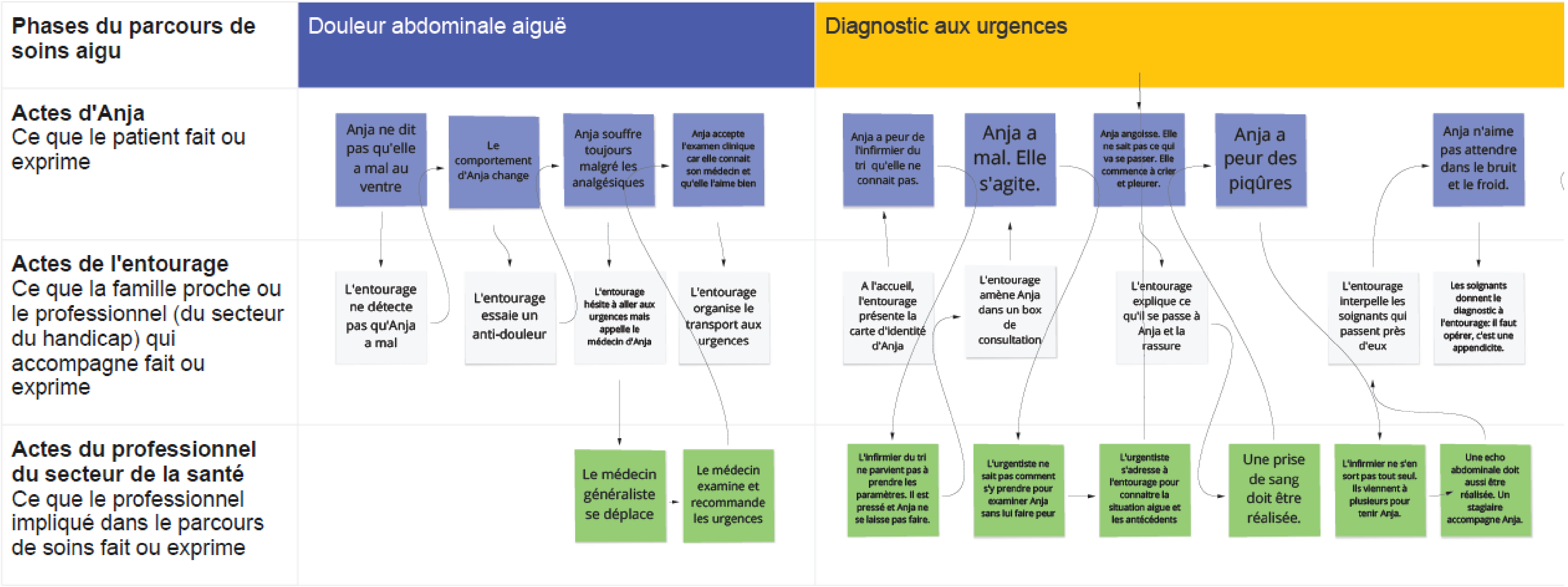
De huisarts had Céline's vroege terugkeer niet verwacht. Hij kan vandaag niet langskomen.

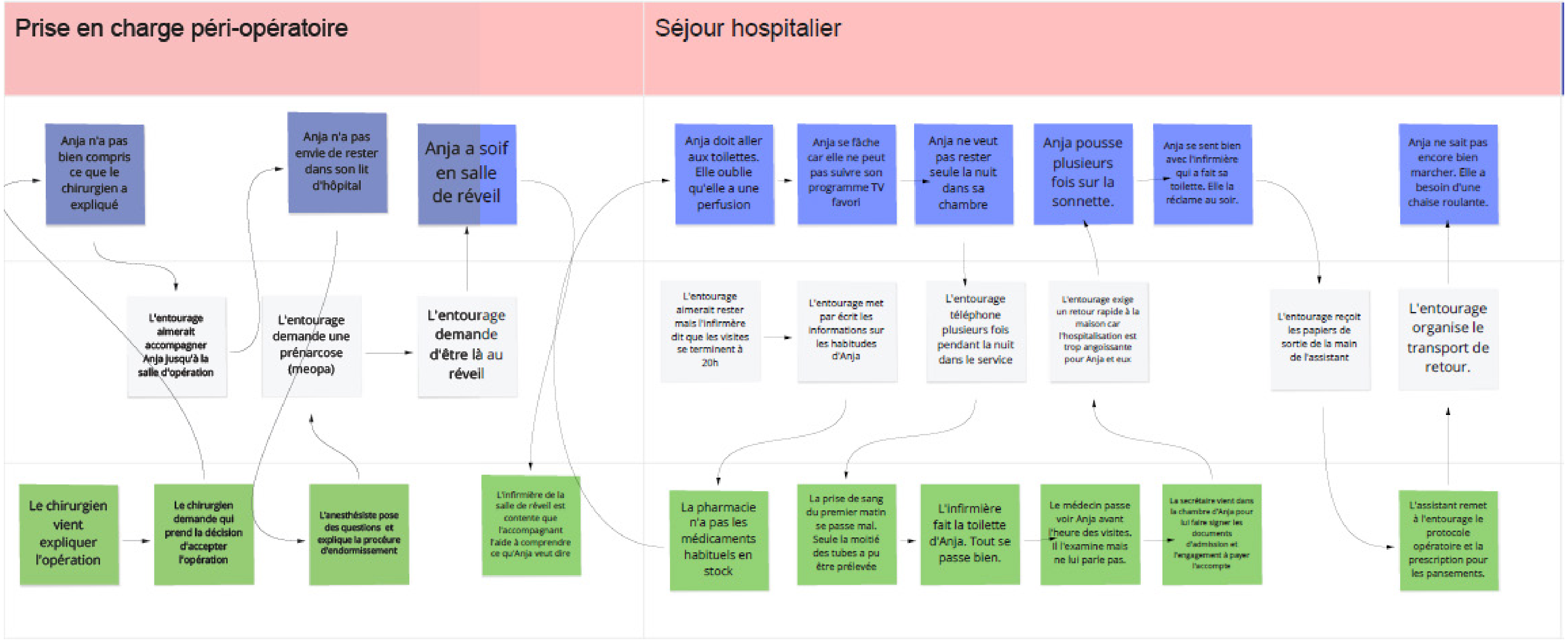
De verpleegkundige vraagt via telefoon aan de familie om de verbanden te gaan halen bij de apotheek.

Tijdens het bezoek van de huisarts, neemt hij de ontslagpapieren door. Er is geen informatie vermeld over de nazorg.

Acute patient journey (French version)







Prise en charge péri-opératoire

Anja n'a pas bien compris ce que le chirurgien a expliqué

Anja n'a pas envie de rester dans son lit d'hôpital

Anja a soif en salle de réveil

L'entourage aimerait accompagner Anja jusqu'à la salle d'opération

L'entourage demande une prénarcose (meopa)

L'entourage demande d'être là au réveil

Le chirurgien vient expliquer l'opération

Le chirurgien demande qui prend la décision d'accepter l'opération

L'anesthésiste pose des questions et explique la procédure d'endormissement

L'infirmière de la salle de réveil est contente que l'accompagnant l'aide à comprendre ce qu'Anja veut dire

Séjour hospitalier

Anja doit aller aux toilettes. Elle oublie qu'elle a une perfusion

Anja se fâche car elle ne peut pas suivre son programme TV favori

Anja ne veut pas rester seule la nuit dans sa chambre

Anja pousse plusieurs fois sur la sonnette.

Anja se sent bien avec l'infirmière qui a fait sa toilette. Elle la réclame au soir.

Anja ne sait pas encore bien marcher. Elle a besoin d'une chaise roulante.

L'entourage aimerait rester mais l'infirmère dit que les visites se terminent à 20h

L'entourage met par écrit les informations sur les habitudes d'Anja

L'entourage téléphone plusieurs fois pendant la nuit dans le service

L'entourage exige un retour rapide à la maison car l'hospitalisation est trop angoissante pour Anja et eux

L'entourage reçoit les papiers de sortie de la main de l'assistant

L'entourage organise le transport de retour.

La pharmacie n'a pas les médicaments habituels en stock

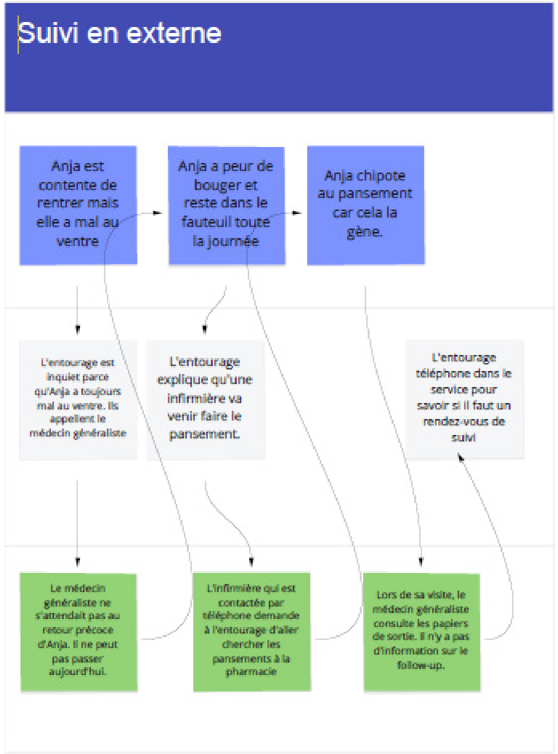
La prise de sang du premier matin se passe mal. Seule la moitié des tubes a pu être prélevée

L'infirmière fait la toilette d'Anja. Tout se passe bien.

Le médecin passe voir Anja avant l'heure des visites. Il l'examine mais ne lui parle pas.

La secrétaire vient dans la chambre d'Anja pour lui faire signer les documents d'admission et l'engagement à payer l'accompte

L'assistant remet à l'entourage le protocole opératoire et la prescription pour les pansements.



Suivi en externe

Anja est contente de rentrer mais elle a mal au ventre

Anja a peur de bouger et reste dans le fauteuil toute la journée

Anja chipote au pansement car cela la gène.

L'entourage est inquiet parce qu'Anja a toujours mal au ventre. Ils appellent le médecin généraliste

L'entourage explique qu'une infirmière va venir faire le pansement.

L'entourage téléphone dans le service pour savoir si il faut un rendez-vous de suivi

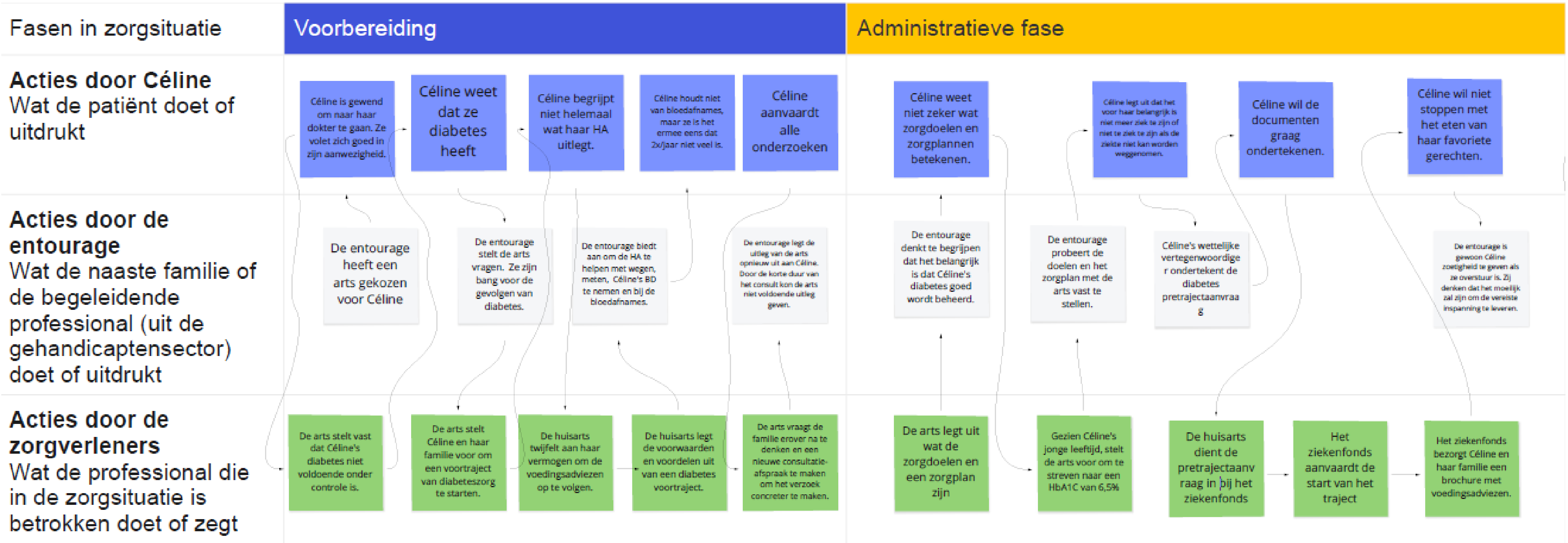
Le médecin généraliste ne s'attendait pas au retour précoce d'Anja. Il ne peut pas passer aujourd'hui.

L'infirmière qui est contactée par téléphone demande à l'entourage d'aller chercher les pansements à la pharmacie

Lors de sa visite, le médecin généraliste consulte les papiers de sortie. Il n'y a pas d'information sur le follow-up.

Chronic patient journey (Dutch version)

Fasen in zorgsituatie	Voorbereiding	Administratieve fase	Aanpak	Opvolging
Acties door Céline Wat de patiënt doet of uitdrukt	Céline is gewend om naar haar dokter te gaan. Ze voelt zich goed in zijn aanwezigheid. Céline weet dat ze diabetes heeft Céline begrijpt niet helemaal wat haar HA uitlegt. Céline houdt niet van bloedafnames, maar ze is het ermee eens dat 2x/jaar niet veel is. Céline aanvaardt alle onderzoeken	Céline weet niet zeker wat zorgdoelen en zorgplannen betekenen. Céline legt uit dat het voor haar belangrijk is niet meer ziek te zijn of niet te ziek te zijn als de ziekte niet kan worden weggenomen. Céline wil de documenten graag ondertekenen. Céline wil niet stoppen met het eten van haar favoriete gerechten.	Céline vindt het niet leuk om twee andere zorgverleners te zien die ze niet kent. Céline verkiest over haar diabetes te praten met haar entourage.	Céline wil echt niet haar voedingspatroon veranderen. Céline verkiest haar TV boven te gaan wandelen.
Acties door de entourage Wat de naaste familie of de begeleidende professional (uit de gehandicaptensector) doet of uitdrukt	De entourage heeft een arts gekozen voor Céline De entourage stelt de arts vragen. Ze zijn bang voor de gevolgen van diabetes. De entourage biedt aan om de HA te helpen met wegen, meten, Céline's BD te nemen en bij de bloedafnames. De entourage legt de uitleg van de arts opnieuw uit aan Céline. Door de korte duur van het consult kon de arts niet voldoende uitleg geven.	De entourage denkt te begrijpen dat het belangrijk is dat Céline's diabetes goed wordt beheerd. De entourage probeert de doelen en het zorgplan met de arts vast te stellen. Céline's wettelijke vertegenwoordiger ondertekent de diabetes pretrajectaanvraag De entourage is gewoon Céline zoetigheid te geven als ze overstuur is. Zij denken dat het moeilijk zal zijn om de vereiste inspanning te leveren.	geen besluitvorming De entourage vraagt de huisarts advies rond professionals die opgeleid zijn in begijpelijke taal De entourage zoekt professionals om voor Céline te zorgen	De entourage is blij dat Céline heeft toegestemd om naar het consult van de diëtiste te gaan. De entourage vraagt zich af of het de moeite waard is om 100km te rijden om de diabetes educator te zien.
Acties door de zorgverleners Wat de professional die in de zorgsituatie is betrokken doet of zegt	De arts stelt vast dat Céline's diabetes niet voldoende onder controle is. De arts stelt Céline en haar familie voor om een voortraject van diabeteszorg te starten. De huisarts twijfelt aan haar vermogen om de voedingsadviezen op te volgen. De huisarts legt de voorwaarden en voordelen uit van een diabetes voortraject. De arts vraagt de familie erover na te denken en een nieuwe consultatie-afspraak te maken om het verzoek concreter te maken.	De arts legt uit wat de zorgdoelen en een zorgplan zijn Gezien Céline's jonge leeftijd, stelt de arts voor om te streven naar een HbA1C van 6,5% De huisarts dient de pretrajectaanvraag in bij het ziekenfonds Het ziekenfonds aanvaardt de start van het traject Het ziekenfonds bezorgt Céline en haar familie een brochure met voedingsadviezen.	De huisarts schrijft educatie en voedingsadvies voor. De huisarts wist niet dat het moeilijk was om een diabetes educator te vinden.	De diëtiste voelt zich ongemakkelijk. Ze kan Céline niet uitleggen hoe belangrijk het is om te bewegen. het begrijpen en ontcijferen van informatie



Fasen in zorgsituatie	Voorbereiding	Administratieve fase
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Acties door de entourage Wat de naaste familie of de begeleidende professional (uit de gehandicaptensector) doet of uitdrukt	De entourage heeft een arts gekozen voor Céline De entourage stelt de arts vragen. Ze zijn bang voor de gevolgen van diabetes. De entourage biedt aan om de HA te helpen met wegen, meten, Céline's BD te nemen en bij de bloedafnames. De entourage legt de uitleg van de arts opnieuw uit aan Céline. Door de korte duur van het consult kon de arts niet voldoende uitleg geven.	De entourage denkt te begrijpen dat het belangrijk is dat Céline's diabetes goed wordt beheerd. De entourage probeert de doelen en het zorgplan met de arts vast te stellen. Céline's wettelijke vertegenwoordiger ondertekent de diabetes pretrajectaanvraag De entourage is gewoon Céline zoetigheid te geven als ze overstuur is. Zij denken dat het moeilijk zal zijn om de vereiste inspanning te leveren.
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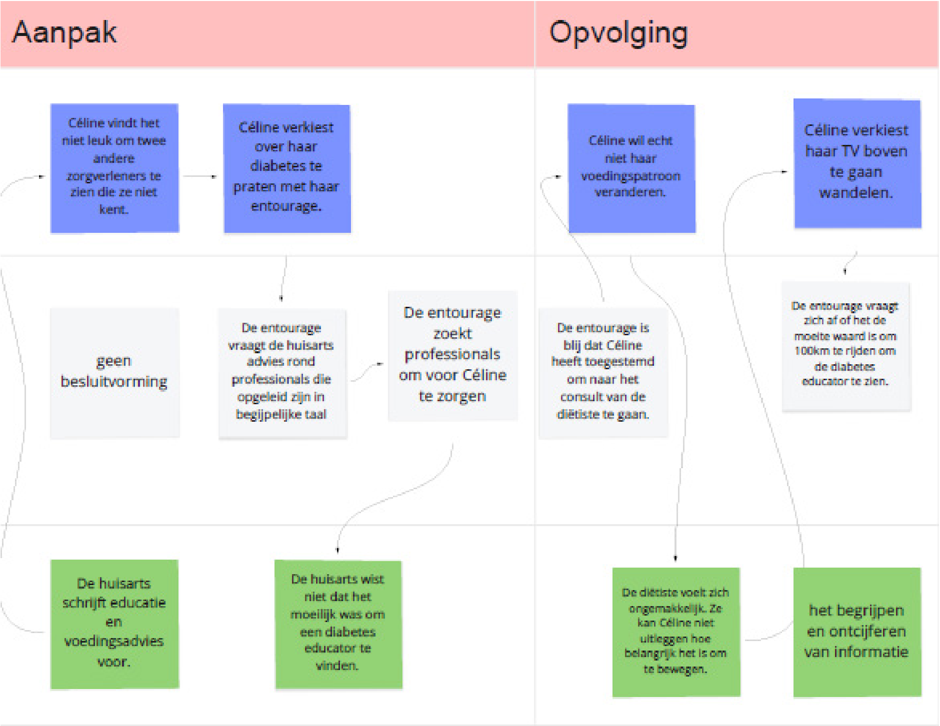


Aanpak

Céline vindt het niet leuk om twee andere zorgverleners te zien die ze niet kent.

Céline verkiest over haar diabetes te praten met haar entourage.

geen besluitvorming

De entourage vraagt de huisarts advies rond professionals die opgeleid zijn in begijpelijke taal

De entourage zoekt professionals om voor Céline te zorgen

De huisarts schrijft educatie en voedingsadvies voor.

De huisarts wist niet dat het moeilijk was om een diabetes educator te vinden.

Opvolging

Céline wil echt niet haar voedingspatroon veranderen.

Céline verkiest haar TV boven te gaan wandelen.

De entourage is blij dat Céline heeft toegestemd om naar het consult van de diëtiste te gaan.

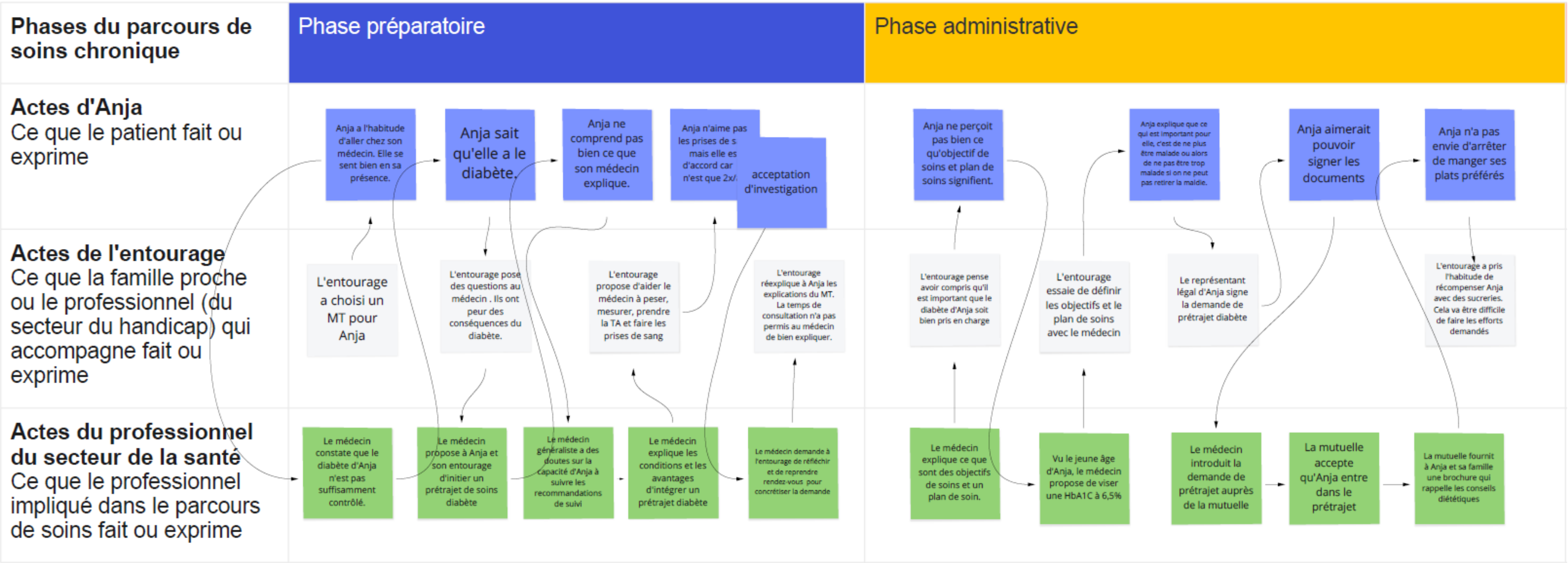
De entourage vraagt zich af of het de moeite waard is om 100km te rijden om de diabetes educator te zien.

De diëtiste voelt zich ongemakkelijk. Ze kan Céline niet uitleggen hoe belangrijk het is om te bewegen.

het begrijpen en ontcijferen van informatie

Chronic patient journey (French version)

Phases du parcours de soins chronique	Phase préparatoire	Phase administrative	Phase de mise en place	Phase de suivi
Actes d'Anja Ce que le patient fait ou exprime	Anja a l'habitude d'aller chez son médecin. Elle se sent bien en sa présence. Anja sait qu'elle a le diabète. Anja ne comprend pas bien ce que son médecin explique. Anja n'aime pas les prises de s mais elle es d'accord car n'est que 2x/ acceptation d'investigation	Anja ne perçoit pas bien ce qu'objectif de soins et plan de soins signifient. Anja explique que ce qui est important pour elle, c'est de ne plus être malade ou alors de ne pas être trop malade si on ne peut pas retirer la maladie. Anja aimerait pouvoir signer les documents Anja n'a pas envie d'arrêter de manger ses plats préférés	Anja n'aime pas trop l'idée de voir deux autres soignants qu'elle ne connait pas. Anja préfèrerait discuter du diabète avec son entourage	Anja n'a vraiment pas envie de changer de régime alimentaire Anja aime beaucoup mieux la télé que les promenades
Actes de l'entourage Ce que la famille proche ou le professionnel (du secteur du handicap) qui accompagne fait ou exprime	L'entourage a choisi un MT pour Anja L'entourage pose des questions au médecin . Ils ont peur des conséquences du diabète. L'entourage propose d'aider le médecin à peser, mesurer, prendre la TA et faire les prises de sang L'entourage réexplique à Anja les explications du MT. La temps de consultation n'a pas permis au médecin de bien expliquer.	L'entourage pense avoir compris qu'il est important que le diabète d'Anja soit bien pris en charge L'entourage essaie de définir les objectifs et le plan de soins avec le médecin Le représentant légal d'Anja signe la demande de prétrajet diabète L'entourage a pris l'habitude de récompenser Anja avec des sucreries. Cela va être difficile de faire les efforts demandés	L'entourage demande au médecin de conseiller des professionnels formé au langage FALC. L'entourage cherche des professionnels prêts à prendre en charge Anja	L'entourage est content qu'Anja ait accepté de venir à la consultation de la diététicienne. L'entourage se demande si faire 100 km pour aller chez l'éducateur du diabète en vaut la peine.
Actes du professionnel du secteur de la santé Ce que le professionnel impliqué dans le parcours de soins fait ou exprime	Le médecin constate que le diabète d'Anja n'est pas suffisamment contrôlé. Le médecin propose à Anja et son entourage d'initier un prétrajet de soins diabète Le médecin généraliste a des doutes sur la capacité d'Anja à suivre les recommandations de suivi Le médecin explique les conditions et les avantages d'intégrer un prétrajet diabète Le médecin demande à l'entourage de réfléchir et de reprendre rendez-vous pour concrétiser la demande	Le médecin explique ce que sont des objectifs de soins et un plan de soin. Vu le jeune âge d'Anja, le médecin propose de viser une HbA1C à 6,5% Le médecin introduit la demande de prétrajet auprès de la mutuelle La mutuelle accepte qu'Anja entre dans le prétrajet La mutuelle fournit à Anja et sa famille une brochure qui rappelle les conseils diététiques	Le médecin prescrit l'éducation thérapeutique, et le suivi diététique Le médecin ne savait pas que c'était difficile à trouver un éducateur diabète.	La diététicienne est mal à l'aise. Elle ne parvient pas à bien expliquer à Anja l'importance de faire du sport. compréhension et décryptage des informations



Phases du parcours de soins chronique

Phase préparatoire

Phase administrative

Actes d'Anja
Ce que le patient fait ou exprime

Anja a l'habitude d'aller chez son médecin. Elle se sent bien en sa présence.

Anja sait qu'elle a le diabète.

Anja ne comprend pas bien ce que son médecin explique.

Anja n'aime pas les prises de s mais elle es d'accord car n'est que 2x/

acceptation d'investigation

Anja ne perçoit pas bien ce qu'objectif de soins et plan de soins signifient.

Anja explique que ce qui est important pour elle, c'est de ne plus être malade ou alors de ne pas être trop malade si on ne peut pas retirer la maldie.

Anja aimerait pouvoir signer les documents

Anja n'a pas envie d'arrêter de manger ses plats préférés

Actes de l'entourage
Ce que la famille proche ou le professionnel (du secteur du handicap) qui accompagne fait ou exprime

L'entourage a choisi un MT pour Anja

L'entourage pose des questions au médecin . Ils ont peur des conséquences du diabète.

L'entourage propose d'aider le médecin à peser, mesurer, prendre la TA et faire les prises de sang

L'entourage réexplique à Anja les explications du MT. La temps de consultation n'a pas permis au médecin de bien expliquer.

L'entourage pense avoir compris qu'il est important que le diabète d'Anja soit bien pris en charge

L'entourage essaie de définir les objectifs et le plan de soins avec le médecin

Le représentant légal d'Anja signe la demande de prétrajet diabète

L'entourage a pris l'habitude de récompenser Anja avec des sucreries. Cela va être difficile de faire les efforts demandés

Actes du professionnel du secteur de la santé
Ce que le professionnel impliqué dans le parcours de soins fait ou exprime

Le médecin constate que le diabète d'Anja n'est pas suffisamment contrôlé.

Le médecin propose à Anja et son entourage d'initier un prétrajet de soins diabète

Le médecin généraliste a des doutes sur la capacité d'Anja à suivre les recommandations de suivi

Le médecin explique les conditions et les avantages d'intégrer un prétrajet diabète

Le médecin demande à l'entourage de réfléchir et de reprendre rendez-vous pour concrétiser la demande

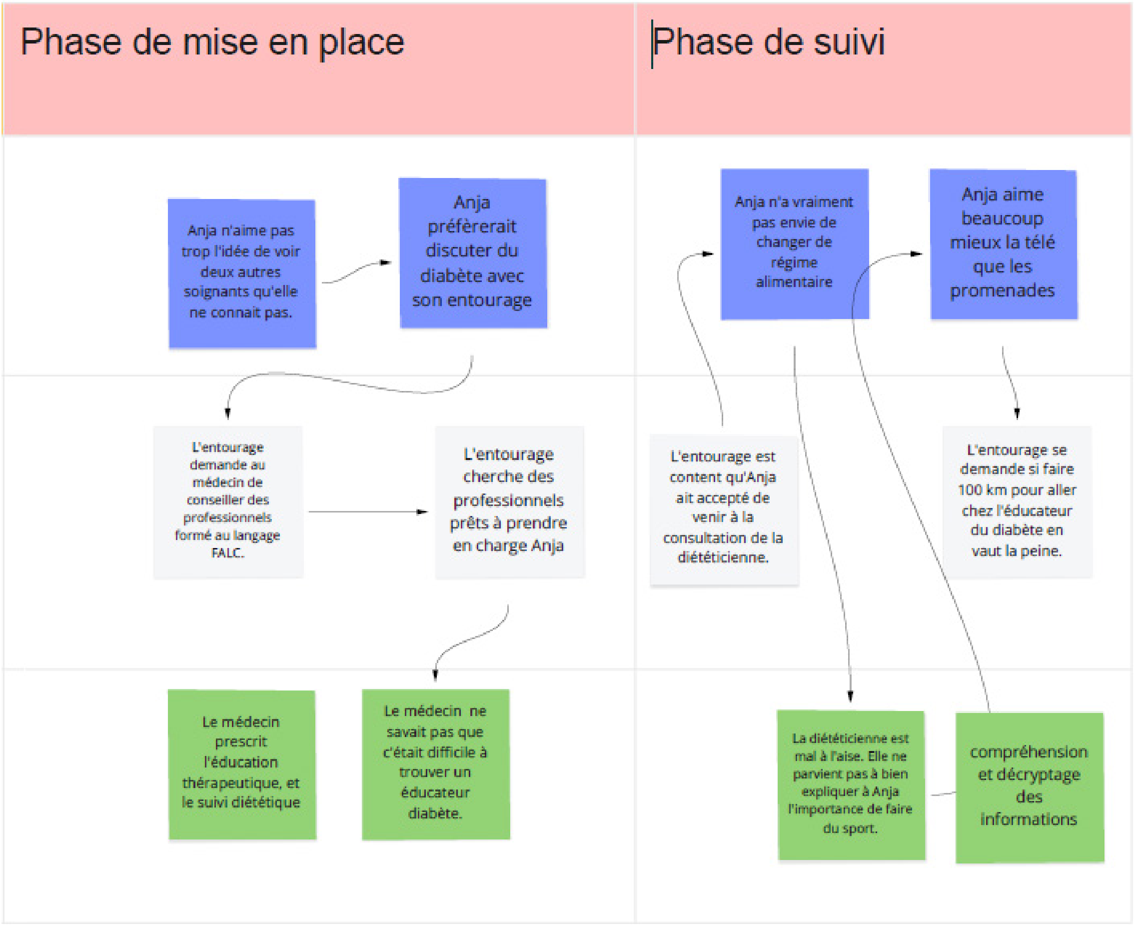
Le médecin explique ce que sont des objectifs de soins et un plan de soin.

Vu le jeune âge d'Anja, le médecin propose de viser une HbA1C à 6,5%

Le médecin introduit la demande de prétrajet auprès de la mutuelle

La mutuelle accepte qu'Anja entre dans le prétrajet

La mutuelle fournit à Anja et sa famille une brochure qui rappelle les conseils diététiques



Phase de mise en place

Anja n'aime pas trop l'idée de voir deux autres soignants qu'elle ne connait pas.

Anja préfèrerait discuter du diabète avec son entourage

L'entourage demande au médecin de conseiller des professionnels formé au langage FALC.

L'entourage cherche des professionnels prêts à prendre en charge Anja

Le médecin prescrit l'éducation thérapeutique, et le suivi diététique

Le médecin ne savait pas que c'était difficile à trouver un éducateur diabète.

Phase de suivi

Anja n'a vraiment pas envie de changer de régime alimentaire

Anja aime beaucoup mieux la télé que les promenades

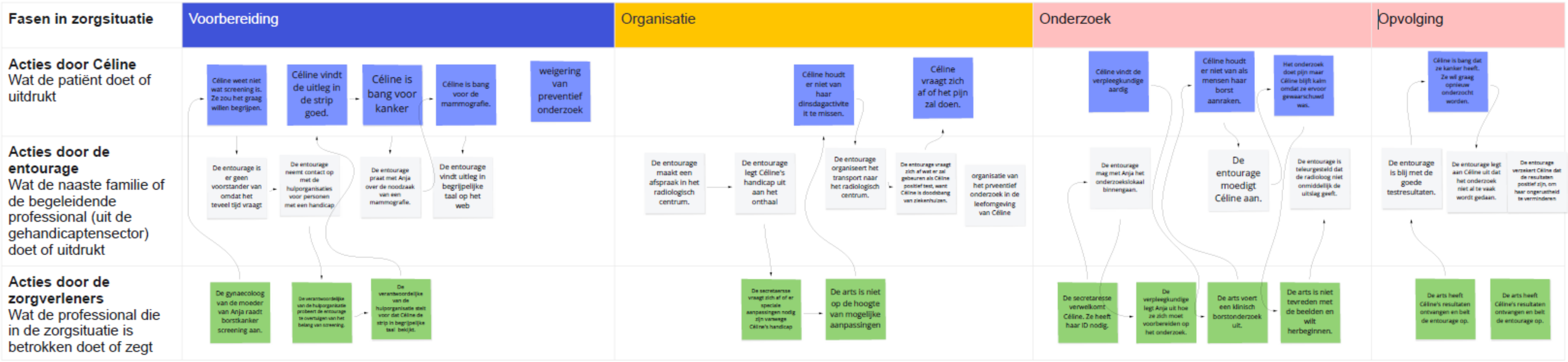
L'entourage est content qu'Anja ait accepté de venir à la consultation de la diététicienne.

L'entourage se demande si faire 100 km pour aller chez l'éducateur du diabète en vaut la peine.

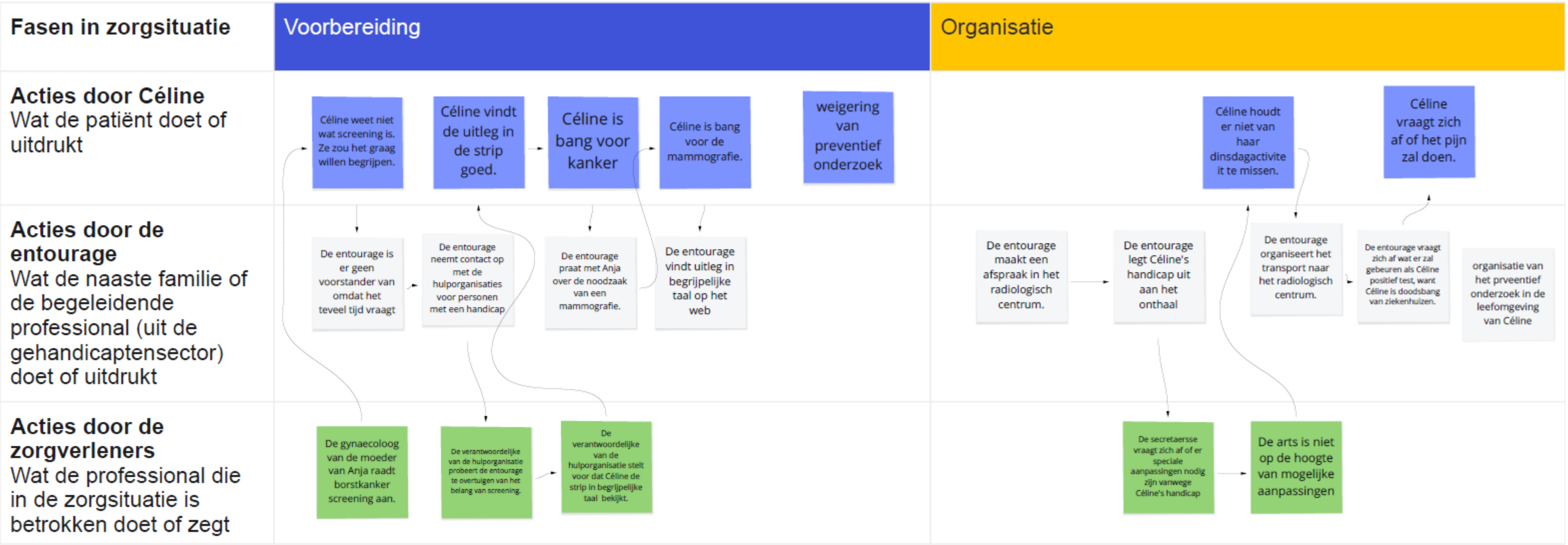
La diététicienne est mal à l'aise. Elle ne parvient pas à bien expliquer à Anja l'importance de faire du sport.

compréhension et décryptage des informations

Preventive patient journey (Dutch version)



Fasen in zorgsituatie	Voorbereiding	Organisatie	Onderzoek	Opvolging
Acties door Céline Wat de patiënt doet of uitdrukt	Céline weet niet wat screening is. Ze zou het graag willen begrijpen. Céline vindt de uitleg in de strip goed. Céline is bang voor kanker Céline is bang voor de mammografie. weigering van preventief onderzoek	Céline houdt er niet van haar dinsdagactiviteit te missen. Céline vraagt zich af of het pijn zal doen.	Céline vindt de verpleegkundige aardig Céline houdt er niet van als mensen haar borst aanraken. Het onderzoek doet pijn maar Céline blijft kalm omdat ze ervoor gewaarschuwd was.	Céline is bang dat ze kanker heeft. Ze wil graag opnieuw onderzocht worden.
Acties door de entourage Wat de naaste familie of de begeleidende professional (uit de gehandicaptensector) doet of uitdrukt	De entourage is er geen voorstander van omdat het teveel tijd vraagt De entourage neemt contact op met de hulporganisaties voor personen met een handicap De entourage praat met Anja over de noodzaak van een mammografie. De entourage vindt uitleg in begrijpelijke taal op het web	De entourage maakt een afspraak in het radiologisch centrum. De entourage legt Céline's handicap uit aan het onthaal De entourage organiseert het transport naar het radiologisch centrum. De entourage vraagt zich af wat er zal gebeuren als Céline positief test, want Céline is doodsbang van ziekenhuizen. organisatie van het prveentief onderzoek in de leefomgeving van Céline	De entourage mag met Anja het onderzoekslokaal binnengaan. De entourage moedigt Céline aan. De entourage is teleurgesteld dat de radioloog niet onmiddellijk de uitslag geeft.	De entourage is blij met de goede testresultaten. De entourage legt aan Céline uit dat het onderzoek niet al te vaak wordt gedaan. De entourage verzekert Céline dat de resultaten positief zijn, om haar ongerustheid te verminderen
Acties door de zorgverleners Wat de professional die in de zorgsituatie is betrokken doet of zegt	De gynaecoloog van de moeder van Anja raadt borstkanker screening aan. De verantwoordelijke van de hulporganisatie probeert de entourage te overtuigen van het belang van screening. De verantwoordelijke van de hulporganisatie stelt voor dat Céline de strip in begrijpelijke taal bekijkt.	De secretaresse vraagt zich af of er speciale aanpassingen nodig zijn vanwege Céline's handicap De arts is niet op de hoogte van mogelijke aanpassingen	De secretaresse verwelkomt Céline. Ze heeft haar ID nodig. De verpleegkundige legt Anja uit hoe ze zich moet voorbereiden op het onderzoek. De arts voert een klinisch borstonderzoek uit. De arts is niet tevreden met de beelden en wilt herbeginnen.	De arts heeft Céline's resultaten ontvangen en belt de entourage op. De arts heeft Céline's resultaten ontvangen en belt de entourage op.



Fasen in zorgsituatie	Voorbereiding	Organisatie
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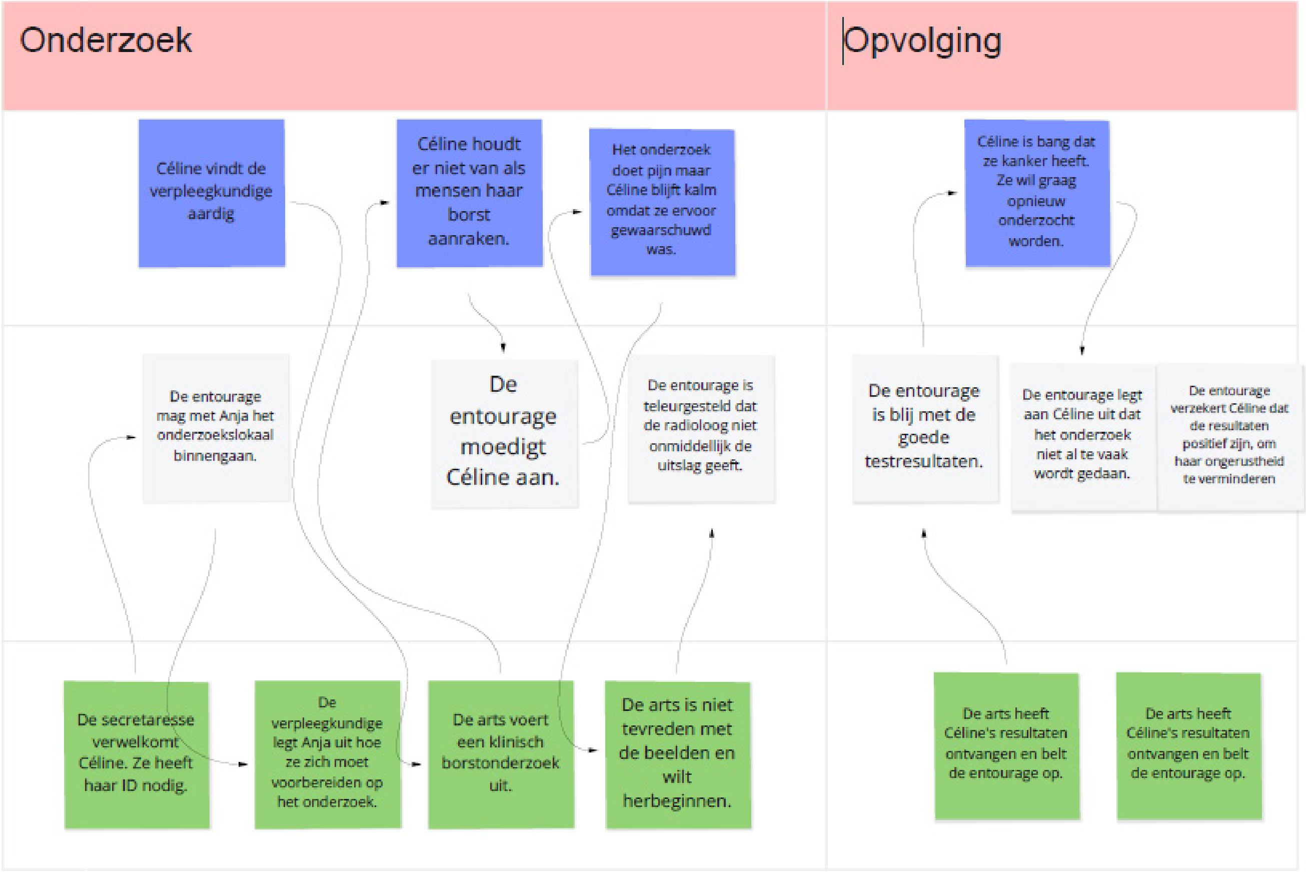
Acties door de zorgverleners Wat de professional die in de zorgsituatie is betrokken doet of zegt	De gynaecoloog van de moeder van Anja raadt borstkanker screening aan. De verantwoordelijke van de hulporganisatie probeert de entourage te overtuigen van het belang van screening. De verantwoordelijke van de hulporganisatie stelt voor dat Céline de strip in begrijpelijke taal bekijkt.	De secretaersse vraagt zich af of er speciale aanpassingen nodig zijn vanwege Céline's handicap De arts is niet op de hoogte van mogelijke aanpassingen



Onderzoek

Céline vindt de verpleegkundige aardig

Céline houdt er niet van als mensen haar borst aanraken.

Het onderzoek doet pijn maar Céline blijft kalm omdat ze ervoor gewaarschuwd was.

De entourage mag met Anja het onderzoekslokaal binnengaan.

De entourage moedigt Céline aan.

De entourage is teleurgesteld dat de radioloog niet onmiddellijk de uitslag geeft.

De secretaresse verwelkomt Céline. Ze heeft haar ID nodig.

De verpleegkundige legt Anja uit hoe ze zich moet voorbereiden op het onderzoek.

De arts voert een klinisch borstonderzoek uit.

De arts is niet tevreden met de beelden en wilt herbeginnen.

Opvolging

Céline is bang dat ze kanker heeft. Ze wil graag opnieuw onderzocht worden.

De entourage is blij met de goede testresultaten.

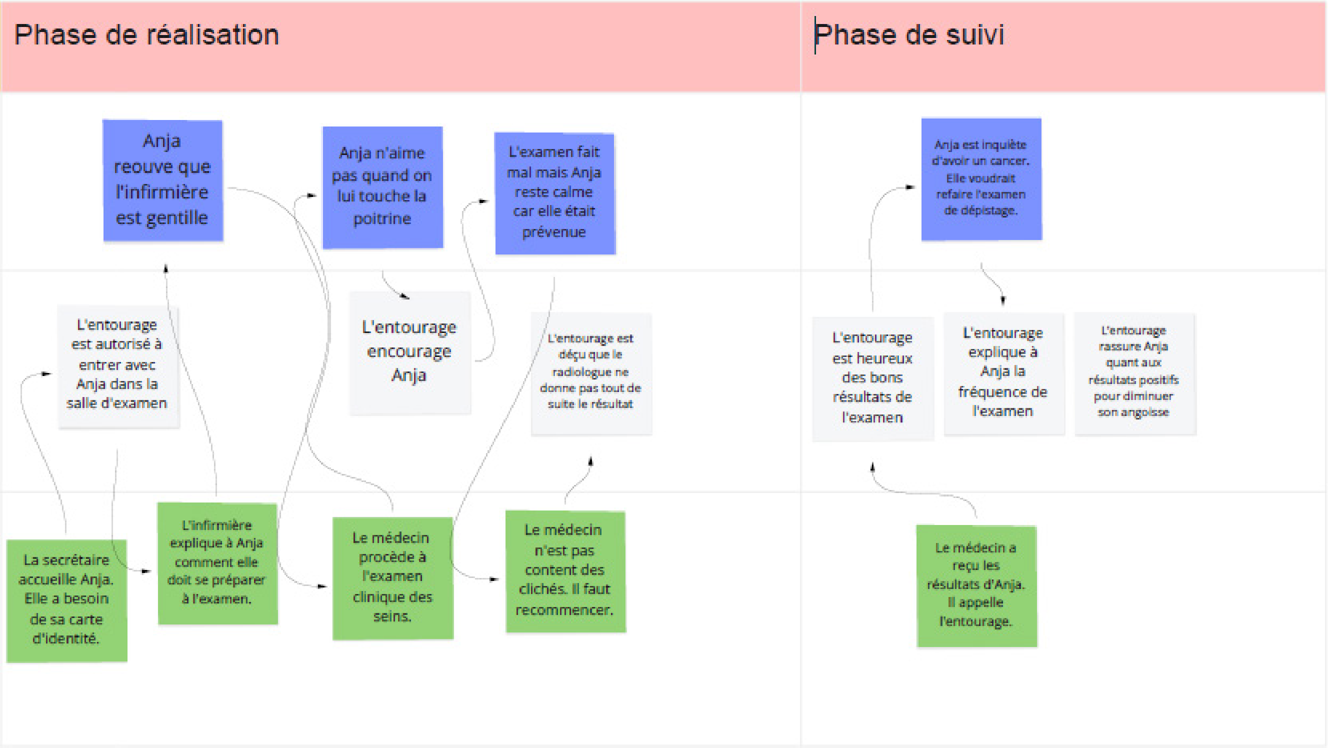
De entourage legt aan Céline uit dat het onderzoek niet al te vaak wordt gedaan.

De entourage verzekert Céline dat de resultaten positief zijn, om haar ongerustheid te verminderen

De arts heeft Céline's resultaten ontvangen en belt de entourage op.

De arts heeft Céline's resultaten ontvangen en belt de entourage op.

Preventive patient journey (French version)



Phase de réalisation

Anja reouve que l'infirmière est gentille

Anja n'aime pas quand on lui touche la poitrine

L'examen fait mal mais Anja reste calme car elle était prévenue

L'entourage est autorisé à entrer avec Anja dans la salle d'examen

L'entourage encourage Anja

L'entourage est déçu que le radiologue ne donne pas tout de suite le résultat

La secrétaire accueille Anja. Elle a besoin de sa carte d'identité.

L'infirmière explique à Anja comment elle doit se préparer à l'examen.

Le médecin procède à l'examen clinique des seins.

Le médecin n'est pas content des clichés. Il faut recommencer.

Phase de suivi

Anja est inquiète d'avoir un cancer. Elle voudrait refaire l'examen de dépistage.

L'entourage est heureux des bons résultats de l'examen

L'entourage explique à Anja la fréquence de l'examen

L'entourage rassure Anja quant aux résultats positifs pour diminuer son angoisse

Le médecin a reçu les résultats d'Anja. Il appelle l'entourage.

APPENDIX 5. INTERVIEW GUIDES IN EASY READ FORMAT

Instructions	Guide d'entretien – French version	Dutch version
General information on the interview guide	Ce guide d'entretien est rédigé en grande partie en langage facile à lire et à comprendre (FALC) étant donné qu'il s'adresse principalement à des personnes en situation de handicap intellectuel. Il est divisé en quatre parties. La première partie est la phase d'introduction. La seconde partie sert à briser la glace. La troisième et la quatrième contiennent les questions ciblées sur les barrières et les facilitateurs, d'une part adressée à la personne en situation de handicap, d'autre part adressée à l'accompagnant. Seul un des trois parcours de soins (aigu, chronique, préventif) sera aborder lors d'un entretien. La troisième partie est toujours structurée de la même façon : - Une phrase de contexte suivie d'une question de mise en contexte pour raviver les souvenirs - Une question sur les barrières - Une question sur les facilitateurs - Une question sur les solutions - Une question facultative sur le ressenti sera posée occasionnellement pour raviver l'attention à l'aide d'émoticônes. La quatrième partie est succincte mais concerne également les barrières, facilitateurs et solutions. Les phrases en retrait sont des phrases de relance.	Deze interviewgids is grotendeels geschreven in gemakkelijk te lezen en te begrijpen taal (FALC), aangezien hij vooral gericht is op mensen met verstandelijke handicap. Het is verdeeld in vier delen. Het eerste deel is de inleidende fase. Het tweede deel is de ijsbreker. Het derde en vierde deel bevatten de gerichte vragen over belemmeringen en faciliterende factoren, enerzijds gericht aan de persoon met een handicap, anderzijds aan de begeleider. Slechts één van de drie zorgpaden (acuut, chronisch, preventief) naar keuze zal in het interview aan bod komen. Het derde deel is altijd op dezelfde manier opgebouwd: - Een contextzin gevolgd door een contextualiserende vraag om herinneringen op te halen - Een vraag over barrières - Een vraag over facilitators - Een vraag over oplossingen - Een optionele gevoelsvraag zal af en toe worden gesteld om de aandacht weer op te wekken met behulp van emoticons. Het vierde deel is kort, maar gaat ook in op belemmeringen, faciliterende factoren en oplossingen. De ingesprongen zinnen zijn stimulanszinnen.
Presentation/ consent	**Présentation – mise en confiance — confirmation orale d'enregistrement**	**Presentatie - vertrouwen wekken - mondelinge bevestiging van inschrijving**
Introduction by the researcher	Bonjour. Bienvenue. Je m'appelle Céline Ricour. Je suis chercheur pour le KCE. Au KCE, les chercheurs aident les ministres à décider comment bien soigner les gens en Belgique.	Hallo. Welkom. Mijn naam is Anja Desomer. Ik ben een onderzoeker voor de KCE. Bij het KCE helpen onderzoekers ministers te beslissen hoe ze voor mensen in België moeten zorgen.
Question to participant	*Aujourd'hui, est-ce qu'on utilise le TU ou le VOUS quand on se parle ?* *Est-ce que vous voulez-vous présenter ?*	Wil je jezelf voorstellen?
Explanation by the researcher	Aujourd'hui, on cherche comment améliorer la santé des personnes qui ont des difficultés pour comprendre. Parce que les hôpitaux et les médecins ne savent pas toujours comment bien s'occuper des personnes	Vandaag gaan we kijken hoe we de gezondheid kunnen verbeteren van mensen die moeite hebben met begrijpen. Ben je het daarmee eens? Waarom doen we dit? Omdat ziekenhuizen en dokters niet altijd

	qui ont des difficultés pour comprendre. Aujourd'hui, vous aussi, vous pouvez aider les hôpitaux et les médecins. Pour aider, vous pouvez m'expliquer les consultations chez votre médecin ou à l'hôpital. D'autres personnes vont (ou m'ont) aussi m'expliquer(é) leurs visites chez le médecin ou à l'hôpital. Toutes ces explications permettront d'aider à mieux soigner les personnes qui ont des difficultés à comprendre. Merci beaucoup d'avoir accepté de me parler aujourd'hui. Vous vous rappelez ? On avait dit qu'on allait enregistrer ce qu'on va se dire aujourd'hui. Mais ce que vous direz restera entre nous. Il n'y a que moi qui écouterai l'enregistrement. Si vous êtes fatigué, vous pouvez me faire signe.	weten hoe om te gaan met mensen die moeite hebben met begrijpen. Jouw rol vandaag is om ziekenhuizen en dokters te helpen om beter te weten. Om te helpen, kan je mij de consulten bij je dokter of in het ziekenhuis uitleggen. Andere mensen zullen (of hebben) mij ook uitleg geven over hun bezoek aan de dokter of het ziekenhuis. Al deze verklaringen zullen helpen om betere zorg te verlenen aan mensen die moeite hebben met begrijpen. Hartelijk dank dat je vandaag met mij wilde praten. Weet je nog? We zeiden dat we zouden opnemen wat we vandaag gaan zeggen. Maar wat je zegt blijft tussen ons. Alleen ik zal naar de opname luisteren. Nog steeds oké? Als je moe bent, kun je me een teken geven.
Question to participant	Quel signe voulez-vous me faire pour me dire que vous êtes fatigué pendant la discussion ?	Welk teken wil je me geven om te zeggen dat je moe bent tijdens het gesprek?
Instruction to participant	Après avoir discuté avec vous, je discuterai avec [nom de la personne accompagnante]. C'est important de ne pas parler quand ce n'est pas son tour.	Nadat ik met jou gesproken heb, zal ik met [begeleider] praten. Het is belangrijk niet te praten als je niet aan de beurt bent.
Ice breaker	**Briser la glace**	**Het ijs breken**
Icebreaker **(Material: pictograms with émotions)**	Faisons d'abord un jeu. Voici un petit bonhomme. (Montrer le picto de la joie). A votre avis, que ressent ce petit bonhomme ? (Montrer le picto de la tristesse) Et ce bonhomme-ci, que ressent-il ?	Laten we eerst een spelletje spelen. Hier is het gezicht van een kleine man. (Toon de foto van vreugde) Hoe denk je dat deze kleine man zich voelt? En deze kleine man, wat voelt hij? (Toon de foto van droefheid)
Instructions to researcher	Pistes pour aider à reconnaitre les émotions représentées par chaque picto. La joie : le bonhomme est content. Il a un grand sourire. C'est celui qu'on choisit quand on est heureux. La tristesse : le bonhomme est triste. Il pleure. La colère : le bonhomme est fâché. Il a de la fumée qui sort de son nez. C'est celui qu'on choisit quand on est énervé. La peur : le bonhomme a peur. Il est inquiet. Il ne sait pas bien ce qui va se passer. Le dégout : le bonhomme est dégouté. Il tire la langue parce que c'est berk/ dégueulasse. L'étonnement : le bonhomme est surpris. Il ne s'attendait pas à ce qui se passe.	*Tips om de emoties te helpen herkennen die door elk pictogram worden vertegenwoordigd.* **Vreugde:** de man is gelukkig. Hij heeft een grote glimlach. Het is degene die we kiezen als we gelukkig zijn. **Verdriet:** de man is verdrietig. Hij huilt. **Boosheid:** de man is boos. Er komt rook uit zijn neus. Hij is degene die je kiest als je boos bent. **Angst:** de man is bang. Hij is bezorgd. Hij weet niet wat er gaat gebeuren. **Afschuw:** de man walgt. Hij steekt zijn tong uit omdat het vies is. **Verbazing:** de man is verrast. Hij had niet verwacht dat dit zou gebeuren.
Transition topic 1	Merci beaucoup pour vos réponses. Maintenant, on va parler des consultations chez le médecin ou à l'hôpital.	Hartelijk dank voor je antwoorden. Nu gaan we het hebben over bezoeken aan de dokter of het ziekenhuis.

Acute situation	Situation aigue	Acute situatie
Introduction	Au téléphone, vous m’avez expliqué/on m’a expliqué que vous aviez déjà été à l’hôpital/ chez le médecin en urgence. Vous aviez mal [compléter selon la situation vécue] / vous étiez tombé [compléter selon la situation vécue] / parce que [compléter selon la situation vécue]. Repensez à ce jour-là.	Aan de telefoon heb je me uitgelegd dat je al in een noodgeval naar het ziekenhuis/de dokter was geweest. Je had pijn [lichaam deel]/ je was gevallen [situatie]/ omdat [situatie]. Denk terug aan die dag.
Symptoms **Phase symptomatologique** **Symptomen**	• Vous étiez à [compléter selon la situation vécue] avec [compléter selon la situation vécue]. Pouvez-vous me dire ce qui était le plus difficile ? o Qu’est-ce qui s’est mal passé ? o De quoi aviez-vous besoin ? ▪ *Qu’avez-vous ressenti à ce moment-là ?* ▪ *Quel picto représente ce que vous avez ressenti ?* • Maintenant, pouvez-vous me dire ce qui s’est bien passé lors de [compléter selon la situation vécue] ? o Qu’est-ce qui vous a fait plaisir ? o Qu’est-ce qui vous a soulagé ? • Imaginez que vous pouvez changer ce qui s’est mal passé o Que feriez-vous ? o Qu’aimeriez-vous changer ?	• Je was in [plaats] met [naam persoon]. Kun je me vertellen wat het moeilijkste was? o Wat ging er mis? o Wat had je nodig? ▪ Wat voelde je op dat moment? ▪ Welk pictogram geeft weer wat je voelde? • Kunt u mij nu vertellen wat er goed ging tijdens [event]? o Wat maakte je gelukkig? o Waardoor voelde je je beter? • Stel je voor dat je kon veranderen wat verkeerd ging o Wat zou jij doen? o Wat zou je willen veranderen?
Transportation in acute phase **Phase de transport en urgence** **Vervoer naar het ziekenhuis/de dokter**	• Ensuite, [compléter selon la situation vécue] vous a amené chez le docteur/ à l’hôpital. Vous souvenez-vous comment [compléter selon la situation vécue] vous a amené chez le docteur/ à l’hôpital ? • Pouvez-vous me dire ce qui était le plus difficile pendant ce trajet ? o Qu’est-ce qui s’est mal passé ? o De quoi aviez-vous besoin ? ▪ Qu’avez-vous ressenti à ce moment-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Maintenant, pouvez-vous me dire ce qui s’est bien passé lors de ce trajet ? o Qu’est-ce qui vous a fait plaisir ? o Qu’est-ce qui vous a soulagé ? • Imaginez que vous pouvez changer ce qui s’est mal passé o Que feriez-vous ? o Qu’aimeriez-vous changer ?	• Toen bracht [begeleider] je naar de dokter/het ziekenhuis. Herinner je je nog hoe [begeleider] je naar de dokter/het ziekenhuis bracht? • Kun je me vertellen wat het moeilijkste deel van de reis was? o Wat ging er mis? o Wat had je nodig? ▪ Hoe voelde je je op dat moment? ▪ Welk pictogram geeft weer hoe je je voelde? • Nu, kan je me vertellen wat er goed ging op deze reis? o Wat maakte je gelukkig? o Waardoor voelde je je beter? • Stel je voor dat je kon veranderen wat verkeerd ging o Wat zou jij doen? o Wat zou je willen veranderen?
Diagnosis	• Ensuite, vous êtes arrivé chez le docteur/ à l’hôpital. Vous souvenez-vous des tests que vous avez passés ? o Avez-vous eu une prise de sang ?	• Toen kwam je bij de dokter/het ziekenhuis aan. Weet je nog welke testen je hebt gehad? o Heb je een bloedtest gehad?

Phase de mise au point diagnostique **Diagnose**	o Vous a-t-on fait une radio ? • Pouvez-vous me dire ce qui était le plus difficile chez le docteur/à l'hôpital ? o Qu'est-ce qui s'est mal passé ? o De quoi aviez-vous besoin ? ▪ Qu'avez-vous ressenti à ce moment-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Maintenant, pouvez-vous me dire ce qui s'est bien passé chez le docteur/à l'hôpital ? • Qu'est-ce qui vous a fait plaisir ? • Qu'est-ce qui vous a soulagé ? • Imaginez que vous pouvez changer ce qui s'est mal passé o Que feriez-vous ? o Qu'aimeriez-vous changer ?	o Kreeg je een röntgenfoto? • Kun je me vertellen wat het moeilijkste was bij de dokter/in het ziekenhuis? o Wat ging er mis? o Wat had je nodig? ▪ Hoe voelde je je op dat moment? ▪ Welk pictogram geeft weer hoe je je voelde? • Nu, kan je me vertellen wat er goed ging bij de dokter/het ziekenhuis? o Wat maakte je gelukkig? o Waardoor voelde je je beter? • Stel je voor dat je kon veranderen wat verkeerd ging o Wat zou jij doen? o Wat zou je willen veranderen?
Treatment / **Phase de prise en charge thérapeutique** **Behandeling**	• Ensuite, les docteurs et/ou les infirmières vous ont soigné. Vous souvenez-vous ce qu'ils ont fait pour vous soigner ? o Ont-ils fait des pansements ? o Des bandages ? o Des piqûres ? • Pouvez-vous me dire ce qui était le plus difficile quand on vous a soigné ? o Qu'est-ce qui s'est mal passé ? o De quoi aviez-vous besoin ? ▪ Qu'avez-vous ressenti à ce moment-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Maintenant, pouvez-vous me dire ce qui s'est bien passé quand on vous a soigné? o Qu'est-ce qui vous a fait plaisir ? o Qu'est-ce qui vous a soulagé ? • Imaginez que vous pouvez changer ce qui s'est mal passé o Que feriez-vous ? o Qu'aimeriez-vous changer ?	• Toen behandelden de dokters en/of verpleegkundigen je. Weet je nog wat ze deden om je te behandelen? o Hebben ze je verbonden? o Verband? o Injecties? • Kun je me vertellen wat het moeilijkste was aan behandeld worden? o Wat ging er mis? o Wat had je nodig? ▪ Hoe voelde je je op dat moment? ▪ Welk pictogram geeft weer hoe je je voelde? • Nu, kan je me vertellen wat er goed ging toen je behandeld werd? o Wat maakte je gelukkig? o Waardoor voelde je je beter? • Stel je voor dat je kon veranderen wat verkeerd ging o Wat zou jij doen? o Wat zou je willen veranderen?
Follow-up after discharge	• Après la visite chez le médecin/à l'hôpital, vous êtes rentré chez vous. Vous souvenez-vous où vous avez dormi à votre retour chez vous ? • Pouvez-vous me dire ce qui était le plus difficile quand vous êtes rentré chez vous ?	• Na het bezoek aan de dokter/ziekenhuis ging je naar huis. Weet je nog waar je sliep toen je thuiskwam? • Kun je me vertellen wat het moeilijkste was aan naar huis gaan? o Wat ging er mis?

Phase de suivi immédiat (hôpital ou domicile) **Follow-up (thuis of in ziekenhuis)**	o Qu’est-ce qui s’est mal passé ? o De quoi aviez-vous besoin ? • Qu’avez-vous ressenti à ce moment-là ? • Quel picto représente ce que vous avez ressenti ? • Maintenant, pouvez-vous me dire ce qui s’est bien passé quand vous êtes rentrés chez vous ? o Qu’est-ce qui vous a fait plaisir ? o Qu’est-ce qui vous a soulagé ? • Imaginez que vous pouvez changer ce qui s’est mal passé o Que feriez-vous ? o Qu’aimeriez-vous changer ?	o Wat had je nodig? ▪ Hoe voelde je je op dat moment? ▪ Welk pictogram geeft weer hoe je je voelde? • Nu, kan je me vertellen wat er goed ging toen je thuiskwam? o Wat maakte je gelukkig? o Waardoor voelde je je beter? • Stel je voor dat je kon veranderen wat verkeerd ging o Wat zou jij doen? o Wat zou je willen veranderen?
Chronic situation	**Situation chronique**	**Chronische situatie**
Introduction	Au téléphone, vous m’avez expliqué/on m’a expliqué que vous avez un problème de santé qu’on appelle [remplacer par ce qui s’applique]. C’est bien juste ? Pour soigner ce problème de [remplacer par ce qui s’applique], vous allez régulièrement chez le médecin [nom médecin]. On va parler des visites chez le médecin [nom médecin] pour ce problème de [remplacer par ce qui s’applique].	Aan de telefoon legde je me uit dat je een gezondheidsprobleem hebt, [naam gezondheidsprobleem] genaamd. Is dat juist? Om dit probleem van [naam gezondheidsprobleem] te behandelen, ga je regelmatig naar de dokter [naam]. We praten over bezoeken aan de dokter [naam] voor dit probleem van [naam gezondheidsprobleem].
Making an appointment **Phase de prise de rendez-vous et de préparation** **Afspraak maken**	• Pour aller chez le médecin [nom médecin], il faut prendre rendez-vous. • Qui prend rendez-vous ? • Pouvez-vous me dire ce qui est difficile quand on doit prendre rendez-vous chez le médecin [nom médecin] ? o Qu’est-ce qui peut mal se passer ? o Qu’est-ce qui empêche d’avoir rendez-vous ? ▪ Que ressentez-vous dans ces moments-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Pouvez-vous aussi me dire ce qui se passe bien quand on prend rendez-vous chez le médecin [nom médecin] ? o Qu’est-ce qui vous fait plaisir ? o Qu’est-ce qui vous arrange/convient ? • Imaginez que vous pouvez changer ce qui est difficile quand on prend rendez-vous o Qu’aimeriez-vous changer ? o Que faut-il changer ? o Comment ça pourrait mieux se passer ?	• Om naar de dokter [naam] te gaan, moet je een afspraak maken. Wie maakt de afspraak? • Kan je me vertellen wat er moeilijk is aan het maken van een afspraak bij dokter [naam]? o Wat ging er mis? o Wat hield de afspraak tegen? ▪ Wat voelde je op dat moment? ▪ Welk pictogram geeft weer wat je voelde? • Kan je mij nu vertellen wat er goed ging bij het maken van een afspraak bij dokter [naam]? o Wat maakte je gelukkig? o Waardoor voelde je je beter? • Stel je voor dat je kon veranderen wat verkeerd ging o Wat zou je willen veranderen? o Wat moet er veranderd worden? o Hoe kan het beter ?

Transportation **Phase het transport** **Vervoer naar het ziekenhuis/de dokter**	• Pour voir le médecin [nom du médecin], il faut aller jusque-là. Comment allez-vous jusque chez le médecin [nom du médecin] ? • Pouvez-vous me dire ce qui est difficile quand on doit aller jusque chez le médecin [nom du médecin] ? ○ Qu'est-ce qui peut mal se passer ? ○ Qu'est-ce qui empêche d'y aller facilement ? ▪ Qu'avez-vous ressenti à ce moment-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Pouvez-vous aussi me dire ce qui se passe bien quand on va jusque chez le médecin [nom du médecin] ? ○ Qu'est-ce qui fait plaisir pendant le trajet ? ○ Qu'est-ce qui se met bien ? ○ Qu'est-ce qui est facile ? • Imaginez que vous pouvez changer ce qui est difficile quand on va jusque chez le médecin ○ Comment ça pourrait mieux se passer ? ○ Que faut-il changer ? ○ Qu'aimeriez-vous changer ?	• Om dokter [naam] te zien, moet je erheen. Hoe kom je bij dokter [naam]? • Kun je me vertellen wat het moeilijkste deel van de reis was? ○ Wat ging er mis? ○ Wat houdt je tegen om daar zo gemakkelijk heen te gaan? ▪ Hoe voelde je je op dat moment? ▪ Welk pictogram geeft weer hoe je je voelde? • Nu, kan je me vertellen wat er goed ging op deze reis? ○ Wat maakte de reis leuk? ○ Wat gaat er goed? ○ Wat is makkelijk? • Stel je voor dat je kon veranderen wat verkeerd ging ○ Hoe kan het beter? ○ Wat moet er veranderen? ○ Wat zou je willen veranderen?
Waiting room **Phase dans la salle d'attente** **In de wachtzaal**	• Quand on va voir le médecin [nom], il faut attendre son tour dans la salle d'attente. Est-ce qu'il y a beaucoup de monde dans la salle d'attente du médecin [nom] ? • Pouvez-vous me dire ce qui est difficile quand on doit attendre dans la salle d'attente du médecin [nom] ? ○ Qu'est-ce qui est désagréable ? ○ Qu'est-ce qui empêche que l'attente se passe bien ? ▪ Qu'avez-vous ressenti à ce moment-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Pouvez-vous aussi me dire ce qui se passe bien quand on attend dans la salle d'attente du médecin [nom] ? ○ Qu'est-ce qui fait plaisir pendant cette attente ? ○ Qu'est-ce qui est chouette ? ○ Qu'est-ce qui est facile ? • Imaginez que vous pouvez changer ce qui est difficile quand on attend dans la salle d'attente du médecin [nom] ○ Comment ça pourrait mieux se passer ? ○ Que faut-il changer ? ○ Qu'aimeriez-vous changer ?	• Als je naar dokter [naam] gaat, moet je in de wachtzaal op je beurt wachten. Zitten er veel mensen in de wachtzaal van dokter [naam]? • Kunt u mij vertellen wat er moeilijk is aan wachten in de wachtkamer van de dokter [naam]? ○ Wat is er onaangenaam? ○ Wat houdt het wachten tegen? ○ Hoe voelde je je op dat moment? ○ Welk pictogram geeft weer hoe je je voelde? • Nu, kan je me vertellen wat er goed ging bij het wachten in de wachtzaal? • Wat voelt goed tijdens het wachten? ○ Wat is leuk? ○ Wat is makkelijk? ○ Waardoor voelde je je beter? • Stel je voor dat je kon veranderen wat verkeerd ging ○ Hoe kan het beter? ○ Wat zou jij doen? ○ Wat zou je willen veranderen?

Consultation - explanation **Phase de consultation – on explique** **Op consultatie- uitleg**	• Quand on va voir le médecin [nom], il pose des questions et on y répond. Est-ce que le médecin [nom] vous pose beaucoup de questions ? • Pouvez-vous me dire ce qui est difficile quand le médecin [nom] pose des questions ? ○ Qu'est-ce qui est désagréable ? ○ Qu'est-ce qui empêche de pouvoir bien répondre aux questions du médecin [nom] ? ▪ Qu'avez-vous ressenti à ce moment-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Pouvez-vous aussi me dire ce qui se passe bien quand le médecin [nom] pose des questions ? ○ Qu'est-ce qui se passe bien ? ○ Qu'est-ce qui est chouette ? ○ Qu'est-ce qui est facile ? • Imaginez que vous pouvez changer ce qui est difficile quand le médecin [nom] pose des questions et qu'on y répond ○ Comment ça pourrait mieux se passer ? ○ Que faut-il changer ? ○ Qu'aimeriez-vous changer ?	• Als je naar dokter [naam] gaat, stelt hij vragen en jij beantwoordt ze. Stelt dokter [naam] je veel vragen? • Kun je me vertellen wat er moeilijk was als dokter [naam] je vragen stelde? ○ Wat is er onaangenaam? ○ Wat belet jou om de vragen van dokter [naam] te kunnen beantwoorden? ▪ Hoe voelde je je op dat moment? ▪ Welk pictogram geeft weer hoe je je voelde? • Nu, kan je me vertellen wat er goed ging als de dokter vragen stelde? ○ Wat gaat er goed? ○ Wat is leuk? ○ Wat is makkelijk? • Stel je voor dat je kon veranderen wat verkeerd ging ○ Hoe kan het beter? ○ Wat moet er veranderen? ○ Wat zou je willen veranderen?
Consultation – clinical examination **Phase de consultation – on examine** **Op consultatie - onderzoek**	• Quand on va voir le médecin [nom], il nous examine. Il regarde notre corps, pose ses mains, écoute le cœur et prend des mesures. Est-ce que le médecin [nom] vous examine quand vous allez le voir ? • Pouvez-vous me dire ce qui est difficile quand le médecin [nom] vous examine ? ○ Qu'est-ce qui est désagréable ? ○ Qu'est-ce qui empêche que ça se passe bien ? ▪ Qu'avez-vous ressenti à ce moment-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Pouvez-vous aussi me dire ce qui se passe bien quand le médecin [nom] vous examine ? • Qu'est-ce qui est chouette ? ○ Qu'est-ce qui est facile ? • Imaginez que vous pouvez changer ce qui est difficile quand le médecin [nom] vous examine ○ Comment ça pourrait mieux se passer ? ○ Que faut-il changer ? ○ Qu'aimeriez-vous changer ?	• Als we naar dokter [naam] gaan, onderzoekt hij ons. Hij bekijkt ons lichaam, legt er zijn handen op, luistert naar het hart en neemt de maat. Onderzoekt dokter [naam] je als je naar hem toe gaat? • Kan je me vertellen wat er moeilijk was als de dokter je onderzocht? ○ Wat is er onaangenaam? ○ Wat verhindert dat het goed gaat? ▪ Hoe voelde je je op dat moment? ▪ Welk pictogram geeft weer hoe je je voelde? • Nu, kan je me vertellen wat er goed ging als de dokter je onderzocht? ○ Wat is leuk? ○ Wat is makkelijk? • Stel je voor dat je kon veranderen wat verkeerd ging ○ Hoe kan het beter? ○ Wat moet er veranderen? ○ Wat zou je willen veranderen?

Consultation – the doctor explains / Phase de consultation – le docteur explique / Op consultatie – de dokter geeft uitleg	• A la fin de la visite chez le médecin [nom], le docteur donne des explications sur le problème de santé. Il explique ce qui va bien, ce qui va moins bien et ce qu'on doit faire à la maison pour aller encore mieux. Est-ce que le médecin [nom] vous explique ce que vous devez faire à la maison pour aller encore mieux ? • Pouvez-vous me dire ce qui est difficile quand le médecin [nom] donne des explications ? ○ Qu'est-ce qui est désagréable ? ○ Qu'est-ce qui empêche que ça se passe bien ? ▪ Qu'avez-vous ressenti à ce moment-là ? ▪ Quel picot représente ce que vous avez ressenti ? • Pouvez-vous aussi me dire ce qui se passe bien quand le médecin [nom] donne des explications ? ○ Qu'est-ce qui est chouette ? ○ Qu'est-ce qui nous aide ? ○ Qu'est-ce qui est facile ? • Imaginez que vous pouvez changer ce qui est difficile quand le médecin [nom] donne des explications. ○ Comment le médecin pourrait mieux expliquer ? ○ Que devrait-il changer à ses explications ? ○ Qu'aimeriez-vous qu'il change à ses explications ?	• Aan het eind van het bezoek aan de dokter [naam], legt de dokter het gezondheidsprobleem [naam] uit. Hij legt uit wat er goed gaat, wat niet zo goed is en wat je thuis moet doen om beter te worden. Legt de dokter [naam] uit wat je thuis moet doen om beter te worden? • Kan je me vertellen wat er moeilijk was als de dokter je uitleg gaf? ○ Wat is er onaangenaam? ○ Wat verhindert dat het goed gaat? ▪ Hoe voelde je je op dat moment? ▪ Welk pictogram geeft weer hoe je je voelde? • Nu, kan je me vertellen wat er goed ging als de dokter uitleg gaf? ○ Wat is leuk? ○ Wat is makkelijk? ○ Wat helpt ons? • Stel je voor dat je kon veranderen wat verkeerd ging ○ Hoe kon de dokter het beter uitleggen? ○ Wat moet hij veranderen in zijn uitleg? ○ Wat zou je willen dat hij verandert in zijn uitleg?
Follow-up at home **Phase d'application des conseils à la maison** **Thuis opvolgen van doktersadvies**	• Après la visite chez le médecin [nom], on rentre à la maison. Quand on est à la maison, on doit se souvenir des conseils du médecin [nom]. Vous souvenez-vous des conseils que le médecin [nom] vous a donnés ? • Pouvez-vous me dire ce qui est difficile quand on doit suivre les conseils du médecin [nom] ? ○ Qu'est-ce qui est désagréable ? ○ Qu'est-ce qui empêche que ça se passe bien ? ▪ Qu'avez-vous ressenti à ce moment-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Pouvez-vous aussi me dire ce qui permet de bien suivre les conseils du médecin [nom] ? ○ Qu'est-ce qui nous aide ? ○ Qu'est-ce qui est facile ? ○ Qu'est-ce qui est chouette ? • Imaginez que vous pouvez changer ce qui rend difficile de suivre les conseils du médecin [nom].	• Na het bezoek aan dokter [naam], gaan we naar huis. Als je thuis bent, moet je het advies van dokter [naam] onthouden. Herinner je je het advies dat dokter [naam] je gaf? • Kan je me vertellen wat er moeilijk was om het advies op te volgen? ○ Wat is er onaangenaam? ○ Wat verhindert dat het goed gaat? ▪ Hoe voelde je je op dat moment? ▪ Welk pictogram geeft weer hoe je je voelde? • Nu, kan je me vertellen wat er goed ging bij het opvolgen van het advies? ○ Wat is leuk? ○ Wat is makkelijk? ○ Wat helpt ons? • Stel je voor dat je kon veranderen wat verkeerd ging ○ Wat zou je helpen om het advies beter op te volgen?

	o Qu’est-ce qui vous aiderait à mieux suivre les conseils ? o Qu’est-ce qui devrait changer dans les conseils pour pouvoir mieux les suivre ? o Qu’aimeriez-vous qu’on change aux conseils à suivre ?	o Wat zou er in het advies moeten veranderen om het beter te kunnen opvolgen? o Wat zou je graag veranderd zien in het op te volgen advies?
At the pharmacy **Phase d’obtention des médicaments et/ou matériels (pharmacie/ bandagiste)** **Bij de apotheek – kopen van geneesmiddelen/ materiaal**	• Lors de la visite chez le médecin [nom], on reçoit parfois un papier pour des médicaments. On doit ensuite aller chercher les médicaments choisis par le médecin [nom] à la pharmacie. Est-ce que le médecin [nom] vous a dit de prendre des médicaments ? • Pouvez-vous me dire ce qui est difficile quand on doit prendre des médicaments ? o Qu’est-ce qui est désagréable ? o Qu’est-ce qui empêche que ça se passe bien ? ▪ Qu’avez-vous ressenti à ce moment-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Pouvez-vous aussi me dire ce qui permet de bien prendre ses médicaments ? o Qu’est-ce qui nous aide ? o Qu’est-ce qui est facile ? o Qu’est-ce qui est chouette ? • Imaginez que vous pouvez changer ce qui rend difficile de prendre ses médicaments. o Qu’est-ce qui vous aiderait à mieux prendre vos médicaments ? o Qu’est-ce qui devrait changer à la pharmacie pour pouvoir mieux prendre ses médicaments ? o Qu’aimeriez-vous qu’on change aux médicaments que vous devez prendre ?	• Bij een bezoek aan de dokter [naam], krijgt men soms een papier voor medicijnen. Je moet dan naar de apotheek om de medicijnen op te halen die dokter [naam] heeft gekozen. Heeft dokter [naam] je gezegd medicijnen te nemen? • Kan je me vertellen wat er moeilijk was om medicijnen te nemen? o Wat is er onaangenaam? o Wat verhindert dat het goed gaat? ▪ Hoe voelde je je op dat moment? ▪ Welk pictogram geeft weer hoe je je voelde? • Nu, kan je me vertellen wat er goed ging bij het nemen van medicijnen? o Wat is leuk? o Wat is makkelijk? o Wat helpt ons? • Stel je voor dat je kon veranderen wat verkeerd ging • Wat zou je helpen om beter je medicijnen te nemen? • Wat moet er in de apotheek veranderen om het makkelijker te maken je medicijnen in te nemen? • Wat zou je graag veranderd zien aan de medicijnen die je moet nemen?
Prevention	**Prevention**	**Preventie**
Introduction	Au téléphone, vous m’avez expliqué/on m’a expliqué que vous aviez déjà eu [mentionner ce qui s’applique] *(un vaccin/ une visite chez le dentiste préventive/ un test COVID préventif/ un dépistage d’un cancer/ une prise de sang de ‘dépistage’/ une visite pour voir si tout va bien (check-up))*. • Vous souvenez-vous de cet examen préventif *(examen préventif sera remplacé par l’acte dont il est question dans toute la section préventive)* ? • Savez-vous pourquoi on doit parfois faire des examens médicaux alors qu’on n’est pas malade ?	Aan de telefoon legde je me uit dat je [prestatie] al had gehad *(een vaccinatie/een preventief tandartsbezoek/een preventieve COVID-test/een kankerscreening/een 'screenend' bloedonderzoek/een check-up)*. • Herinner je je dit preventief onderzoek *(preventief onderzoek wordt vervangen door de procedure die in het hele preventieve deel wordt genoemd)?* • Weet je waarom we soms medische onderzoeken moeten ondergaan terwijl we niet ziek zijn?

Being informed **Mise au courant** **Op de hoogte worden gebracht**	• Avant de faire un examen préventif, quelqu’un nous conseille de le faire. Il nous explique aussi ce que c’est et à quoi ça sert. Vous souvenez-vous qui vous a dit de faire cet examen préventif ? • Pouvez-vous me dire ce qui nous empêche de savoir qu’on doit faire un examen préventif ? o Qu’est-ce qui est difficile ? o Qu’est-ce qui empêche qu’on le sache ? ▪ Qu’avez-vous ressenti à ce moment-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Pouvez-vous aussi me dire ce qui permet de savoir qu’on doit faire un examen préventif ? o Qu’est-ce qui nous aide ? o Qu’est-ce qui est facile ? o Qu’est-ce qui est chouette ? • Imaginez que vous pouvez changer ce qui rend difficile de prendre ses médicaments. o Qu’est-ce qui vous aiderait à mieux savoir les examens préventifs à faire ? o Qu’est-ce qui devrait changer pour mieux savoir les examens préventifs à faire ? o Qu’aimeriez-vous qu’on change aux explications sur les examens préventifs ?	• Voordat we een preventief onderzoek doen, raadt iemand ons aan het te doen. Ze leggen ook uit wat het is en waar het voor dient. Weet je nog wie je zei dit preventief onderzoek te doen? • Kan je me vertellen wat je ervan weerhoudt te weten dat we een preventief onderzoek nodig hebben? o Wat is er moeilijk? o Wat houdt je tegen het niet te weten? ▪ Wat voelde je op dat moment? ▪ Welk pictogram geeft weer wat je voelde? • Kan je mij nu vertellen waardoor men kan weten dat een preventief onderzoek nodig is? o Wat helpt ons? o Wat is makkelijk? o Wat is er leuk aan? • Stel je voor dat je kon veranderen wat verkeerd ging o Wat zou je helpen om beter te weten welke preventieve test je moet doen? o Wat zou er moeten veranderen om beter op de hoogte te zijn van preventieve onderzoeken? o Wat zou je graag veranderd zien aan de uitleg over preventieve onderzoeken?
Looking for the HCP **Phase de recherche d’un prestataire** **Een dokter zoeken**	• Quand on veut passer un examen préventif, on doit chercher l’endroit où faire cet examen préventif. Vous souvenez-vous où vous avez passé votre examen préventif ? • Pouvez-vous me dire ce qui était difficile quand vous avez cherché l’endroit pour faire l’examen préventif ? o Qu’est-ce qui est difficile ? o Qu’est-ce qui empêche de le trouver ? ▪ Qu’avez-vous ressenti à ce moment-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Pouvez-vous aussi me dire ce qui était facile quand vous avez cherché l’endroit pour faire l’examen préventif ? • Qu’est-ce qui vous a aidé ? o Qu’est-ce qui était facile ? o Qu’est-ce qui était chouette ? • Imaginez que vous pouvez changer ce qui rend difficile de trouver l’endroit pour faire l’examen préventif.	• Wanneer je een preventief onderzoek wilt laten uitvoeren, moet je op zoek gaan naar de plaats waar je dit preventieve onderzoek kunt laten uitvoeren. Weet je nog waar je je preventief onderzoek hebt gehad? • Kan je me vertellen wat moeilijk was toen je de plaats zocht voor het preventief onderzoek? o Wat is er moeilijk? o Wat houdt je tegen om het te vinden? ▪ Wat voelde je op dat moment? ▪ Welk pictogram geeft weer wat je voelde? • Kan je mij nu vertellen wat makkelijk was toen je de plaats zocht voor het preventief onderzoek? • Wat heeft je geholpen? o Wat was makkelijk? o Wat was leuk? • Stel je voor dat je kon veranderen wat verkeerd ging

	o Qu’est-ce qui vous aiderait à mieux savoir où on fait les examens préventifs ? o Qu’est-ce qui devrait changer pour mieux savoir où faire les examens préventifs ? o Qu’aimeriez-vous qu’on change aux endroits où on fait les examens préventifs ?	o Wat zou je helpen om beter te weten waar het preventief onderzoek wordt gedaan? o Wat zou er moeten veranderen om het gemakkelijker te maken te weten te komen waar preventieve onderzoek kunnen worden verricht? o Wat zou je graag veranderd zien aan de plaatsen waar preventief onderzoek wordt gedaan?
Ongoing screening or preventive exam **Passage de l’examen préventif** **Het preventief onderzoek zelf**	• Vous souvenez-vous de la personne qui vous a fait passer l’examen préventif ? • Pouvez-vous me dire ce qui était difficile quand vous avez passé l’examen préventif ? o Qu’est-ce qui était difficile ? o Qu’est-ce qui empêchait que cela se passe bien ? ▪ Qu’avez-vous ressenti à ce moment-là ? ▪ Quel picto représente ce que vous avez ressenti ? • Pouvez-vous aussi me dire ce qui était facile quand vous avez passé l’examen préventif ? • Qu’est-ce qui vous a aidé ? o Qu’est-ce qui était facile ? o Qu’est-ce qui était chouette ? • Imaginez que vous pouvez changer ce qui rend difficile de passer cet examen préventif. o Qu’est-ce qui vous aurait aidé à mieux vivre cet examen préventif ? o Qu’est-ce qu’on devrait changer pour mieux vivre les examens préventifs ? o Qu’aimeriez-vous qu’on change aux examens préventifs ?	• Weet je nog wie het preventief onderzoek heeft gedaan? • Kan je mij vertellen wat er moeilijk was toen je het preventieve onderzoek onderging? o Wat was moeilijk? o Wat verhinderde dat het goed ging? ▪ Wat voelde je je op dat moment? ▪ Welk pictogram geeft weer wat je voelde? • Kun je me ook vertellen wat er makkelijk was toen je het preventief onderzoek had? • Wat heeft je geholpen? o Wat was makkelijk? o Wat was leuk? • Stel je voor dat je kunt veranderen wat er verkeerd ging. o Wat zou je geholpen hebben om een betere ervaring te hebben met dit preventieve onderzoek? o Wat moet er veranderd worden om preventieve onderzoeken aangenamer te maken? o Wat zou je willen veranderen aan preventieve onderzoeken?
Receiving results (optional) **Recevoir les résultats à distance (optionnel en fonction du type d’examen préventif)** **De resultaten op afstand ontvangen (optioneel)**	• Après l’examen, on reçoit une lettre avec les résultats de l’examen préventif. Vous souvenez-vous avoir reçu une lettre avec les résultats ? • Pouvez-vous me dire ce qui était difficile quand on reçoit une lettre avec les résultats d’un examen préventif ? o Qu’est-ce qui est difficile ? o Qu’est-ce qui empêche qu’on comprenne bien la lettre ? ▪ Qu’avez-vous ressenti à ce moment-là ?	• Na het onderzoek ontvang je een brief met de uitslag van het preventief onderzoek. Herinner je je dat je een brief kreeg met de resultaten? • Kan je mij vertellen wat er moeilijk was aan het ontvangen van een brief met de resultaten van een preventief onderzoek? o Wat is moeilijk? o Waardoor wordt de brief niet goed begrepen? ▪ Hoe voelde je je op dat moment?

	▪ Quel picto représente ce que vous avez ressenti ? • Pouvez-vous aussi me dire ce qui est facile quand on reçoit une lettre avec les résultats d'un examen préventif ? • Qu'est-ce qui vous a aidé à comprendre la lettre ? o Qu'est-ce qui était facile ? o Qu'est-ce qui était chouette ? • Imaginez que vous pouvez changer ce qui rend difficile de la lettre avec les résultats de l'examen préventif. o Qu'est-ce qui vous aurait aidé à mieux comprendre cette lettre ? o Qu'est-ce qu'on devrait changer pour mieux comprendre les lettres de résultats d'examens préventifs ? o Qu'aimeriez-vous qu'on change aux lettres d'examens préventifs ?	▪ Welk pictogram geeft weer wat je voelde? • Kan je mij ook vertellen wat er gemakkelijk is als je een brief ontvangt met de uitslag van een preventief onderzoek? • Wat hielp je om de brief te begrijpen? o Wat was makkelijk? o Wat was leuk? • Stel je voor dat je kunt veranderen wat de brief met de resultaten van het preventief onderzoek moeilijk maakt. o Wat zou je geholpen hebben om de brief beter te begrijpen? o Wat moet er worden veranderd om de brief met de resultaten van het preventief onderzoek begrijpelijker te maken? o Wat zou je graag veranderd zien in de brieven over preventief onderzoek?
TRANSITION FOR INTERVIEW WITH ACCOMPANIER	**Clôture de l'entretien avec la personne en situation de handicap intellectuel**	**Afronden van het interview met de persoon met verstandelijke handicap**
Information to participant	Voilà, c'est la fin des questions pour vous. J'espère que vous avez aimé participer à cette discussion. Je vous remercie pour toutes vos réponses. Ce que vous avez expliqué est très intéressant. Après avoir discuté avec d'autres personnes, mes collègues chercheurs et moi allons écrire un document pour aider les Ministres, les médecins et les hôpitaux. Si vous avez encore envie de dire quelque chose plus tard, vous pouvez m'envoyer un courriel. Je vais maintenant poser des questions à [accompagnant] qui vous accompagne. Vous pouvez écouter la discussion avec [accompagnant] ou quitter l'écran, comme vous préférez.	Dit is het einde van de vragen voor jou. Ik hoop dat je met plezier aan deze discussie hebt deelgenomen. Ik dank je voor al je antwoorden. Wat je hebt uitgelegd is zeer interessant. Na besprekingen met andere mensen gaan mijn collega's en ik een document schrijven om de ministers, de artsen en de ziekenhuizen te helpen. Als je later nog iets wilt zeggen, kun je me een e-mail sturen of bellen. Ik zal nu [begeleider], die je vergezelt, enkele vragen stellen. Je kunt luisteren naar de discussie met [begeleider] of het scherm verlaten, zoals je verkiest.
ACUTE CARE	**SITUATION AIGUE**	**ACUTE SITUATIE**
Questions to accompanier	• Concernant la visite en urgences chez le médecin/à l'hôpital, vous étiez avec [participant] quand il/elle s'est [mentionner ce qui s'applique]. Pouvez-vous me dire ce qui était le plus difficile à gérer dans cette situation d'urgence ? o Qu'est-ce qui s'est mal passé ? o Qu'est-ce qui vous a empêché de pouvoir gérer la situation au mieux ? • Qu'avez-vous ressenti à ce moment-là ?	• Wat betreft het spoedbezoek aan de dokter/het ziekenhuis, je was bij [participant] toen hij/zij [acute situatie]. Kan je mij vertellen wat het moeilijkste was aan deze noodsituatie? o Wat ging er mis? o Wat weerhield je ervan om de situatie zo goed mogelijk aan te kunnen? • Hoe voelde je je op dat moment? • Kan je mij ook vertellen wat er goed ging tijdens dit noodgeval? o Waardoor voelde je je beter?

	• Pouvez-vous également me dire ce qui s'est bien passé lors de cet évènement d'urgence ? ○ Qu'est-ce qui vous a soulagé ? ○ Qu'est-ce qui vous a aidé ? • Imaginez que vous pouvez changer le système des soins de santé ○ Que feriez-vous ? ○ Qu'aimeriez-vous changer à ce système pour améliorer la prise en charge en urgences ?	○ Wat heeft je geholpen? • Stel je voor dat je het gezondheidszorgsysteem kon veranderen ○ Wat zou jij doen? ○ Wat zou je aan het systeem willen veranderen om de spoedeisende hulp te verbeteren?
CHRONIC CARE	**SITUATION CHRONIQUE**	**CHRONISCHE SITUATIE**
Questions to accompanier	• Concernant le problème de santé de [participant], vous l'accompagnez lorsqu'il/elle se rend en consultation chez le médecin [nom médecin] pour son suivi. Pouvez-vous me dire ce qui est le plus difficile à gérer dans le suivi en consultation du problème chronique de [participant] ? ○ Qu'est-ce qui peut mal se passer ? ○ Qu'est-ce qui vous empêche de pouvoir gérer la situation au mieux ? • Que ressentez-vous lors des consultations ou lorsque le moment de la consultation approche ? • Pouvez-vous également me dire ce qui se passe bien lors des consultations de suivi de [participant] ? ○ Qu'est-ce qui fait plaisir dans le déroulement du suivi ? ○ Qu'est-ce qui vous aide dans l'organisation ? • Imaginez que vous pouvez changer le système des soins de santé ○ Que feriez-vous ? ○ Qu'aimeriez-vous changer à ce système pour améliorer la prise en charge des maladies chroniques chez les personnes en situation de handicap intellectuel ?	• Wat het gezondheidsprobleem van [participant] betreft, ga je met hem/haar mee wanneer hij/zij voor follow-up naar dokter [arts] gaat. Kunt u mij zeggen wat het moeilijkste is bij de follow-up van het chronische probleem van [participant]? ○ Wat kan er misgaan? ○ Wat weerhoudt u ervan om de situatie zo goed mogelijk te beheersen? • Hoe voelt u zich tijdens de raadpleging of wanneer het tijdstip van de raadpleging nadert? • Kan je mij ook vertellen wat er goed gaat bij de vervolgconsulten van [participant]? ○ Wat is er goed aan het opvolgingsproces? ○ Wat helpt je in de organisatie? • Stel je voor dat je het gezondheidszorgsysteem kon veranderen ○ Wat zou jij doen? ○ Wat zou je willen veranderen aan het systeem om de aanpak van chronische ziekten voor mensen met een verstandelijke beperking te verbeteren?
PREVENTION	**PREVENTION**	**PREVENTIEVE SITUATIE**
Questions to accompanier	• Concernant l'examen préventif dont a bénéficié [nom de la personne], vous étiez avec lui/elle quand il/elle [mentionner ce qui s'applique] *(a reçu un vaccin, a fait un dépistage de cancer etc. à compléter)*. • Pouvez-vous me dire ce qui était le plus difficile à gérer lors de ce dépistage/vaccination/etc… ? ○ Qu'est-ce qui s'est mal passé ? ○ Qu'est-ce qui a entravé le bon déroulement de l'examen préventif ?	• Wat het preventief onderzoek betreft dat [naam] heeft gekregen, was je bij hem/haar toen hij/zij [prestatie] *(een vaccinatie kreeg, een kankerscreening liet uitvoeren, enz.…)*. • Kan mij vertellen wat het moeilijkste was aan deze screening/vaccinatie/etc.? ○ Wat ging er mis? ○ Waarom was het preventief onderzoek moeilijk uit te voeren?

	• Qu’avez-vous ressenti à ce moment-là ? • Pouvez-vous également me dire ce qui s’est bien passé lors de cet évènement préventif ? • Qu’est-ce qui en a amélioré le déroulement ? ○ Qu’est-ce qui a aidé à son bon déroulement ? • Imaginez que vous pouvez changer le système des soins de santé ○ Que feriez-vous ? ○ Qu’aimeriez-vous changer à ce système pour améliorer les examens préventifs chez les personnes en situation de handicap intellectuel ?	• Hoe voelde je je op dat moment? • Kan je mij ook vertellen wat er goed ging tijdens dit preventief onderzoek? ○ Wat maakte het beter? ○ Wat hielp het om goed te gaan? • Stel je voor dat je het gezondheidszorgsysteem kon veranderen ○ Wat zou jij doen? ○ Wat zou je willen veranderen aan het systeem om de preventieve onderzoeken voor mensen met een verstandelijke beperking te verbeteren?
CLOSING	**CLOTURE**	**EIND**
Acknowledgements to participants	Nous voilà arrivés à la fin de cet entretien. Je vous remercie chaleureusement pour votre active et précieuse participation. Comme je le disais à [nom du participant], le contenu de nos discussions va être analysé et intégré au contenu d’autres discussions. Ensuite, les membres de l’équipe de recherche et moi-même allons rédiger des recommandations pour les décideurs et les prestataires du secteur des soins de santé en Belgique. Le rapport final de notre recherche sera publié l’année prochaine, en 2022. Bonne journée à tous les deux. Au revoir et encore merci.	Dit brengt ons aan het einde van dit interview. Ik dank je hartelijk voor uw actieve en waardevolle deelname. Zoals ik al tegen [naam] zei, zal de inhoud van onze discussies worden geanalyseerd en geïntegreerd met de inhoud van andere discussies. Daarna zullen de leden van het onderzoeksteam en ikzelf aanbevelingen opstellen voor beleidsmakers en zorgverstrekkers in de Belgische gezondheidszorg. Het eindverslag van ons onderzoek zal volgend jaar, in 2022, worden gepubliceerd. Goedendag, jullie beiden. Tot ziens en nogmaals bedankt.

APPENDIX 6. ORGANISATIONAL PROCEDURE FOR THE INTERVIEWS

- Call the applicant or accompanying person by telephone
    - Collecting demographic information:
        - Full name of the person with ID, of the accompanying person and of the administrator, if any
        - The email addresses of the person (if autonomous), of the accompanying person and of the administrator (if applicable)
        - A telephone number
        - The level of disability if known
        - The province
        - The recruitment channel
        - The preference between formal or informal language
    - Collect information on the content of the care pathway (either acute, chronic or preventive) (see questionnaire)
    - Explain the steps for reading, questioning and signing the consent
        - Read the document attached to the email entitled "consent document
        - Ask questions during the video call. Make an appointment for the call.
        - Explain that the consent will have to be signed not on the document received as an attachment but online following receipt of another email
- Ask the secretariat to generate a zoom link on the date agreed with the participants and send it to us
- Send one or two or three emails with the consent document to be read at each address received depending on the autonomy situation. This email contains:
    - The right 'informed consent form' document
    - KCE's video on what informed consent is for the administrator and the accompanying person
    - The date of the first video call and the zoom link
    - The video explaining how to connect to zoom
- Make the video call for the informed consent question session. Depending on the case, there will be 1 or 2 or 3 participants.
    - Answer the questions
    - Explain signing with Adobe Sign
        - They will receive 3 emails: the first with a written explanation of how to sign; the second asking them to sign; the third confirming that the document is signed
    - Schedule the video call for the interview
- Send an email to participants inviting them to sign the adobe sign and explain at the end of the email that the zoom link will be in a subsequent email. As an attachment, put the written procedure for signing Adobe Sign
- Ask the secretariat to send the Adobe Sign email to the participants
- Signing of consents by the participants
- Ask the secretariat to generate the zoom link on the set date and send it to us
- Send an email with the zoom invitation, the link and as an attachment, the video how to connect to zoom.
- Make the zoom video call, collect information on the care pathway.
    - Provide smileys
    - Provide for the image pathway in *Miro.com*
    - Plan the questionnaire adapted to the personal pathway

APPENDIX 7. BARRIERS IDENTIFIED IN THE QUALITATIVE DATA BY CATEGORIES COMPARED TO THE BARRIERS IDENTIFIED IN THE LITERATURE

Table 47 – Common and different attitudinal barriers in literature and qualitative data collection

Protagonists	Barriers only identified in the literature or only in the qualitative data collection	Barriers identified in both literature and qualitative data collection
People with ID	Not coping with loneliness Lack of flexibility/fixed time slot for consultations Reluctance to change in habits	Being frightened by unfamiliar person or place Care refusal/behaviour viewed as challenging Great impact of a previous negative experience in health care Frequent high intensity reaction and anxiety related to pain
Informal caregivers	Variability and incoherence in relatives' opinions related to health care for the loved one Professional administrators few involved in decisions concerning the person Great difficulty in getting the family to comply with diet Deciding everything without taking the opinion of the person with ID	Reluctant to attend screening appointments, believing that the health gain is less than the effort required to carry out the test
Staff in the disability sector	Fear of disturbing HCP Refusal to "play policeman" for non-vital health-care directives Insufficient organisation of healthcare visits	
Health care professionals	Overestimation of the capacity to deliver care by professional in institutions/Insufficient preparation of patient discharge Not talking directly and mainly to the person with ID Exclusion of the patient and the family from conversation Lack of trust in the supporters	Reluctance to care for people with ID Choice of referral to a hospital ward based on the person's mental age rather than their chronological age Admission refusal in psychiatric ward or intensive care ward

Table 48 – Common and different communication barriers in literature and qualitative data collection

Protagonists	Barriers only identified in the literature or only in the qualitative data collection	Barriers identified in both literature and qualitative data collection
People with ID	Problems to express themselves hardly be the sole bearer of her/his medical history Diminished ability to understand the information:	Information must be repeated and illustrated
Informal caregivers		Neglect to give long explanation before health care appointment due to lack of time or energy
Staff in the disability sector	Lack of harmonisation of health-care plan between all the protagonists: family, disability sector professionals, HCP and patient: divergent information can lead to confusion and refusal of care Relational problems between families and institutions	
Health care professionals	Do not involve sufficiently people with ID in the treatment plan ER's HCP do not have the time to read or do not prioritise reading the transfer forms of patients Medical record does not contain the habits, preferences and abilities of the person Lack of a single point of contact to coordinate the care of people with ID within the hospital	Do not always listen to and hear the supporters: both family members and professional caregivers Incoherence between different HCP

In italics, common barriers with international literature findings

Table 49 – Common and different skills and knowledge barriers in literature and qualitative data collection

Protagonists	Barriers only identified in the literature or only in the qualitative data collection	Barriers identified in both literature and qualitative data collection
People with ID	Great diversity of individual capacities of people with intellectual disabilities Anxiety reactions induced by information on the purpose of prevention Lack of skills in describing symptoms	Lack knowledge (health literacy) about common chronic diseases: better knowledge leads to better involvement and therefore better compliance Do not always know how to use the Internet
Informal caregivers	Lack knowledge (health literacy) about common chronic diseases: the knowledge deficit is even more pronounced in prevention care (lack knowledge about healthy behaviours) Difficulty in using existing scales by non-healthcare workers Questioned the real impact of prevention on the quality of life Interpret the situation they observe in the person with ID according to their personality Not well informed about existing financial and logistical support Do not always know how to use the Internet	
Staff in the disability sector	Difficulty in using existing scales by non-healthcare workers Questioned the real impact of prevention on the quality of life Interpret the situation they observe in the person with ID according to their personality Do not seem to receive training on health problems and related care Not trained to accompany people with ID at the end of life or with serious pathologies: difficulties, particularly regarding the management of physical and moral suffering	
Health care professionals	Not well versed in communication techniques Not specialised in intellectual disabilities: very little knowledge about intellectual disabilities Not often confronted with this population in their practice/reflexes quickly lost if there is little opportunity to practice Misinterpret clinical symptoms as consequences of intellectual disability	
System	Referring people to other hospitals with less experienced staff Lack of a centralised information system in appropriate language Information sources adapted to people with ID concerning pathologies and care procedures are not well known	

In italics, common barriers with literature abroad findings

Table 50 – Common and different programmatic barriers in literature and qualitative data collection

Protagonists	Barriers only identified in the literature or only in the qualitative data collection	Barriers identified in both literature and qualitative data collection
People with ID		Loss of effectiveness in understanding when consultations are long or during full days of several consultations
Informal caregivers		Family and friends also struggle to cope with the many trips to the HC centre
Staff in the disability sector	Educational teams present at weekends and at night different as those during the week	
Health-care professionals	Highly agitated people are sometimes denied access to consultation or care Group practice in general practice destabilise people with ID because they are reassured to always be examined by the same doctor	Few HCP are used to provide longer and more frequent consultations Even the most committed doctors do not have enough time for high quality care
System	Administrative procedures Volunteers cannot be present 24/7, nor are they allowed to assist with activities of daily living Longer and frequent visit/consultation no longer sufficiently efficient	Administrative procedures and internal signage (as mentioned above) not adapted to people with ID Consultation's organisation not adapted: frequent delays, crowded and noisy waiting rooms, long delays in receiving results Ethical questionability of a system of identification of people with behaviours viewed as challenging to enable them to avoid (or reduce) this waiting time Lack of coordination of care: absence of an in-hospital reference person

Table 51 – Common and different policy and social barriers in literature and qualitative data collection

Protagonists	Barriers only identified in the literature or only in the qualitative data collection	Barriers identified in both literature and qualitative data collection
People with ID		Problem of resources can also affect people with ID and their supporters
Informal caregivers		Neither family carers nor professionals from institutions have the resources and support to provide 24/7 care for hospitalised people with intellectual disabilities Lack the time to organise and accompany people to preventive appointments
Staff in the disability sector	Educational staff must take over the health care of people with ID Lack of a dietician or diabetes educator in the institutions Problems in recruiting care staff	Specialised institutions for people with ID are understaffed Lack of care staff and of specific means to finance them
Health-care professionals	A lack of professionals competent in the care of people with ID	
System	Not enough emphasis on prevention: difficulties in accessing preventive care and screening; lack of funding for the prevention sector; and geographical coverage seems insufficient	Restricted access to some speech therapy or psychological services Mobile palliative care teams at home cannot always intervene in residential institutions Problem of financial resources that prevent hospitals from financing an in-hospital reference person and initiatives in agreement with the RIZIV – INAMI
Society	Insufficient inclusion of people with ID in society: inability to change the way society views, or rather discards, people with ID Belgian legislation is too vague regarding the status of trusted persons	

APPENDIX 8. TRIANGULATION OF SOLUTIONS

Table 52 presents the 65 solutions per data source: solutions in bold are the solutions which were compiled to obtain the first proposal of solutions and actions submitted to stakeholders (see 7.2.1). Each solution was discussed between the researchers: reason for exclusion is indicated in the table below. Solutions from the different data sources were merged in order to make them clear for the stakeholders.

Table 52 – Solutions retrieved from the literature, the qualitative research activities and the context description

Solutions from literature	Solutions from qualitative research activities	Solutions from context description
1. Full access, without any exclusion criteria, of people with ID to all health programs, services and activities: this requires adapted organisational policies and practices within institutions (with the input of people with ID) in all aspects of programs' planning, development and implementation	**1. Recognizing nomenclature codes for longer consultation (+ funding)**	1. Updating crisis plans with the inclusion of the needs of persons with handicap *Excluded: out-of-scope*
2. Promoting inclusion of people with ID into the organisational culture of health care facilities, and, as such, promote diversity. It requires changes at professionals and managerial levels. Also in the primary care, people with ID ask for more collaborative relationship with their provider in managing their health conditions and status.	**2. Having visit of medical specialists in residential facility of people with ID?**	2. Ensuring the availability of the crisis communication in tailored and available format *Excluded: out-of-scope*
3. Relying on tools to help introducing and developing inclusive culture and practice	**3. Creating an intensive follow-up approach, based on the Global medical file: e.g., 3 visits per year + list of screening and preventive tests + access to the register of health professionals trained to perform these tests**	3. Defining, in collaboration with the federated entities, the thresholds of access to health care aimed at persons with handicap, particularly for health care at the border of the distribution of the competences in public health and wellbeing (e.g., Speech therapy nomenclature, physiotherapy related to rehabilitation centres). *Excluded: specialised care*

Solutions from literature	Solutions from qualitative research activities	Solutions from context description
4. Promoting the use of an accessible language and of images	**4. Promoting the use of the Global medical file + referring GP for coordination of ambulatory care + integration of the whole health history**	4. Reforming the law of June 26, 1990, related to the protection of the person of mentally ills in the respect of the rights of the persons with handicap *Excluded: out-of-scope, specialised care*
5. Where forms need to be completed, an in-person assistance should be provided to ensure that people with ID understand materials	**5. Creating multidisciplinary and coordination centres adapted to people with disabilities (children and adults) (cf. geriatric day hospital) with a centralised contact point at the hospital + link with GP. Example: AZ Delta, Down poli**	5. Supporting innovative initiatives in mental health services of hospitals to deliver more human health care and to reduce the use of coercive measures *Excluded: out-of-scope, specialised care*
6. Promoting the role reception staff as offering high level welcoming attitudes	**6. Increasing the number of intra-hospital (volunteer?) reference persons**	**6. Developing a network of experts by experience in the handicap to support federal administration in the development of more inclusive services.**
7. Sharing of information about the management of people with ID behaviour viewed as challenging. In addition to the usual completion of the electronic patients records with data on the people with ID, the formalisation on an info transmission into a common system to people with ID, families and professionals.	**7. Improving the coordination of specialised care (cf. geriatric liaison/ reference person): part of a multidisciplinary centre with a mission of supporting the staff and connecting with the multidisciplinary centre**	**7. Generalising of the use of Easy read format of important official documents for citizens**
8. Developing collaboration with professionals specialised in key issues like pain management	**8. Developing/updating guidelines on follow-up of persons with ID**	8. Publishing and vulgarising the information related to the United Nations convention related to the rights of persons with handicap, including the general observations of the Committee of the United Nations to make them accessible, in the three national languages in Easy read format and in sign languages. *Excluded: not related to health care*
9. Supporting the implementation of reasonable adjustments: the reasonable adjustments like flexibility in the appointment system, effective communication tips implementation or provision of accessible information. Some reasonable adjustments do not cost anything.	**9. Improving knowledge by launching point of contact for GP and promoting existing websites on health and disability**	9. Investing in health care team able to care for persons with handicap in prisons *Excluded: out-of-scope, particular situations, unsure that persons with ID can be incarcerated but not clear information about this topic*
10. **Creating specialised health care trajectories** **Excluded: too specific**	**10. Improving communication via basic or specialised training**	10. Highlighting the handicap in the framework of the action plan against gender violence Excluded: specialised care

Solutions from literature	Solutions from qualitative research activities	Solutions from context description
11. Planning extra-time: HCP should plan for additional time during examination. Additional support should be implemented in avoiding positive discrimination and keeping extra-cost reasonable	**11. Developing an Easy read version of MaSanté**	11. Raising the awareness of the emergency services to the European Disability Card. *Excluded after additional search: the EDC is currently not related to health care*
12. **Developing targeted interventions for specific subgroups of people with ID should be necessary like for those difficult to reach by health promotion broad-based programs, those with higher risks of co-morbidities and those requiring close ongoing care** **Excluded: specific approach – not inclusive**	**12. Linking the existing guidelines to adapted information in Easy read language**	12. Assessing the accessibility of Centres for the Management of Sexual Violence for persons with handicap *Excluded: out-of-scope, particular situation*
13. Development of specialist learning disability liaison nurses who provide knowledge and expertise to support staff working in acute hospital settings (see UK).	**13. Launching an E-learning program on masanté.be**	**13. Prolonging the project « Improving Equality Data Collection in Belgium » to enlarge it to other criteria of discrimination such as handicap.**
14. Supporting primary care providers via specialised services and experts by providing comprehensive assessment and multidisciplinary feedback	**14. Enforcing liaison tools (e.g., Smile booklet, Down passport) in order to gather medical information and information on patient preferences**	**14. Creating a working group in charge of identifying needs and opportunities in data collection and statistics related to persons with handicap (including other criteria such as gender, age, etc.).**
	15. Disseminating tools for anticipation/participation of the preferences of people with ID (e.g., Smile booklet) in order to reinforce their capacities of being actors of their care, thanks to their supporters	15. Ensuring an appropriate evaluation to quickly and correctly identify the specific needs of asylum seekers with handicap living in the reception network and ensuring the follow-up. *Excluded: out-of-scope, not considered as being part of the mainstream health care system, under the responsibility of the State Secretary for Asylum and Migrations*
	16. Supporting parents through communication tools	16. Promoting the mobility and an appropriate communication for asylum seekers with handicap in the reception network *Excluded: out-of-scope, not considered as being part of the mainstream health care system, under the responsibility of the State Secretary for Asylum and Migrations*
	17. Creating a (compulsory) permanent accompaniment / structural arrangement (e.g.,	**17. Developing outreach screening program**

Solutions from literature	Solutions from qualitative research activities	Solutions from context description
	volunteer waiting for the person in the hospital hall) with the patient's consent (respect of privacy) and if there is no danger for the supporters	
	18. Anticipating as much as possible unforeseen situation:	**18. Increasing resources of support and social services**
	19. Devoting more resources for counselling outside residential facilities	
	20. Adapted form of hospital stay, e.g., possibility for a relative to spend the night with an adult with ID	
	21. Recognition of convention for ID/ rare diseases *Excluded: not adapted to current Belgian context*	
	22. Improving knowledge of all healthcare providers in basic training	
	23. Developing a specialised training of GP	
	24. Implementing of annual check-up for adult people with ID	
	25. Increasing supply of care staff in residential facilities	
	26. Facilitating detection of symptoms by tools	
	27. Implementing reference persons within hospitals: social-pedagogical supervisor in hospitals	
	28. Considering *Warme zorg* versus *traumatiserende zorg*: use of sedation	
	29. Improving empathic communication with healthcare providers, adapted to the world of people with ID	
	30. Developing a website for providing health information to people with ID, such as *SantéBDd*	

Solutions from literature	Solutions from qualitative research activities	Solutions from context description
	31. Shortening the time spent in hospitals (shortened trajectories)	
	32. Hiring diabetes educator in residential facilities *Excluded: residential facilities are not licensed at the time for this profile*	
	33. Developing a list of clinical examination for follow-up (guidelines)	

APPENDIX 9. EVOLUTION OF ACTIONS BETWEEN STAKEHOLDERS AND EXPERTS’ CONSULTATION

As explained in section 7.2, solutions submitted to experts were adapted based on comments and additional actions based on the stakeholder’s consultation. These adaptations were made in French and Dutch. Additional actions are indicated in red.

Table 53 – Actions submitted to stakeholders and to experts in French and in Dutch per theme

Global solutions		Actions submitted to stakeholders		Actions submitted to experts	
French version	*Dutch version*	*French version*	*Dutch version*	*French version*	*Dutch version*
Empowerment of people with ID and their supporters					
La capacité des personnes en situation de handicap intellectuel à être actrices de leur santé doit être renforcée, notamment en améliorant leur accès à de l’information claire, fiable et centralisée et en leur fournissant les outils et ressources adaptés à leur niveau de compréhension pour s'approprier ces informations. L’entourage des	**Het vermogen van personen met een verstandelijke beperking om verantwoordelijkheid te nemen voor hun gezondheid moet worden versterkt, met name door hun toegang tot duidelijke, betrouwbare en gecentraliseerde informatie te verbeteren en door hun de instrumenten en middelen te geven die aangepast zijn aan hun begripsniveau om zich deze informatie eigen te maken. De entourage van personen met een verstandelijke**	• Les gestionnaires du site InfoSante.be développent une version Facile à Lire et à Comprendre (FALC) du site en collaboration avec le secteur du handicap. • Le SPF Santé Publique, l'INAMI, les mutualités, les associations de patients et les autorités compétentes informent régulièrement les personnes en situation de handicap intellectuel et leur entourage de l’existence du site InfoSante.be en veillant à l’utilisation d’un langage FALC.	• De beheerders van de website gezondheidenwetenschap.be gezondheidenwetenschap.be ontwikkelen in samenwerking met de gehandicaptensector een versie van de site die gemakkelijk te lezen en te begrijpen is (FALC). • De FOD Volksgezondheid, het RIZIV, de ziekenfondsen, de patiëntenverenigingen en de bevoegde instanties informeren regelmatig personen met een verstandelijke beperking en hun entourage over het bestaan van de website gezondheidenwetenschap.be , waarbij zij erop toezien dat de FALC-taal wordt gebruikt.	• Développement d’une version Facile à Lire et à Comprendre (FALC) des sites InfoSanté.be et Gezondheid en Wetenschap.be • Information en FALC régulière des personnes en situation de handicap intellectuel et de leur entourage de l’existence du site InfoSante.be / Gezondheid en Wetenschap.be • Information et diffusion annuelle des outils permettant aux personnes en	• Ontwikkeling van een gemakkelijk te lezen en te begrijpen versie van de websites InfoSanté.be en Gezondheid en Wetenschap.be • Regelmatig informatie verstrekken in eenvoudige taal aan personen met een verstandelijke beperking en hun entourage over het bestaan van de website InfoSante.be / Gezondheid en Wetenschap.be • Voorlichting en jaarlijkse verspreiding van tools die personen met een verstandelijke beperking in staat stellen betrokken te worden bij beslissingen over hun gezondheid

personnes en situation de handicap intellectuel doit être capable de détecter les symptômes de la personne en situation de handicap intellectuel et de l'aider à exprimer ses plaintes.	**beperking moeten in staat zijn om symptomen bij de persoon met een verstandelijke beperking op te sporen en hem te helpen zijn klachten te uiten.**	• Les autorités compétentes, en collaboration avec les associations du secteur du handicap, informent et diffusent annuellement des outils permettant aux personnes en situation de handicap intellectuel d'être impliquées dans les décisions qui concernent leur santé. • Les autorités compétentes améliorent les conditions de vie des aidants proches et les conditions de travail des professionnels du secteur du handicap pour leur permettre, en autres, de disposer de temps de qualité pour discuter des préférences et besoins de leur proche/patient en situation de handicap intellectuel.	• De bevoegde autoriteiten verstrekken en verspreiden jaarlijks, in samenwerking met gehandicaptenorganisaties, tools om mensen met een beperking in staat te stellen betrokken te worden bij beslissingen die van invloed zijn op hun gezondheid. • De bevoegde instanties verbeteren de levensomstandigheden van mantelzorgers en de arbeidsomstandigheden van beroepskrachten in de gehandicaptensector, zodat zij onder meer voldoende tijd hebben om de voorkeuren en behoeften van hun familielid/patiënt met een verstandelijke beperking te bespreken.	situation de handicap intellectuel d'être impliquées dans les décisions qui concernent leur santé • Poursuite d'une politique de développement permanent et d'amélioration des outils • Soutien de l'entourage dans ses démarches à faire respecter les préférences des personnes en situation de handicap intellectuel • Amélioration des conditions de vie des aidants proches et des conditions de travail des professionnels du secteur du handicap • Organisation de campagnes annuelles d'information et de diffusion quant à l'utilisation d'outils permettant d'identifier et d'évaluer correctement les symptômes • Formation des professionnels de	• Voortzetting van het beleid van permanente ontwikkeling en verbetering van de tools • De entourage steunen bij hun inspanningen om de voorkeuren van personen met een verstandelijke beperking te laten respecteren • Verbetering van de levensomstandigheden van mantelzorgers en van de arbeidsomstandigheden van professionals in de gehandicaptensector • Organisatie van jaarlijkse voorlichtingscampagnes en informatie te verspreiden over het gebruik van tools voor de correcte detectie en inschatting van symptomen • Opleiding van zorgverleners in tools voor de detectie en inschatting van symptomen van personen met een verstandelijke beperking • Bewustmaking en opleiding van personen met een verstandelijke beperking om hun symptomen te herkennen

				santé aux outils de détection et d’évaluation des symptômes des personnes en situation de handicap intellectuel • Sensibilisation et formation des personnes en situation de handicap intellectuel à reconnaitre leurs symptômes	
Coordination and integration of health information and health care by primary care					
Chaque personne en situation de handicap intellectuel doit avoir un médecin généraliste de référence (chargé de la concertation multidisciplinaire et du suivi préventif), un dossier médical global et un outil de liaison.	**Elke persoon met een verstandelijke beperking moet beschikken over een huisarts als referentiepersoon (verantwoordelijk voor multidisciplinair overleg en preventieve controle), een globaal medisch dossier en een opvolgboekje**	• Les autorités compétentes, en collaboration avec les mutualités, la Société Scientifique de Médecine Générale (SSMG) et Domus Medica, organisent une campagne annuelle de sensibilisation et d'information des personnes en situation de handicap intellectuel et de leur entourage à l'importance d'avoir un médecin généraliste de référence et un dossier médical global. • Le médecin généraliste de référence veille à ce que chaque personnes en situation de handicap intellectuel dispose d’un outil de liaison : l’outil de liaison est un support	• De bevoegde autoriteiten organiseren in samenwerking met de ziekenfondsen, SSMG en Domus Medica een jaarlijkse campagne om mensen bewust te maken van het belang van het hebben van een huisarts en een globaal medisch dossier. • De vaste huisarts zorgt ervoor dat elke PVB over een opvolgboekje beschikt: het opvolgboekje is een medium voor het delen van informatie die nodig is voor de gepaste zorg voor de behoeften en voorkeuren van de PVB door de gezondheidszorgdiensten (bv. Babbelgids van Dito VZW). • SSMG en Domus Medica werken samen met verenigingen die	• Organisation d’une campagne annuelle de sensibilisation et d'information des personnes en situation de handicap intellectuel et de leur entourage à l'importance d'avoir un médecin généraliste de référence et un dossier médical global. • Mise en place d’un outil de liaison pour le partage des besoins, informations de santé et préférences pour chaque personne en situation de handicap intellectuel • Sélection, adaptation, mise à	• Organisatie van een jaarlijkse campagne om personen met een verstandelijke handicap en hun entourage bewust te maken en te informeren over het belang van een huisarts en een globaal medisch dossier. • Het opzetten van een opvolgboekje voor het delen van noden, gezondheidsinformatie en voorkeuren van elke persoon met verstandelijke beperkingen • Selectie, aanpassing, verstrekking en verspreiding van opvolgboekjes onder huisartsen. • Organisatie van een jaarlijks multidisciplinair overleg voor elke persoon met een verstandelijke handicap, en opstelling van een verslag in

	permettant de partager les informations nécessaires à la prise en charge adaptée aux besoins et préférences de la personnes en situation de handicap intellectuel par les services de soins de santé (exemple : Babbelgids de Dito vzw). - La SSMG et Domus Medica se concertent avec les associations promouvant des outils de liaison pour sélectionner, adapter, rendre accessibles et diffuser les outils de liaison auprès des médecins généralistes. - Le médecin généraliste de référence organise une concertation pluridisciplinaire annuelle pour chaque personne en situation de handicap intellectuel, et rédige un rapport en langage FALC transmis à la personne en situation de handicap intellectuel pour approbation. - L'INAMI crée un code de nomenclature pour une consultation de longue durée en médecine générale visant à faire le bilan de santé et à organiser le suivi préventif des personnes	opvolgboekjes promoten om deze boekjes te selecteren, aan te passen, beschikbaar te stellen en te verspreiden onder huisartsen. - De vaste huisarts organiseert jaarlijks een multidisciplinair overleg voor elke PVB, en schrijft een verslag in FALC-taal dat ter goedkeuring naar de PVB wordt gestuurd. - Het RIZIV creëert een nomenclatuurcode voor een langere consultatie in de huisartsgeneeskunde met het oog op het uitvoeren van een health check en het organiseren van een preventieve opvolging van de PVB. Deze controle moet ten minste eenmaal per jaar worden uitgevoerd. - Het RIZIV past de verpleegkundige nomenclatuur aan om de tarifering van sessies door de diabeteseducator in de thuis- of gemeenschapswoning van PVB mogelijk te maken, met aanvullende opleiding in FALC.	disposition et diffusion des outils de liaison auprès des médecins généralistes. - Organisation d'une concertation pluridisciplinaire annuelle pour chaque personne en situation de handicap intellectuel, et rédaction d'un rapport en langage FALC transmis à la personne en situation de handicap intellectuel pour approbation - Création d'un code de nomenclature pour une consultation de longue durée en médecine générale visant à faire le bilan de santé et à organiser le suivi préventif des personnes en situation de handicap intellectuel, minimum une fois par an. - Mise en place d'incitants financiers pour augmenter la couverture en matière de soins préventifs et de dépistage parmi les personnes en	eenvoudige taal dat ter goedkeuring aan de persoon met een verstandelijke beperking wordt voorgelegd - Creatie van een nomenclatuurcode voor minstens een jaarlijkse consultatie met langere duur in de huisartsgeneeskunde gericht op het uitvoeren van een gezondheidsbilan en het organiseren van preventieve monitoring van personen met een verstandelijke handicap. - Het creëren van (financiële) incentieven om de dekking van preventieve zorg en screening bij personen met een verstandelijke beperking te verhogen - Invoering van (financiële) incentieven ter ondersteuning van de proactieve aanpak van huisartsen om jaarlijks personen met een verstandelijke beperking te bereiken in hun patiëntenbestand - Het verschaffen van de nodige middelen voor de uitvoering van een preventie- en gezondheidspromotiebeleid dat is afgestemd op personen met een verstandelijke beperking en hun leefomgeving(en)

	en situation de handicap intellectuel. Ce bilan doit être réalisé au minimum une fois par an. • L'INAMI adapte la nomenclature des soins infirmiers pour autoriser la tarification de séances d'éducation thérapeutique du diabète au domicile ou à la résidence communautaire des personnes en situation de handicap intellectuel, moyennant une formation complémentaire en langage FALC.		situation de handicap intellectuel • Mise en place d'incitants (financiers) pour soutenir les démarches proactives des médecins généralistes pour le suivi préventif annuel des personnes en situation de handicap intellectuel dans leur patientèle • Prévision des moyens nécessaires à la mise en œuvre d'une politique de prévention et de promotion de la santé adaptée aux personnes en situation de handicap intellectuel et à leur(s) milieu(x) de vie • Adaptation de la nomenclature des soins infirmiers pour autoriser la tarification de séances d'éducation thérapeutique du diabète au domicile ou à la résidence communautaire des personnes en situation de handicap intellectuel,	• Aanpassing van de verpleegkundige nomenclatuur om de certificatie van diabetes-educatie in de gemeenschappelijke woon- of verblijfsplaats van personen met een verstandelijke beperking mogelijk te maken, met bijkomende opleiding van verpleegkundigen in het hanteren van een eenvoudige taal.

				moyennant une formation complémentaire des infirmiers au langage FALC	
Reachability of health care and outreaching					
Les personnes en situation de handicap intellectuel doivent avoir la possibilité d'être soignées dans leur lieu de vie habituel. **Les personnes en situation de handicap intellectuel doivent pouvoir être accompagnées par la personne de leur choix lors d'un transport urgent pour autant que la sécurité de cette personne soit assurée.**	**Personen met een verstandelijke beperking moeten de mogelijkheid hebben om verzorgd te worden op hun gebruikelijke plaats van wonen.** **Personen met een verstandelijke beperking moeten zich tijdens dringend vervoer kunnen laten vergezellen door een persoon van hun keuze, op voorwaarde dat de veiligheid van die persoon gewaarborgd is.**	• Les médecins spécialistes se rendent au domicile familial ou communautaire de la personne en situation de handicap intellectuel sur demande du médecin généraliste pour un avis, tel que repris dans l'article 2 de la nomenclature. • La SSMG et Domus Medica, en collaboration avec l'INAMI et les mutualités, informent annuellement les médecins généralistes quant à la possibilité de demander à un médecin spécialiste de se rendre au domicile familial ou communautaire de la personne en situation de handicap intellectuel pour un avis. • Les associations professionnelles de médecins spécialistes, en collaboration avec la SSMG, Domus Medica, l'INAMI et les mutualités, informent annuellement les médecins spécialistes quant à la possibilité de	• Specialisten bezoeken het gezins- of gemeenschapshuis van de persoon met een verstandelijke beperking op verzoek van de huisarts voor een advies, zoals vermeld in artikel 2 van de nomenclatuur. • SSMG en Domus Medica, in samenwerking met het RIZIV en de ziekenfondsen, informeren jaarlijks de huisartsen over de mogelijkheid om een specialist voor advies te vragen in het gezins- of gemeenschapshuis van de PVB. • De beroepsverenigingen van specialisten, in samenwerking met SSMG, Domus Medica, het RIZIV en de ziekenfondsen, informeren jaarlijks de specialisten over de mogelijkheid om op verzoek van een huisarts een bezoek te brengen aan het gezins- of gemeenschapshuis van de PVB voor advies. • De FOD Binnenlandse Zaken en de FOD Volksgezondheid werken aan de ontwikkeling	• Augmentation des visites au domicile familial ou communautaire de la personne en situation de handicap intellectuel sur demande du médecin généraliste pour un avis, tel que repris dans le Chapitre II de la nomenclature. • Information annuelle des médecins généralistes quant à la possibilité de demander à un médecin spécialiste de se rendre au domicile familial ou communautaire de la personne en situation de handicap intellectuel pour un avis. • Information annuelle des médecins spécialistes quant à la possibilité de se rendre au domicile familial ou communautaire de la personne en situation de handicap	• Toename van het bezoeken aan de thuis- of gemeenschapsvoorziening van de persoon met een verstandelijke handicap op verzoek van de huisarts voor advies, zoals vermeld in hoofdstuk II van de nomenclatuur. • Jaarlijkse voorlichting aan huisartsen over de mogelijkheid om een arts-specialist te vragen voor advies in de thuis- of gemeenschapsvoorziening van de persoon met een verstandelijke beperking. • Jaarlijkse informatie aan specialisten over de mogelijkheid om op verzoek van een huisarts een bezoek te brengen aan de thuis- of gemeenschapsvoorziening van de persoon met een verstandelijke beperking voor een advies. • Aanpassing van de infrastructuur van de voorzieningen om de organisatie van raadplegingen mogelijk te maken, met name wanneer zij onderdak bieden aan bewoners voor wie

	se rendre au domicile familial ou communautaire de la personne en situation de handicap intellectuel à la demande d’un médecin généraliste pour un avis. • Le SPF Intérieur et le SPF Santé publique développent et diffusent des bonnes pratiques pour la prise en charge des personnes en situation de handicap intellectuel dans les situations d’urgence, y compris le transport, en insistant sur la possibilité d’avoir un accompagnant en permanence pour autant que sa sécurité soit assurée. • Lorsque les circonstances le permettent, les équipages chargés du transport d’urgence demandent l’accord au régulateur 112 de la zone de secours pour transférer la personne en situation de handicap intellectuel vers son lieu de soins habituel.	en verspreiding van goede praktijken voor de verzorging van PVB in dringende medische situaties, met inbegrip van het vervoer, waarbij de nadruk wordt gelegd op de mogelijkheid om te allen tijde een begeleider te hebben, op voorwaarde dat diens veiligheid gewaarborgd is. • Wanneer de omstandigheden het toelaten, vraagt het ziekenvervoer de toestemming van de 112-telefonist van de hulpverleningszone om de hulpbehoevende naar zijn gebruikelijke plaats van verzorging over te brengen.	intellectuel à la demande d’un médecin généraliste pour un avis. • Adaptation des infrastructures des institutions pour permettre l’organisation de consultations, notamment lorsqu’elles accueillent des résidents pour qui le déplacement est compliqué, voire impossible • Soutien structurel et élargissement des initiatives de soins mobiles adaptées aux besoins des personnes en situation de handicap intellectuel • Coordination et organisation de la participation aux activités de dépistage lors de la venue d’un dispositif mobile de dépistage dans la commune • Développement et diffusion de bonnes pratiques pour la prise en charge des personnes en situation de handicap intellectuel dans les situations d’urgence,	verplaatsingen moeilijk of onmogelijk is. • Structurele ondersteuning en uitbreiding van mobiele zorginitiatieven die zijn aangepast aan de behoeften van personen met een verstandelijke handicap • Coördinatie en organisatie van de deelname aan screeningactiviteiten wanneer een mobiele screeningsapparaat naar de gemeente komt • Ontwikkeling en verspreiding van goede praktijken voor de aanpak van personen met een verstandelijke handicap in noodsituaties, met inbegrip van vervoer, waarbij de nadruk wordt gelegd op de mogelijkheid om te allen tijde een begeleider te hebben, zolang hun veiligheid gewaarborgd is. • De toestemming vragen van de 112-telefonist van de desbetreffende zone om de persoon met een verstandelijke beperking naar zijn gebruikelijke plaats van zorg over te brengen

				y compris le transport, en insistant sur la possibilité d'avoir un accompagnant en permanence pour autant que sa sécurité soit assurée. • Demande de l'accord au régulateur 112 de la zone de secours pour transférer la personne en situation de handicap intellectuel vers son lieu de soins habituel	
Availability of HCP during consultations and visits					
L'INAMI doit mettre en œuvre un statut préférentiel pour les personnes à besoins spécifiques pour qu'elles bénéficient d'un temps de consultation ou de visite plus long.	**Het RIZIV moet een voorkeursstatuut invoeren voor personen met specifieke behoeften, zodat zij kunnen profiteren van een langere consultatie- of bezoektijd.**	• Les discussions en cours dans les conseils médico-mutualistes concernant le développement de consultations plus longues du fait de la complexité du patient doivent intégrer les besoins spécifiques de la personne en situation de handicap intellectuel en termes de communication et de compréhension . • L'INAMI prévoit le budget nécessaire au financement de ces consultations et visites plus longues.	• Bij de lopende besprekingen in de artsen-ziekenfondsen raden over de ontwikkeling van langere consulten wegens de complexiteit van de patiënt moet rekening worden gehouden met de specifieke behoeften van PVB op het gebied van communicatie en begrip . • Het RIZIV stelt het nodige budget ter beschikking om deze langere consultaties en bezoeken te financieren.	• Initiation d'une réflexion sur la création d'un code de nomenclature spécifique pour des consultations plus longues du fait de la complexité du patient • Prévision du budget nécessaire au financement des consultations et visites plus longues	• Start van een beraad over de invoering van een specifieke nomenclatuurcode voor langere consulten wegens de complexiteit van de patiënt • Budgettering van langere consultaties en bezoeken
Tous les hôpitaux et services de santé doivent	**Alle ziekenhuizen en gezondheidsdiensten moeten voorzien in een**	• Les autorités compétentes prévoient les moyens financiers	• De bevoegde autoriteiten verstrekken de nodige financiële middelen om	• Prévision des moyens financiers nécessaires pour	• Beschikbaarstelling van de nodige financiële middelen ter ondersteuning van

prévoir une infrastructure permettant aux personnes en situation de handicap intellectuel d'être accompagnées en tout temps et tout lieu par la personne de leur choix, pour autant que cet accompagnement respecte la volonté de la personne, son intimité et soit sans danger pour l'accompagnant. **Les hôpitaux, disposant d'un centre de génétique clinique ou d'un service de neuropédiatrie, doivent organiser un centre de coordination et de consultation interdisciplinaire pour les personnes en situation de handicap intellectuel, indépendamment de leur âge.**	**infrastructuur die het mogelijk maakt dat personen met een verstandelijke beperking te allen tijde en op alle plaatsen worden begeleid door een persoon van hun keuze, op voorwaarde dat deze begeleiding de wensen en de privacy van de persoon in kwestie respecteert en veilig is voor de begeleider.** **Ziekenhuizen met een centrum voor klinische genetica of een neuro-paediatrische afdeling moeten een interdisciplinair coördinatie- en consultatiecentrum voor personen met een verstandelijke beperking organiseren, ongeacht hun leeftijd.**	nécessaires pour soutenir les hôpitaux et services de santé dans l'aménagement de l'infrastructure pour permettre l'accompagnement des personnes en situation de handicap intellectuel adultes. • Les hôpitaux organisent des formations concernant les besoins spécifiques des personnes en situation de handicap intellectuel à destination des bénévoles qui accueillent et accompagnent les patients . • les hôpitaux et les services de santé doivent collaborer avec les associations de personnes en situation de handicap intellectuel, la Ligue des Usagers des Services de Santé (LUSS), la Vlaamse PatiëntenPlatform (VPP) et le Patienten Rat und Treff (PRT) pour adapter leurs infrastructures, en ce compris la documentation en FALC et la signalétique hospitalière. • Le centre de coordination et de consultation interdisciplinaire (ci-après : « le centre ») inclut un	ziekenhuizen en gezondheidsdiensten te ondersteunen bij de ontwikkeling van de infrastructuur ter ondersteuning van de PVB voor volwassenen. • Ziekenhuizen organiseren opleidingen over de specifieke behoeften van mensen met een verstandelijke beperking voor vrijwilligers die patiënten opvangen en begeleiden . • Ziekenhuizen en gezondheidsdiensten moeten samenwerken met de PVB-verenigingen, de Ligue des Usagers des Services de Santé (LUSS), het Vlaamse PatiëntenPlatform (VPP) en het Patienten Rat und Treff (PRT) om hun infrastructuur aan te passen, met inbegrip van FALC-documentatie en ziekenhuisbewegwijzering. • Het interdisciplinair overleg- en coördinatiecentrum (hierna: "het centrum") omvat een gecentraliseerd contactpunt binnen het ziekenhuis waartoe PVB, hun familieleden en begeleidende zorgverleners zich kunnen wenden om de uitwisseling van informatie met de eerstelijnszorg te vergemakkelijken en de intramurale en residentiële zorg te coördineren.	soutenir les hôpitaux et services de santé dans l'aménagement de l'infrastructure pour permettre l'accompagnement des personnes en situation de handicap intellectuel, particulièrement les adultes • Organisation de formations concernant les besoins spécifiques des personnes en situation de handicap intellectuel à destination des bénévoles et accueillant des réseaux hospitaliers • Adaptation des infrastructures des hôpitaux et services de santé aux personnes avec des besoins spécifiques comme les personnes en situation de handicap intellectuel • Création d'un centre interdisciplinaire de coordination et de consultations • Inclusion d'un point de contact centralisé au sein du réseau hospitalier auquel s'adressent les	ziekenhuizen en gezondheidsdiensten bij de ontwikkeling van infrastructuur voor de ondersteuning van personen met een verstandelijke beperking, met name volwassenen • Organisatie van opleidingscursussen over de specifieke behoeften van personen met een verstandelijke handicap voor vrijwilligers en zorgverleners in ziekenhuisnetwerken • Aanpassing van de ziekenhuis- en gezondheidszorginfrastructuur voor personen met specifieke behoeften, zoals verstandelijke beperkingen • Oprichting van een interdisciplinair coördinatie- en overlegcentrum • Opname van een centraal contactpunt binnen het ziekenhuisnetwerk waar personen met verstandelijke beperkingen, hun entourage en de professionals die hen ondersteunen terecht kunnen • Coördinatie van het interdisciplinair coördinatie- en overlegcentrum • Ontwikkeling en coördinatie van een ondersteuningsaanbod voor andere zorgverleners in het ziekenhuis: liaisonpersoon en liaisonteam

	point de contact centralisé au sein de l'hôpital auquel s'adressent les personnes en situation de handicap intellectuel, leur entourage et les soignants qui les accompagnent pour faciliter les échanges d'informations avec la première ligne de soins et coordonner les soins hospitaliers ambulatoires et résidentiels. • Ce centre est coordonné de préférence par un médecin (généraliste ou spécialiste) avec une expertise reconnue dans l'accompagnement des personnes en situation de handicap intellectuel. • Le centre développe et coordonne une offre de soutien pour les autres soignants hospitaliers : personne-relais et équipe de liaison . • Le centre accueille les spécialistes et autres prestataires réalisant les bilans et suivis dans ses propres locaux, quand c'est possible, pour offrir aux personnes en situation de handicap intellectuel un environnement rassurant et calme .	• Dit centrum wordt bij voorkeur gecoördineerd door een arts (huisarts of specialist) met erkende deskundigheid in de ondersteuning van mensen met een verstandelijke beperking. • Het centrum ontwikkelt en coördineert een ondersteuningsaanbod voor andere ziekenhuiszorgverleners, referentiepersoon en liaisonteam . • Het centrum biedt, waar mogelijk, onderdak aan de specialisten en andere zorgverleners die de beoordelingen en follow-ups uitvoeren in zijn eigen gebouwen, om de PVB een geruststellende en rustige omgeving te bieden. • Het centrum zorgt voor een groep van opgeleidde vrijwilligers die de PVB en zijn entourage (indien zij dit wenst) begeleidt naar de verschillende afspraken in het ziekenhuis. • Het centrum biedt biopsychosociale ondersteuning en ontwikkelt in samenwerking met lokale en regionale deskundigen een focus op voorlichting aan patiënten en gezinnen, gezondheidspromotie en niet-	personnes en situation de handicap intellectuel, leur entourage et les professionnels qui les accompagnent • Coordination du centre interdisciplinaire de coordination et de consultations • Développement et coordination d'une offre de soutien pour les autres professionnels hospitaliers : personne-relais et équipe de liaison • Accueil des spécialistes et autres prestataires réalisant les bilans et suivis dans ses propres locaux, quand c'est possible • Inclusion d'une équipe de bénévoles formés accompagnant les personnes en situation de handicap intellectuel et leur entourage (si souhaité) lors des différents rendez-vous dans l'hôpital • Organisation d'un bilan biopsychosocial,	• Het voorzien van een polyvalente consultatieruimte binnen het interdisciplinair centrum waar specialisten en andere zorgverleners, waar mogelijk, onderzoeken en follow-ups kunnen uitvoeren • Het opzetten van een team van getrainde vrijwilligers om personen met verstandelijke beperkingen en hun entourage (indien gewenst) te begeleiden naar verschillende afspraken in het ziekenhuis • Organisatie van een biopsychosociale bilan, met inbegrip van niet-medische gezondheidsdeterminanten, en deelname aan gezondheidseducatie voor de patiënt en zijn entourage, therapeutische educatie en gezondheidspromotie • Doorverwijzing van de patiënt naar ondersteunende organisaties voor patiënten en gehandicapten • Coördinatie van de vertaling van in het ziekenhuisnetwerk beschikbare informatie in eenvoudige taal (website, verklarende of oriënterende panelen, enz.) • Integratie van een ervaringsdeskundige op het gebied van handicaps in het centrum • Integratie en financiering van personen met een

	• Le centre inclut une équipe de bénévoles formés qui accompagne la personnes en situation de handicap intellectuel et son entourage (si elle le souhaite) lors des différents rendez-vous dans l'hôpital. • Le centre fournit un soutien biopsychosocial et développe une attention à l'éducation du patient et de son entourage, à la promotion de la santé et aux déterminants non-médicaux de la santé en partenariat avec les acteurs locaux et régionaux experts en la matière. • Le centre connecte le patient aux associations de patients et de soutien des personnes en situation de handicap. • Le centre coordonne la mise en langage FALC des informations disponibles à l'hôpital (site internet, panneau explicatif ou d'orientation,…) avec l'appui d'associations spécialisées en FALC. • L'équipe du centre inclut un expert du vécu (cf. méthodologie) en situation de handicap.	medische gezondheidsdeterminanten. • Het centrum brengt de patiënt in contact met ondersteunende organisaties voor patiënten en personen met een beperking • Het centrum coördineert de vertaling van de in het ziekenhuis beschikbare informatie in eenvoudige taal (website, verklarend of oriënterend paneel, enz.) met de steun van in het FALC gespecialiseerde verenigingen. • In het team van het centrum zit een ervaringsdeskundige (cf. methodologie) op het gebied van beperkingen. • Het RIZIV en de FOD Maatschappelijke Integratie integreren en financieren de PVB in het ervaringsdeskundigenprogramma.	incluant les déterminants non médicaux de la santé, et participation à l'éducation pour la santé du patient, de ses proches, à l'éducation thérapeutique, et à la promotion de la santé • Connection du patient aux associations de patients et de soutien des personnes en situation de handicap • Coordination de la mise en langage FALC des informations disponibles dans le réseau hospitalier (site internet, panneaux explicatifs ou d'orientation…) • Inclusion d'un expert du vécu en situation de handicap dans le centre • Intégration et financement de personnes en situation de handicap intellectuel dans le programme des experts du vécu	verstandelijke handicap in het programma van ervaringsdeskundigen

		• L'INAMI et le SPP Intégration Sociale intègrent et financent des personnes en situation de handicap intellectuel dans le programme experts du vécu.			
		Competences of the educational staff in the disability sector			
Les professionnels non-soignants du secteur du handicap doivent être mieux informés et formés par rapport à la santé et aux soins pour les personnes en situation de handicap intellectuel. **Les professionnels non-soignants du secteur du handicap doivent être mieux formés quant à l'utilisation d'outils permettant d'identifier correctement les plaintes et problèmes de santé exprimés par les personnes en situation de handicap intellectuel, comme la douleur.**	**Niet-zorgverleners in de gehandicaptensector moeten beter geïnformeerd en opgeleid worden in verband met gezondheid en zorg voor personen met een verstandelijke beperking.** **Niet-zorgverleners in de gehandicaptensector moeten beter opgeleid worden in het gebruik van tools om klachten en gezondheidsproblemen van personen met een verstandelijke beperking, zoals pijn, correct te herkennen.**	• Le secteur du handicap, avec le soutien financier et logistique des autorités compétentes et en collaboration avec le secteur de la santé, organise la formation continue des professionnels concernant la santé des personnes en situation de handicap intellectuel, incluant la reconnaissance des symptômes et des besoins de santé, le décodage des plaintes et l'utilisation des outils d'évaluation des symptômes et de la douleur en particulier. • La participation aux formations continues fait partie des indicateurs de qualité dans les référentiels des services concernés avec un seuil minimal de personnes formées par institution. • Les autorités compétentes, avec le soutien des associations	• De gehandicaptensector organiseert, met de financiële en logistieke steun van de bevoegde autoriteiten en in samenwerking met de gezondheidssector, permanente opleiding voor professionals met betrekking tot de gezondheid van PVB, waaronder de herkenning van symptomen en gezondheidsbehoeften, de decodering van klachten en het gebruik van instrumenten voor de beoordeling van symptomen en pijn in het bijzonder. • Deelname aan bijscholing is een van de kwaliteitsindicatoren in de referentiekaders van de betrokken diensten, met een minimum aantal opgeleide personen per voorziening. • De bevoegde autoriteiten verspreiden jaarlijks, met de steun van gehandicaptenverenigingen, instrumenten voor de correcte identificatie van symptomen en gezondheidsbehoeften onder	• Organisation de la formation continue des professionnels concernant la santé des personnes en situation de handicap intellectuel, incluant la reconnaissance des symptômes et des besoins de santé, le décodage des plaintes et l'utilisation des outils d'évaluation des symptômes et de la douleur en particulier. • Diffusion annuelle des outils permettant d'identifier correctement les symptômes et les besoins en santé aux professionnels du secteur du handicap • Concertation sur le cadre de la dispensation de soins dans les institutions accueillant des personnes en situation de handicap intellectuel	• Organisatie van permanente opleiding voor professionals betreffende de gezondheid van personen met een verstandelijke beperking, met inbegrip van het herkennen van symptomen en gezondheidsbehoeften, het decoderen van klachten en het gebruik van tools om symptomen en pijn in het bijzonder te beoordelen. • Jaarlijkse verspreiding van tools om symptomen en gezondheidsbehoeften correct vast te stellen onder professionals in de gehandicaptensector • Overleg over het kader rond de organisatie van zorg in voorzieningen voor personen met een verstandelijke beperking • Opname van deelname aan bij- en nascholing als kwaliteitsindicator in de referentiesystemen van de betrokken diensten, met een minimum aantal opgeleide personen per voorziening

		du secteur du handicap, diffusent annuellement des outils permettant d'identifier correctement les symptômes et les besoins en santé aux professionnels du secteur du handicap.	professionals in de gehandicaptensector.	• Inclusion de la participation aux formations continues comme indicateurs de qualité dans les référentiels des services concernés avec un seuil minimal de personnes formées par institution	
Skills of HCP outside the disability sector					
Les professionnels de santé, et en particulier les médecins généralistes, doivent être mieux formés et préparés à accompagner les personnes en situation de handicap intellectuel et leur entourage.	**Zorgverleners, en in het bijzonder huisartsen, moeten beter opgeleid en voorbereid worden om personen met een verstandelijke beperking en hun entourage te ondersteunen.**	• Ebpracticenet , en partenariat avec la Société Scientifique de Médecine Générale (SSMG) et Domus Medica, développe et diffuse un guideline pour le suivi des personnes en situation de handicap intellectuel par les médecins généralistes, en ce compris les dépistages et examens préventifs et les outils d'évaluation des symptômes adaptés aux personnes en situation de handicap intellectuel. • Les professionnels de santé somatique et de la santé mentale, en partenariat avec les associations de personnes en situation de handicap intellectuel, développent et diffusent des recommandations de bonne pratique pour une	• Ebpracticenet ontwikkelt en verspreidt, in samenwerking met de Société Scientifique de Médecine Générale (SSMG) en Domus Medica, een richtlijn voor de follow-up van mensen met een verstandelijke beperking door huisartsen, met inbegrip van screenings- en preventieve onderzoeken en instrumenten voor symptoombeoordeling die zijn aangepast aan de PVB. • Professionals in de somatische en mentale gezondheidszorg ontwikkelen en verspreiden, in samenwerking met verenigingen voor mensen met een verstandelijke beperking, aanbevelingen voor goede praktijken voor de juiste aanpak van angst en agitatie bij mensen met een verstandelijke beperking tijdens de zorg .	• Développement et diffusion d'un guideline pour le suivi des personnes en situation de handicap intellectuel par les médecins généralistes, en ce compris les dépistages et examens préventifs • Développement et diffusion des recommandations de bonne pratique pour une gestion adaptée de l'angoisse et de l'agitation chez les personnes en situation de handicap intellectuel lors des soins et des actes techniques • Mise à disposition des professionnels de la santé du matériel nécessaire pour diminuer l'angoisse	• Ontwikkeling en verspreiding van een richtlijn voor de follow-up van personen met verstandelijke beperkingen door huisartsen, met inbegrip van screening en preventief onderzoek • Ontwikkeling en verspreiding van aanbevelingen voor goede praktijken voor de juiste aanpak van angst en agitatie bij personen met een verstandelijke beperking tijdens zorg- en technische procedures • Zorgverleners voorzien van het nodige materiaal om de angst en onrust van personen met verstandelijke beperkingen te verminderen • Ontwikkeling, verspreiding en voortzetting van een geaccrediteerde e-learningscursus voor zorgverleners over de benadering en ondersteuning van personen met verstandelijke beperkingen,

	gestion adaptée de l'angoisse et de l'agitation chez les personnes en situation de handicap intellectuel lors des soins. • Les directions hospitalières mettent à disposition des soignants le matériel nécessaire pour diminuer l'angoisse et l'agitation des personnes en situation de handicap intellectuel. • Le SPF Santé Publique et l'INAMI développent, diffusent et pérennisent une formation e-learning accréditée à destination des soignants concernant l'approche et l'accompagnement des personnes en situation de handicap intellectuel , en collaboration avec les associations professionnelles et les associations du secteur du handicap. • Les autorités compétentes, avec le soutien des associations du secteur du handicap, informent annuellement les professionnels de la santé de l'existence d'outils permettant d'identifier les symptômes et les besoins en santé des	• De ziekenhuisdirecties voorzien de zorgverleners van de nodige uitrusting om de angst en onrust van de PVB te verminderen. • De FOD Volksgezondheid en het RIZIV ontwikkelen, verspreiden en onderhouden een geaccrediteerde e-learningcursus voor zorgverleners over de aanpak en ondersteuning van mensen met een verstandelijke beperking , in samenwerking met beroepsverenigingen en verenigingen uit de gehandicaptensector. • De bevoegde autoriteiten informeren, met de steun van gehandicaptenorganisaties, zorgverleners jaarlijks over het bestaan van instrumenten om de symptomen en gezondheidsbehoeften van mensen met een beperking vast te stellen.	et l'agitation des personnes en situation de handicap intellectuel • Développement, diffusion et pérennisation d'une formation e-learning accréditée à destination des professionnels de santé concernant l'approche et l'accompagnement des personnes en situation de handicap intellectuel, en collaboration avec les associations professionnelles et les associations du secteur du handicap. • Information annuelle des professionnels de santé de l'existence d'outils permettant d'identifier les symptômes et les besoins en santé des personnes en situation de handicap intellectuel	in samenwerking met beroepsverenigingen en verenigingen in de gehandicaptensector. • Jaarlijkse informatie aan zorgverleners over het bestaan van tools om de symptomen en gezondheidsbehoeften van personen met verstandelijke beperkingen te identificeren

		personnes en situation de handicap intellectuel.			
Monitoring and follow-up of the health care needs					
Les opportunités en matière de collecte de données et de statistiques relatives à la santé des personnes en situation de handicap intellectuel doivent être développées.	Mogelijkheden voor het verzamelen van gegevens en statistieken over de gezondheid van personen met een verstandelijke beperking moeten worden ontwikkeld.	• Les autorités compétentes, avec le soutien des mutualités, créent un set d'indicateurs permettant un suivi des besoins de santé des personnes en situation de handicap intellectuel. • Sciensano prévoit un échantillon représentatif des personnes en situation de handicap intellectuel dans l'enquête nationale de santé par interview (HIS). • L'INAMI analyse annuellement les données de visites effectuées au domicile familial ou communautaire des personnes en situation de handicap intellectuel par les médecins spécialistes et investiguent les freins et incitants y afférant. • Les autorités compétentes, en collaboration avec la SSMG, Domus Medica et les mutualités, développent des indicateurs de suivi pour la prise en charge des personnes en situation	• De bevoegde autoriteiten werken, met de steun van de ziekenfondsen, aan een reeks indicatoren om de gezondheidsbehoeften van de PVB te monitoren. • Sciensano zorgt voor een representatieve steekproef van PVB in de Nationale Gezondheidsenquête (HIS). • Het RIZIV analyseert jaarlijks de gegevens over de bezoeken van de medisch specialisten aan de gezins- of gemeenschapshuizen van de PVB en onderzoekt de daarmee samenhangende ontmoedigende en stimulerende factoren. • De bevoegde autoriteiten ontwikkelen in samenwerking met SSMG, Domus Medica en de ziekenfondsen kwaliteitsindicatoren voor het management van PVB in de huisartsenpraktijk. • De bevoegde autoriteiten bepalen jaarlijks welke doelstellingen moeten worden bereikt op het gebied van de gezondheidsmonitoring van PVB door en met de voorzieningen van de gehandicaptensector.	• Création d'un set d'indicateurs permettant d'évaluer la performance du système de santé par rapport aux besoins de santé des personnes en situation de handicap intellectuel • Identification des besoins non rencontrés des personnes en situation de handicap intellectuel via la méthodologie développée par le KCE • Inclusion d'un échantillon représentatif des personnes en situation de handicap intellectuel dans l'enquête nationale de santé par interview (HIS) • Analyse annuelle des données de visites effectuées au domicile familial ou communautaire des personnes en situation de handicap intellectuel par les médecins	• Ontwikkeling van een reeks indicatoren om de performantie van het gezondheidssysteem met betrekking tot de gezondheidsbehoeften van personen met een verstandelijke beperking te monitoren • Identificatie van de onvervulde behoeften van personen met een verstandelijke beperking aan de hand van de door het KCE ontwikkelde methodologie • Opname van een representatieve steekproef van personen met verstandelijke beperkingen in de nationale gezondheidsenquête door middel van interviews (HIS) • Jaarlijkse analyse van gegevens over bezoeken van medisch specialisten aan de thuis- of gemeenschapswoningen van personen met verstandelijke beperkingen en onderzoek naar de belemmeringen en stimulansen daarvoor • Ontwikkeling van monitoring indicatoren voor de zorg voor personen met verstandelijke beperkingen in de huisartsenpraktijk

	de handicap intellectuel en médecine générale. • Les autorités compétentes déterminent annuellement des objectifs à atteindre en matière de suivi de santé des personnes en situation de handicap intellectuel par et avec les institutions du secteur du handicap.		spécialistes et investigation des freins et incitants y afférant • Développement d’indicateurs de suivi pour la prise en charge des personnes en situation de handicap intellectuel en médecine générale • Détermination annuelle des objectifs à atteindre en matière de suivi de santé des personnes en situation de handicap intellectuel par et avec les institutions du secteur du handicap	• Jaarlijkse vaststelling van de te bereiken doelstellingen op het gebied van gezondheidsmonitoring van personen met een verstandelijke handicap door en met de voorzieningen van de gehandicaptensector

APPENDIX 10. DETAILED RESULTS OF STAKEHOLDERS AND EXPERTS CONSULTATION

Appendix 10.1. Stakeholder consultation

The following tables present the detailed results of the stakeholder consultation (see 7.3.1).

Table 54 – Perception of the relevance of actions as expressed by stakeholder, by decreasing order of relevance

Categories	Action	Relevance (n=28)
Availability of HCP during consultations and visits	Planning an additional budget for longer consultations	22
Empowerment of people with ID and their supporters	Diffusing tools for empowerment	21
Availability of HCP during consultations and visits	Developing longer consultations for people with comprehension problems	21
Coordination and integration of health information and health care by the primary care	Creation of a nomenclature code for long consultation in general practice	20
Coordination and accompaniment in hospital context	Organising training for volunteers in hospitals	20
Coordination and accompaniment in hospital context	Creating interdisciplinary centre of coordination and consultation in hospital	20
Skills of HCP outside the disability sector	Diffusing tools for management of stress and anxiety	20
Skills of HCP outside the disability sector	Developing a training for HCP outside disability sector	20
Empowerment of people with ID and their supporters	Developing Easy read version of *Gezondheid en Wetenschap – Infosanté.be*	19
Coordination and integration of health information and health care by the primary care	Generalising the use of a liaison tool	19
Reachability of health care and outreaching	Informing GP about home visits by specialists	19
Coordination and accompaniment in hospital context	Planning of a budget for the adaptation of hospitals	19
Coordination and accompaniment in hospital context	Developing a support offer for other HCP by the centre	19
Skills in health of professionals inside the disability sector	Organising continuing education of staff of disability sector	19
Skills of HCP outside the disability sector	Developing guidelines for practice	19
Skills of HCP outside the disability sector	Diffusing tools for assessment of symptoms and needs	19
Empowerment of people with ID and their supporters	Informing about InfoSante.be	18
Empowerment of people with ID and their supporters	Improving living and working conditions of supporters	18

Coordination and integration of health information and health care by the primary care	Raising awareness about referent GP and patient health record	18
Coordination and integration of health information and health care by the primary care	Promoting liaison tools among GP	18
Coordination and integration of health information and health care by the primary care	Adaptation of nursing nomenclature for therapeutic education	18
Reachability of health care and outreaching	Increasing the number of home visits by specialists	18
Reachability of health care and outreaching	Diffusion of best practices for 112 transport	18
Skills in health of professionals inside the disability sector	Including continuing education as quality indicators in institutions	18
Monitoring and follow-up of the health care needs	Developing quality indicators in general practice	18
Coordination and accompaniment in hospital context	Including experts by experience	17
Skills in health of professionals inside the disability sector	Informing about assessment tools	17
Monitoring and follow-up of the health care needs	Creating indicators of follow-up of health of people with ID	17
Coordination and integration of health information and health care by the primary care	Organisation of an annual interdisciplinary consultation by the GP	16
Reachability of health care and outreaching	Informing specialists about home visits	16
Reachability of health care and outreaching	Orienting patients to their usual place of care in case of 112 transport	16
Coordination and accompaniment in hospital context	Organising consultations in the centre	16
Coordination and accompaniment in hospital context	Including trained accompanying volunteers in the centre	16
Coordination and accompaniment in hospital context	Increasing the budget for experts by experience	16
Skills of HCP outside the disability sector	Offering material support for management of stress and anxiety	16
Coordination and accompaniment in hospital context	Developing biopsychosocial support in the centre	15
Coordination and accompaniment in hospital context	Connecting people with ID to associations	15
Coordination and accompaniment in hospital context	Adapting hospital information in Easy Read format in hospitals	15
Monitoring and follow-up of the health care needs	Including a representative sample of people with ID in national health interview survey	15
Monitoring and follow-up of the health care needs	Analysing data of home visits by specialists	15

Coordination and accompaniment in hospital context	Adapting hospitals	14
Coordination and accompaniment in hospital context	Coordinating of centres by a medical doctor	12
Monitoring and follow-up of the health care needs	Determining performance indicators in health for institutions	12

Table 55 – Perception of the acceptability of actions by decreasing order of importance according to stakeholders

Categories	Actions	Acceptability (n=28)
Empowerment of people with ID and their supporters	Diffusing tools for empowerment	21
Coordination and integration of health information and health care by the primary care	Promoting liaison tools among GP	21
Availability of HCP during consultations and visits	Developing longer consultations for people with comprehension problems	21
Coordination and integration of health information and health care by the primary care	Raising awareness about referent GP and patient health record	20
Coordination and accompaniment in hospital context	Organising training for volunteers in hospitals	20
Coordination and integration of health information and health care by the primary care	Creation of a nomenclature code for long consultation in general practice	19
Reachability of health care and outreaching	Informing GP about home visits by specialists	19
Coordination and accompaniment in hospital context	Developing a support offer for other HCP by the centre	19
Skills of HCP outside the disability sector	Developing guidelines for practice	19
Empowerment of people with ID and their supporters	Developing Easy read version of *Gezondheid en Wetenschap – Infosanté.be*	18
Availability of HCP during consultations and visits	Planning an additional budget for longer consultations	18
Coordination and accompaniment in hospital context	Planning of a budget for the adaptation of hospitals	18
Coordination and accompaniment in hospital context	Increasing the budget for experts by experience	18
Skills of HCP outside the disability sector	Developing a training for HCP outside disability sector	18
Skills of HCP outside the disability sector	Diffusing tools for assessment of symptoms and needs	18
Empowerment of people with ID and their supporters	Informing about *Gezondheid en Wetenschap – Infosanté.be*	17
Empowerment of people with ID and their supporters	Improving living and working conditions of supporters	17
Coordination and integration of health information and health care by the primary care	Generalising the use of a liaison tool	17

Coordination and integration of health information and health care by the primary care	Adaptation of nursing nomenclature for therapeutic education	17
Coordination and accompaniment in hospital context	Creating interdisciplinary centre of coordination and consultation in hospital	17
Coordination and accompaniment in hospital context	Including trained accompanying volunteers	17
Skills in health of professionals inside the disability sector	Organising continuing education of staff of disability sector	17
Skills in health of professionals inside the disability sector	Including continuing education as quality indicators in institutions	17
Skills in health of professionals inside the disability sector	Informing about assessment tools	17
Skills of HCP outside the disability sector	Diffusing tools for management of stress and anxiety	17
Reachability of health care and outreaching	Increasing the number of home visits by specialists	16
Reachability of health care and outreaching	Diffusion of best practices for 112 transport	16
Monitoring and follow-up of the health care needs	Developing quality indicators in general practice	16
Coordination and integration of health information and health care by the primary care	Organisation of an annual interdisciplinary consultation by the GP	15
Coordination and accompaniment in hospital context	Adapting hospitals	15
Coordination and accompaniment in hospital context	Developing biopsychosocial support in the centre	15
Coordination and accompaniment in hospital context	Connecting people with ID to associations	15
Coordination and accompaniment in hospital context	Including experts by experience	15
Skills of HCP outside the disability sector	Offering material support for management of stress and anxiety	15
Reachability of health care and outreaching	Orienting patients to their usual place of care in case of 112 transport	14
Coordination and accompaniment in hospital context	Adapting hospital information in Easy Read format in hospitals	14
Reachability of health care and outreaching	Informing specialists about home visits	13
Coordination and accompaniment in hospital context	Coordinating of centres by a medical doctor	13
Coordination and accompaniment in hospital context	Organising consultations in the centre	13
Monitoring and follow-up of the health care needs	Including a representative sample of people with ID in national health interview survey	13
Monitoring and follow-up of the health care needs	Creating indicators of follow-up of health of people with ID	12
Monitoring and follow-up of the health care needs	Determining performance indicators in health for institutions	12
Monitoring and follow-up of the health care needs	Analysing data of home visits by specialists	11

Table 56 – Perceived feasibility of actions by decreasing order of feasibility according to stakeholders

Categories	Actions	Feasibility (n=28)
Coordination and integration of health information and health care by the primary care	Raising awareness about referent GP and patient health record	21
Empowerment of people with ID and their supporters	Diffusing tools for empowerment	17
Empowerment of people with ID and their supporters	Developing Easy read version of *Gezondheid en Wetenschap – Infosanté.be*	17
Skills of HCP outside the disability sector	Diffusing tools for assessment of symptoms and needs	17
Availability of HCP during consultations and visits	Developing longer consultations for people with comprehension problems	16
Coordination and accompaniment in hospital context	Organising training for volunteers in hospitals	16
Coordination and integration of health information and health care by the primary care	Creation of a nomenclature code for long consultation in general practice	16
Skills of HCP outside the disability sector	Diffusing tools for management of stress and anxiety	16
Reachability of health care and outreaching	Informing GP about home visits by specialists	15
Skills of HCP outside the disability sector	Developing a training for HCP outside disability sector	15
Empowerment of people with ID and their supporters	Informing about *Gezondheid en Wetenschap – Infosanté.be*	15
Coordination and integration of health information and health care by the primary care	Generalising the use of a liaison tool	15
Coordination and accompaniment in hospital context	Including experts by experience	15
Monitoring and follow-up of the health care needs	Creating indicators of follow-up of health of people with ID	15
Coordination and integration of health information and health care by the primary care	Promoting liaison tools among GP	14
Skills of HCP outside the disability sector	Developing guidelines for practice	14
Availability of HCP during consultations and visits	Planning an additional budget for longer consultations	14
Coordination and accompaniment in hospital context	Increasing the budget for experts by experience	14
Reachability of health care and outreaching	Diffusion of best practices for 112 urgent transport	14
Coordination and accompaniment in hospital context	Connecting people with ID to associations	14

Monitoring and follow-up of the health care needs	Including a representative sample of people with ID in national health interview survey	14
Coordination and accompaniment in hospital context	Creating interdisciplinary centre of coordination and consultation in hospital	13
Coordination and accompaniment in hospital context	Including trained accompanying volunteers	13
Skills in health of professionals inside the disability sector	Organising continuing education of staff of disability sector	13
Skills in health of professionals inside the disability sector	Including continuing education as quality indicators in institutions	13
Skills in health of professionals inside the disability sector	Informing about assessment tools	13
Coordination and accompaniment in hospital context	Developing biopsychosocial support in the centre	12
Coordination and accompaniment in hospital context	Developing a support offer for other HCP by the centre	11
Coordination and accompaniment in hospital context	Planning of a budget for the adaptation of hospitals	11
Monitoring and follow-up of the health care needs	Developing quality indicators in general practice	11
Skills of HCP outside the disability sector	Offering material support for management of stress and anxiety	11
Reachability of health care and outreaching	Orienting patients to their usual place of care in case of 112 urgent transport	11
Coordination and accompaniment in hospital context	Adapting hospital information in Easy Read format in hospitals	11
Reachability of health care and outreaching	Informing specialists about home visits	11
Empowerment of people with ID and their supporters	Improving living and working conditions of supporters	10
Coordination and integration of health information and health care by the primary care	Adaptation of nursing nomenclature for therapeutic education	10
Monitoring and follow-up of the health care needs	Determining performance indicators in health for institutions	10
Monitoring and follow-up of the health care needs	Analysing data of home visits by specialists	10
Coordination and accompaniment in hospital context	Adapting hospitals	9
Coordination and accompaniment in hospital context	Coordinating of centres by a medical doctor	9
Coordination and accompaniment in hospital context	Organising consultations in the centre	8
Coordination and integration of health information and health care by the primary care	Organisation of an annual interdisciplinary consultation by the GP	7
Reachability of health care and outreaching	Increasing the number of home visits by specialists	6

Table 57 – Difference between the perceived relevance and the perceived feasibility as expressed by stakeholders (n=28)

Categories	Actions	Relevance	Feasibility	Difference between the relevance and the feasibility
Reachability of health care and outreaching	Increasing the number of home visits by specialists	18	6	12
Coordination and integration of health information and health care by the primary care	Organisation of an annual interdisciplinary consultation by the GP	16	7	9
Availability of HCP during consultations and visits	Planning an additional budget for longer consultations	22	14	8
Coordination and accompaniment in hospital context	Organising consultations in the centre	16	8	8
Coordination and accompaniment in hospital context	Planning a budget for the adaptation of hospitals	19	11	8
Empowerment of people with ID and their supporters	Improving living and working conditions of supporters	18	10	8
Coordination and integration of health information and health care by the primary care	Adaptation of nursing nomenclature for therapeutic education	18	10	8
Coordination and accompaniment in hospital context	Developing a support offer for other HCP by the centre	19	11	8
Coordination and accompaniment in hospital context	Creating interdisciplinary centre of coordination and consultation in hospital	20	13	7
Monitoring and follow-up of the health care needs	Developing quality indicators in general practice	18	11	7
Skills in health of professionals inside the disability sector	Organising continuing education of staff of disability sector	19	13	6
Monitoring and follow-up of the health care needs	Analysing data of home visits by specialists	15	10	5
Reachability of health care and outreaching	Informing specialists about home visits	16	11	5
Skills of HCP outside the disability sector	Developing a training for HCP outside disability sector	20	15	5
Reachability of health care and outreaching	Orienting patients to their usual place of care in case of 112 urgent transport	16	11	5

Skills in health of professionals inside the disability sector	Including continuing education as quality indicators in institutions	18	13	5
Skills of HCP outside the disability sector	Offering material support for management of stress and anxiety	16	11	5
Availability of HCP during consultations and visits	Developing longer consultations for people with comprehension problems	21	16	5
Skills of HCP outside the disability sector	Developing guidelines for practice	19	14	5
Coordination and accompaniment in hospital context	Adapting hospitals	14	9	5
Skills of HCP outside the disability sector	Diffusing tools for management of stress and anxiety	20	16	4
Coordination and integration of health information and health care by the primary care	Generalising the use of a liaison tool	19	15	4
Reachability of health care and outreaching	Diffusion of best practices for 112 urgent transport	18	14	4
Coordination and integration of health information and health care by the primary care	Creation of a nomenclature code for long consultation in general practice	20	16	4
Coordination and accompaniment in hospital context	Adapting hospital information in Easy Read format in hospitals	15	11	4
Empowerment of people with ID and their supporters	Diffusing tools for empowerment	21	17	4
Coordination and accompaniment in hospital context	Organising training for volunteers in hospitals	20	16	4
Reachability of health care and outreaching	Informing GP about home visits by specialists	19	15	4
Skills in health of professionals inside the disability sector	Informing about assessment tools	17	13	4
Coordination and integration of health information and health care by the primary care	Promoting liaison tools among GP	18	14	4
Empowerment of people with ID and their supporters	Informing about *Gezondheid en Wetenschap – Infosanté.be*	18	15	3
Coordination and accompaniment in hospital context	Developing biopsychosocial support in the centre	15	12	3

Coordination and accompaniment in hospital context	Including trained accompanying volunteers	16	13	3
Coordination and accompaniment in hospital context	Coordinating of centres by a medical doctor	12	9	3
Monitoring and follow-up of the health care needs	Creating indicators of follow-up of health of people with ID	17	15	2
Coordination and accompaniment in hospital context	Including experts by experience	17	15	2
Empowerment of people with ID and their supporters	Developing Easy read version of *Gezondheid en Wetenschap – Infosanté.be*	19	17	2
Skills of HCP outside the disability sector	Diffusing tools for assessment of symptoms and needs	19	17	2
Monitoring and follow-up of the health care needs	Determining performance indicators in health for institutions	12	10	2
Coordination and accompaniment in hospital context	Increasing the budget for experts by experience	16	14	2
Monitoring and follow-up of the health care needs	Including a representative sample of people with ID in national health interview survey	15	14	1
Coordination and accompaniment in hospital context	Connecting people with ID to associations	15	14	1
Coordination and integration of health information and health care by the primary care	Raising awareness about referent GP and patient health record	18	21	-3

Table 58 – Number of stakeholders reporting not being competent to assess the actions

Categories	Actions	Not competent to answer (n=28)
Coordination and accompaniment in hospital context	Planning of a budget for the adaptation of hospitals	5
Coordination and accompaniment in hospital context	Coordinating of centres by a medical doctor	5
Coordination and integration of health information and health care by the primary care	Organisation of an annual interdisciplinary consultation by the GP	5
Coordination and accompaniment in hospital context	Including experts by experience	4
Skills of HCP outside the disability sector	Developing guidelines for practice	4
Coordination and accompaniment in hospital context	Increasing the budget for experts by experience	4
Monitoring and follow-up of the health care needs	Including a representative sample of people with ID in national health interview survey	4
Monitoring and follow-up of the health care needs	Developing quality indicators in general practice	4
Skills of HCP outside the disability sector	Offering material support for management of stress and anxiety	4
Coordination and accompaniment in hospital context	Adapting hospital information in Easy Read format in hospitals	4
Coordination and accompaniment in hospital context	Adapting hospitals	4
Empowerment of people with ID and their supporters	Developing Easy read version of *Gezondheid en Wetenschap – Infosanté.be*	3
Coordination and accompaniment in hospital context	Organising training for volunteers in hospitals	3
Coordination and integration of health information and health care by the primary care	Creation of a nomenclature code for long consultation in general practice	3
Skills of HCP outside the disability sector	Diffusing tools for management of stress and anxiety	3
Coordination and integration of health information and health care by the primary care	Generalising the use of a liaison tool	3
Reachability of health care and outreaching	Diffusion of best practices for 112 urgent transport	3
Coordination and accompaniment in hospital context	Connecting people with ID to associations	3
Coordination and accompaniment in hospital context	Including trained accompanying volunteers	3
Coordination and accompaniment in hospital context	Developing biopsychosocial support in the centre	3

Coordination and accompaniment in hospital context	Developing a support offer for other HCP by the centre	3
Reachability of health care and outreaching	Orienting patients to their usual place of care in case of 112 urgent transport	3
Empowerment of people with ID and their supporters	Improving living and working conditions of supporters	3
Coordination and integration of health information and health care by the primary care	Adaptation of nursing nomenclature for therapeutic education	3
Skills of HCP outside the disability sector	Developing a training for HCP outside disability sector	2
Coordination and integration of health information and health care by the primary care	Promoting liaison tools among GP	2
Availability of HCP during consultations and visits	Planning an additional budget for longer consultations	2
Coordination and accompaniment in hospital context	Creating interdisciplinary centre of coordination and consultation in hospital	2
Reachability of health care and outreaching	Informing specialists about home visits	2
Monitoring and follow-up of the health care needs	Determining performance indicators in health for institutions	2
Monitoring and follow-up of the health care needs	Analysing data of home visits by specialists	2
Coordination and accompaniment in hospital context	Organising consultations in the centre	2
Reachability of health care and outreaching	Increasing the number of home visits by specialists	2
Coordination and integration of health information and health care by the primary care	Raising awareness about referent GP and patient health record	1
Empowerment of people with ID and their supporters	Diffusing tools for empowerment	1
Skills of HCP outside the disability sector	Diffusing tools for assessment of symptoms and needs	1
Availability of HCP during consultations and visits	Developing longer consultations for people with comprehension problems	1
Reachability of health care and outreaching	Informing GP about home visits by specialists	1
Empowerment of people with ID and their supporters	Informing about *Gezondheid en Wetenschap – Infosanté.be*	1
Monitoring and follow-up of the health care needs	Creating indicators of follow-up of health of people with ID	1
Skills in health of professionals inside the disability sector	Organising continuing education of staff of disability sector	1

Skills in health of professionals inside the disability sector	Including continuing education as quality indicators in institutions	1
Skills in health of professionals inside the disability sector	Informing about assessment tools	1

Appendix 10.2. Experts consultation

Table 59 – Perceived relevance of global solutions as expressed by experts

Categories	Global solution	Relevant	Not relevant	Don't know	Abstention	Total
Availability of HCP during consultations and visits	The RIZIV – INAMI must introduce a preferential status for people with special needs, so that they can benefit from a longer consultation or visit.	12	0	2	2	16
Reachability of health care and outreaching	People with ID must have the possibility of being cared for in their usual place of residence.	12	3	2	1	18
Reachability of health care and outreaching	People with ID must be accompanied by a person of their choice during transport in case of emergency, provided that the safety of that person is guaranteed..	16	0	1	1	18
Coordination and accompaniment in hospital context	All hospitals and health services should provide an infrastructure that allows people with ID to be accompanied by a person of their choice at any time and any place.	10	1	5	1	17
Coordination and accompaniment in hospital context	Hospitals with a centre for clinical genetics or a neuro-paediatric department should organise a multidisciplinary coordination and consultation centre for people with ID, regardless of age.	10	0	2	0	12
Skills in health of professionals inside the disability sector	Professionals in the disability sector should be trained in the health of people with ID.	10	0	0	0	10

The variations of the denominators reflect the variation of the presence during the meeting (late arrival, interruptions because of phone calls or personal break…).

Table 60 – Perceived feasibility of global solutions as expressed by experts

Categories	Global solution	Feasible	Not feasible	Don't know	Abstention	Total
Availability of HCP during consultations and visits	The RIZIV – INAMI must introduce a preferential status for people with special needs, so that they can benefit from a longer consultation or visit.	5	1	9	1	16
Reachability of health care and outreaching	People with ID must have the possibility of being cared for in their usual place of residence.	2	7	6	3	18
Reachability of health care and outreaching	People with ID must be accompanied by a person of their choice during transport in case of emergency, provided that the safety of that person is guaranteed..	9	1	7	1	18
Coordination and accompaniment in hospital context	All hospitals and health services should provide an infrastructure that allows people with ID to be accompanied by a person of their choice at any time and any place.	9	0	7	1	17
Coordination and accompaniment in hospital context	Hospitals with a centre for clinical genetics or a neuro-paediatric department should organise a multidisciplinary coordination and consultation centre for people with ID, regardless of age.	9	0	3	0	12
Skills in health of professionals inside the disability sector	Professionals in the disability sector should be trained in the health of people with ID.	8	0	2	0	10

The variations of the denominators reflect the variation of the presence during the meeting (late arrival, interruptions because of phone calls or personal break…).

Table 61 – Difference between the perceived relevance and the perceived feasibility as expressed by experts

Categories	Global solution	Relevant	Feasible	Difference between relevance and feasibility
Reachability of health care and outreaching	People with ID must have the possibility of being cared for in their usual place of residence.	12	2	10
Availability of HCP during consultations and visits	The RIZIV – INAMI must introduce a preferential status for people with special needs, so that they can benefit from a longer consultation or visit.	12	5	7
Reachability of health care and outreaching	People with ID must be accompanied by a person of their choice during transport in case of emergency, provided that the safety of that person is guaranteed. .	16	9	7
Skills in health of professionals inside the disability sector	Professionals in the disability sector should be trained in the health of people with ID.	10	8	2
Coordination and accompaniment in hospital context	All hospitals and health services should provide an infrastructure that allows people with ID to be accompanied by a person of their choice at any time and any place.	10	9	1
Coordination and accompaniment in hospital context	Hospitals with a centre for clinical genetics or a neuro-paediatric department should organise a multidisciplinary coordination and consultation centre for people with ID, regardless of age.	10	9	1