“What matters, doctor?” A qualitative and inclusive study of the experience of mainstream healthcare among people with intellectual disabilities in Belgium

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Abstract

Background This study investigates the healthcare needs and experiences of adults with intellectual disabilities, focusing on identifying areas for improvement. Its innovation lies in including individuals with intellectual disabilities as co-researchers in the research process.
Method Thematic analysis was performed on five focus groups with 30 participants, exploring access to healthcare. Three co-researchers played active roles in reviewing the interview, recruitment, facilitation, and co-analysis of results.
Results Three types of specific needs emerged: communication, relational, and support needs, as well as challenges in empowerment and shortcomings in the skills of professionals.
Conclusions Intervention programmes aimed at training doctors and healthcare professionals should consider the specific difficulties and needs of people with intellectual disability, and their input should be prioritized in the design of these interventions.

Key words: intellectual disability, healthcare, health needs, inclusive research, co-researching

Lay summary

- This study focuses on the needs and experiences of adults with intellectual disability in the context of healthcare to identify and explore avenues for improvement.
- It interviews the people themselves with the help of three people with intellectual disability as co-researchers.
- The results highlighted communicational, relational, and support needs, as well as challenges in empowerment and shortcomings in the skills of professionals.
- The specific difficulties and needs of people with intellectual disability should be considered in the development of intervention programmes aimed at training doctors and healthcare professionals.

1. Introduction

People with intellectual disability are more affected by health problems than the general population (Havercamp & Scott, 2015). This precarious health is not solely attributable to illnesses or health conditions associated with intellectual disability, but also to inequities in access to care (Emerson, 2011, 2021). These inequities include a greater prevalence of adverse conditions, inappropriate attention to health needs, inadequate emphasis on prevention, and insufficient access to quality healthcare services (Havercamp & Scott, 2015; Havercamp & Bonardi, 2022; Johnston et al., 2022; Krahn et al., 2006; Krahn & Fox, 2014; Lauer et al., 2021; Sabatello, 2018; St. John et al., 2018). The World Health Organization (2018) reports a concerning outlook for hospital care and access to general health services for people with intellectual disabilities, emphasizing that, despite some progress made in recent years, they remain far from fulfilling the right to health for many individuals with disabilities, who continue to face earlier mortality, poorer health outcomes, and greater challenges in daily functioning compared to others.

Among the inequities faced by people with intellectual disabilities, the most significant barriers include discrimination resulting from negative attitudes among healthcare professionals (Ali et al., 2013; Bacherini et al., 2021; Drozd & Clinc, 2016; Lewis & Stenfert Kroese, 2010; McConkey & Truesdale, 2000; VanPuymbrouck et al., 2020), as well as stigma and stereotypes (Pelleboer-Gunnink et al., 2017) that is, thinking that people with intellectual disability are unable to describe their symptoms, to understand the information that concerns them and take part in decision-making about their health (Rinaldi & Batselé, 2023). Compounding these

challenges, some healthcare professionals exhibit negative perceptions about disability and report feeling unprepared and uncomfortable when addressing the healthcare needs of patients with disabilities (Desroches et al., 2019; Iezzoni et al., 2021). In fact, the lack of knowledge and skills of healthcare staff regarding intellectual disability is pointed out as a significant factor contributing to this discrimination (Iacono et al., 2014; Kirschner & Curry, 2009). Thus, it is concerning to see that healthcare professionals do not receive specific training in intellectual disability, particularly with regard to medical consultation (Myśliwiec et al., 2015; Rinaldi & Batselé, 2023; Trollor et al., 2016). It stands in stark contrast with the United Nations Convention on the Rights of Persons with Disabilities (article 25) promoting the inherent right to experience the highest possible standard of health (physical, mental, and social) without facing any form of disability-based discrimination (United Nations, 2006).

In this context, it is important to focus on the needs and experience of adult with intellectual disability. As reported in a recent literature review (McCormick et al., 2021), there are still few studies looking specifically at the experiences of people with intellectual disability accessing hospital services, unlike the research focusing on the experiences of healthcare staff supporting adults with intellectual disability (e.g., Appelgren et al., 2018; Drozd & Clinch, 2016; Lewis et al., 2017). The need to improve healthcare for individuals with intellectual disability was highlighted by the deficiencies in communication, insufficient information sharing, and concerns regarding compassionate care and respect (McCormick et al., 2021). The barriers encounter by people with disabilities are not limited to hospitals services but extend to access to healthcare in general. Indeed, individuals with intellectual disabilities often express lower levels of satisfaction with their medical care compared to the general population (Gibson & O'Connor, 2010). In Australia, a recent study that surveyed individuals themselves highlighted barriers such as inequitable healthcare services, the informed consent process, exclusion, and fear. Authors provided recommendations for the use of a more inclusive model of care (Strnadova et al., 2023). In this regard, the use of reasonable accommodations is mentioned in the literature, such as the ability to communicate preferences regarding a communication book (Marsden & Giles, 2017), adjustment of waiting times for treatment (Tuffrey-Wijne et al., 2014), an introduction of the professionals involved in the care (Webber et al., 2010), and a quiet room for waiting (Brown et al., 2012). Although perceived positive outcomes can be recognized, there is limited information regarding the actual implementation and evaluation process, especially considering the need to address the specific needs of individuals with

intellectual disabilities within the care system (Moloney et al., 2021). It is therefore essential to actively engage with their needs in order to identify and address issues from the outset.

In Belgium specifically, the United Nations Convention on the Rights of Persons with Disabilities has been ratified in 2009, and despite a 2021-2024 federal plan for disabled people, not much has been done to improve healthcare access for disabled people, as reported by them in the UNIA[1] consultative report (UNIA, 2020). The Belgian healthcare system is based on a liberal model in which physicians have significant freedom in their practice and patients can choose their providers. Most doctors are self-employed and paid on a fee-for-service basis. The healthcare system is strong in acute care, with many hospital beds and doctor consultations, but preventive services are less developed. There is a growing focus on integrated care, particularly for chronic conditions and mental health, with a shift toward community-based services. While the number of healthcare professionals is stable, there are concerns about a shortage of general practitioners in the future. Thus, the objective of this study is to examine the experience of people with intellectual disability in the context of medical consultation (accessibility, welcoming, support and health care) in Belgium through qualitative and inclusive design (using the focus groups method). This aims to highlight their needs and potential challenges in order to explore possible avenues for enhancing health empowerment by using an approach in which stakeholders (people with life experience of intellectual disability) play an active role in the research. Indeed, inclusive research has experienced significant growth and demonstrated its relevance (Bigby & Frawley, 2010; Garbutt et al., 2010; Kramer et al., 2011; O'Brien et al., 2014; Tuffrey-Wijne & Butler, 2010; Turk et al., 2012; Walmsley et al., 2018). The involvement of people with intellectual disability in research is consistent with the empowering motto, "nothing about us, without us." This principle underscores the importance of including individuals with intellectual disability as active contributors, ensuring that their voices, perspectives, and experiences are not only acknowledged but also integral to the research agenda. By adopting inclusive research practices, we strive to create a more equitable and representative body of knowledge, promoting a shift toward inclusivity in healthcare and recognizing the expertise that individuals with intellectual disability bring to the research endeavour.

[1] UNIA is an independent public institution that fights discrimination and promotes inclusion in Belgium. See https://www.unia.be/fr.

2. Method

2.1. Participants

Experience of healthcare was explored through the organization of focus groups composed of 30 participants with intellectual disability (16 female and 1 ungendered, age = 25-73, M = 47.67, SD = 18.28; the youngest has 22 and the oldest has 92). The age distribution was as follows: 12 were under 40, 9 were between 40 and 60 and 9 were over 60. They lived in a residential (N = 22), family (N = 7), or independent (N=1) environment. Although not mandatory, they could be accompanied by a family member or a carer to support them and feel comfortable. A total of 23 accompanying persons (16 female, age = 19-72, M = 46.05, SD =16.31) were present during focus groups, of whom only 4 were relatives. Inclusion criteria were as follows: being an adult aged 18 years old or older with intellectual disability, being able to communicate verbally in French, willing to participate in the study, and living in the French community of Belgium. There were no exclusion criteria. Institutions supporting adults with intellectual disability were contacted by email. Information about the study was given to institutions' directors and direct-care staff, and an adapted flyer (in "Easy Read") intended to people with intellectual disability was transmitted. The staff of the institutions (i.e. direct-care staff) made the initial contact with people they identified as having had health problems in their lifetime and informed them about the study to determine if they were interested in taking part. Some relatives of the people who accepted to take part in the study heard about the project and asked to join the focus group.

Once the participants were identified, focus groups were organized either in a meeting room rented out by the co-researchers (focus-groups 1 and 2) or within the institution when travels was difficult to manage (focus-groups 3, 4, 5). All participants provided their informed consent. Interview settings were designed to prioritize safety and comfort. Strict measures were implemented to uphold confidentiality. Participants received verbal explanations regarding the research objectives and were assured of the voluntary nature of their participation. They were informed that the data collected would be processed anonymously and were informed of their right to decline to answer any question without providing a reason. Written consent was obtained from each participant, in accordance with the principles outlined in the European Data Protection Law (EDPL). This project has been approved by the ethical committee of the University of Mons.

Three persons (2 females, 1 male; age 39, 62, and 57) with intellectual disability took part in this study as co-researchers. The specific aspects of the process used with the co-researchers will be discussed elsewhere.

2.2. Procedure

A semi-structured interview guide was created based on the literature. The interview started with ice-breaking activities, consisting of initiating conversation by inquiring about the participants' well-being and their preference regarding whether to be addressed by their first or last name. Four themes were then addressed: 1) the experiences of people with intellectual disability in mainstream healthcare; 2) the interaction between people with intellectual disability and healthcare professionals; 3) the knowledge and skills of doctors; and 4) the support needs. A focus was made on doctors through all questions of the interview because this study is part of a larger research project that aims to develop a training on how to take care of people with intellectual disability (and more generally, cognitive and communication difficulties) specifically addressed to doctors. Focus groups were animated and moderated by one researcher and all three co-researchers (see Table 1 for an example of the topics covered).

Table 1. Example of topics covered by the four themes

Themes	Topics	Examples
Theme 1	The experiences of people with intellectual disability	*Are you satisfied with the health services? Why? Are you asked for your consent to prescribe a treatment? Do you feel discriminated against and stigmatized by doctors? Why?*
Theme 2	The interaction between people with intellectual disability and healthcare professionals	*Is it easy to communicate with doctors? Can you give us an example? Do you think the medical facilities are adapted? Can you tell us what you would like? Have you ever received help to find your way around medical facilities such as hospitals?*
Theme 3	The knowledge and skills of doctors	*Do you think that doctors have sufficient skills to take care of patients*

		with intellectual disability? Do you think doctors are used to encountering patients with intellectual disability? Can you explain why?
Theme 4	Support needs	*How can doctors provide better care? Can you think of any improvements that would help? Do you dare to express your needs during a medical consultation?*

A total of five focus groups were held (see Table 2), from December 2023 to February 2024. They were audio and video recorded, but the focus group 4 was not video recorded because of a technical problem with the camera. All audio was transcribed for analysis. Each focus group lasted approximately 2 hours and was co-facilitated by 2 researchers and 3 co-researchers.

Table 2. Participants of the focus-group

Focus groups	Participants with intellectual disability	Accompanying persons	Video records	Audio records
1	4	5	Yes	Yes
2	6	4	Yes	Yes
3	11	5	Yes	Yes
4	4	7	No	Yes
5	5	2	Yes	Yes

A thematic analysis approach was employed to identify pertinent themes within the transcripts. The data were organized and analysed using NVivo® (version 13) to facilitate coding and categorization of units of meaning. In line with Braun and Clarke's (2006) guidelines, one member of the research team (A.M.) meticulously reviewed interview responses multiple times. This iterative process facilitated the initial development of codes and thematic structures through an inductive approach, whereby themes emerged organically from the data without imposing preconceived notions. Subsequently, another team member (E.B.) conducted an independent coding process, with any discrepancies resolved through collaborative discussion

until consensus was achieved. The main themes and subthemes identified in the analysis are described in the Results section (see also appendix A). The number of references refers to the number of times the same topic was discussed (and may concern the same person several times). As not all subjects were equally explored across groups due to time constraints, the number of participants identified for theme emergence was not representative and was not indicated for these reasons.

3. Results

3.1. Thematic analysis

Five main themes emerged from the thematic analysis:

1. Communicational needs
2. Relational needs
3. Support needs
4. Empowerment challenges
5. Professional skills

Communicational needs

This theme included all aspects of the communication between doctors and people with intellectual disability that can be both a barrier and a facilitator to the inclusion of people with intellectual disability in mainstream healthcare. Four categories were identified within this theme: *adaptation of communication, direct/indirect communication, inappropriate vocabulary,* and *posture in communication.*

Participants clarified that **adapting the communication** during medical consultations and/or care has positive consequences (e.g., satisfaction, well-being, compliance) (24 references). It involves paying specific attention to conveying an appropriate amount of information regarding treatment and intervention, clarifying people's medical situation, and giving a rationale for a treatment option using culturally sensitive communication channels; this allowed participants involved to use simplified terms, speak more slowly, and give them time to understand and ask questions. This also involves the ability to question them about their experience, particularly regarding how the treatments are working or not. However, a failure to adapt the explanations during medical care leads to negative consequences such as dissatisfaction, unease, noncompliance, and so on (50 references).

> "The gynaecologist prescribed a drug but explained why I was taking it. If you go into detail, it's fine."

> "What I want from a doctor is for him to explain everything to me and to understand me, because sometimes he doesn't understand what we have. And sometimes their terms are weird."

Regarding **direct/indirect communication**, people with intellectual disability reported that a doctor often addresses their family member or support worker whenever he/she is present, thereby lacking consideration for the person him-/herself (e.g., do not look at them, do not speak to them) (22 reference), which they experience as a form of violence and disrespect towards their own voice and opinions.

> "Me, I was with my social worker for my ears; well, the guy, because I was with a social worker, he thought I was a bit stupid, and he asked my social worker questions."

Disrespect may also take more straightforward forms as some participants reported the use of **inadequate and disrespectful vocabulary** when they are addressed (6 references).

> "We went to the doctor, and the doctor said, 'we're in a madhouse here' [...]. That's when I lost it."

Regarding the **posture in communication**, some people with intellectual disability report they would like to be well received in order to feel secure, which is not the case when doctors adopt a "cold" or "closed" attitude. Also, some suggest that the very first contact with the doctor is important (6 references).

> "And above all, sometimes it's scary because it depends on the doctors and their moods. Sometimes doctors are in a bad mood, I understand, but sometimes you have doctors who are grumpy."

Relational needs

This theme involves aspects of relation, including sensibility, respect, and confidence between the doctor and his patient, that are evoked. Five categories emerged: *respect, discrimination, listening to needs, time,* and *proximal follow-up*.

Respect is highlighted as an important value. It covers the tolerance of other people's differences and being treated as an adult (i.e., dignity) (5 references).

> "And that ... the doctor is decent to us, is respectful, and treats us like human beings and not like guinea pigs or objects; that's something I don't agree with!"

In addition, most of the focus groups mentioned numerous elements of **discrimination** (38 references). Among these, medical *paternalism* and *infantilization* were the sub-categories that emerged. With regard to the first, some people with intellectual disability (13 references)

deplored an attitude on the part of doctors, resulting in the authoritarian imposition of medical decisions without taking their feelings or preferences into account (minimizing, imposing their judgement, and blackmailing). In the second sub-category, some people with intellectual disability (8 references) felt infantilized during medical consultations, particularly when doctors were on a first-name basis with them (2 references).

> "Because they say "you should do that you should do that" it's childish."

Listening to the person's needs implies that the doctor gives them the space to express their needs and requests and to hear what they have to say—for example, by asking them questions to investigate their request. This has positive consequences such as satisfaction, well-being, and confidence in the doctor (32 references).

> "My doctor's name is **** but he's like that, he's an expert, he listens to you, you talk to him, "what do you need?", "I need this", he writes you a prescription and everything."

However, many people with intellectual disability (30 references) have told us that doctors do not listen to their patients, leading to negative consequences such as dissatisfaction, frustration, unease, and negative emotions.

> "For me, they give me some pills; I ask to see the psychiatrist, and she's busy ... she's busy ... she's busy and that's it [...] They wait until I crack and then magically... she takes you, but it really has to be ... [...] the crisis where they have to give you medication and put you ... tied up in bed."

Regarding the **time** category, long delays in obtaining an appointment with a specialist create a feeling of being neglected (6 references). During the appointment, when enough time is devoted to the consultation, people with ID feel satisfied and listened to. On the other hand, insufficient time leads to dissatisfaction and a feeling of not being able to express themselves (13 references).

> "I don't even have time to say a word before the meeting is over ... it's sad because I ... I have the right to express myself, too."

Furthermore, delays in doctors' appointments are a stressful and frustrating moment for people with ID. The long wait in the waiting room can be particularly difficult for some people to cope with (7 references).

> "Delays in the waiting room and also failure to keep appointments, with some people it can be very long and difficult, but sometimes you have to wait 45 minutes in the waiting room, which is a bit difficult."

Regarding the **proximal follow-up**, having a general practitioner (GP) establishes trust and prior knowledge so that continuity of care can be ensured, particularly thanks to the GP's availability. In addition, the GP plays an essential role in referring people to the appropriate specialists (12 references).

> "She takes care of all the paperwork and ... when I had psychiatric crises, she was there. She helped me a lot to avoid going to hospital; she helped me a lot."

It should be noted that requiring a consultation with the GP before being referred to a specialist was also mentioned as a potential difficulty. In addition, some people deplore the lack of adequate follow-up by the GP, who often postpones action until later (3 references).

Support needs

Support needs concerns both *human (family, partner, or professionals*) and *technical (physical) support*, or it includes *both (integrative)*, providing help before, during, or after the consultation.

The **presence of a third party** can improve the healthcare experience and the outcome of medical consultations by helping people with intellectual disability express themselves, understand information, or feel safe in visiting medical environments, managing appointments, and so on (41 references).

> "If I am accompanied, it's because it reassures me and because I don't trust my doctor and the medical jargon."

However, the presence of a third party is a double-edged sword, and the likelihood that this arrangement meets support needs depends heavily on the individual's stance and the doctor's communication, as we have discussed in the theme "Communicational needs."

> "She talks a lot with my mother, and when I'm going alone… she gives me medicines and does not talk too much. She talks more when I go with my mom."

The use of **technical tools** support, such as a diary (1 reference) and a medical notebook (13 references), as well as visual support (e.g., pictograms and pictures) or writing support (13 references), can improve access to the information that concerns them (medication intake, appointments, allergies, etc.) and the transmission of this information to the doctor during the consultation. It can also be used to keep a record of the information discussed during the consultation. Specifically, using a diary can help to manage appointments independently.

Communication with the doctors can also be facilitated thanks to a medical notebook. Also, the use of visual aids, such as written documents containing the main information discussed during the consultation (medication, explanations, etc.), pictograms, and pictures to facilitate understanding and communication, can be very useful. For example, one participant wanted a picture of the medicine box and its purpose on a document to take home. Moreover, in addition to visual support, people with intellectual disability also mentioned the value of using colour codes to help them find their way around hospitals, as well as the need to enlarge characters that are too small to read in order to display information in medical facilities.

> "When you have a prescription […] I was obliged to have a piece of paper to explain it to me, or else if you don't have that, how do you do it? Words are easy, but you forget them, but on paper […] they stick."

In addition, among technical support, one person (1 reference) also pointed out the lack of accommodation available for disabled people; for example, parking spaces were located a far distance from hospital entrances.

Regarding **integrative support**, the presence of a liaison person simplifies the inclusion of people with intellectual disability in healthcare by providing a link to the various specialist services or doctors (4 references). More generally, the presence of services that provide human and logistic support adapted to the person's specific needs (directing the person in the hospital, adapting the brightness of the room, etc.) is appreciated by people with intellectual disability, although this assistance was only available in one hospital (7 references).

Empowerment challenges

This theme includes the challenges that people with intellectual disability face on a daily basis in the context of an asymmetric relationship between health professionals and people with intellectual disability (as a consequence of the relational difficulties mentioned above). This theme covers three categories: *asking for consent, difficulty expressing needs*, and *anger and fear of doctors*.

The absence of a request for consent for a medical procedure or the prescription of medication has been highlighted as a contributor to dissatisfaction, noncompliance, and sometimes aggression (10 references). On the other hand, asking for consent appeared to be essential to ensure compliance with the treatment or examination (5 references).

> "But even when I'm prescribed it, I bang my head on the table. They have to say: do you agree to have this? If I know what it is, yes. If I don't know, no."

People with intellectual disability also report **difficulties in expressing their needs**, especially when the doctor is not attentive, when the doctor changes frequently, or when there is an accompanying person present during medical consultations (5 references). However, they dare to express themselves when they feel confident with the doctor and if they have a certain level of autonomy (11 references).

In addition, many people (25 references) told us about the **anger** and dissatisfaction they feel toward the mainstream healthcare because of the disrespectful and discriminatory way in which they are treated. They feel a deep sense of injustice toward doctors who do not take their needs into account and are often condescending. This situation sometimes leads them to seek care elsewhere, increasing their frustration and sense of mistreatment.

> "Me, I think ... why are doctors like that with us? We're different, and they talk to us like that; what have we done? I don't think it's normal."

In other respects, for some people with intellectual disability, seeing a doctor can be **frightening**, but they are unable to explain why (10 references).

> "I'm scared...That's it. I'm always scared. I go over there, I'm already scared."

Professional skills

This theme covers the skills that professionals lack, according to people with intellectual disability. Two specific categories emerged: *knowledge of intellectual disability* and *diagnostic masking.*

Some people with intellectual disability reported **a lack of knowledge and training about ID** among doctors because they lack empathy and the ability to listen to their specific needs (7 references). However, in their opinion, informing doctors about intellectual disability and specific disability situations (specific needs) would be beneficial for their inclusion in mainstream healthcare (7 references).

> "I think it's a failing on the part of doctors that they don't have a course in training to help people because they don't know about empathy, listening, talking, and all that."

With regard to **diagnostic masking (i.e., overshadowing)**, a number of reports (17 references) highlighted the fact that the difficulties, pain, and symptoms encountered by people with intellectual disability are attributed de facto to disability or to cognitive and communicational particularities.

4. Discussion

The aim of this study was to investigate the experiences and needs of people with intellectual disability regarding healthcare in order to identify avenues for improvement. Conducted inclusively, this study involved the collaboration of three co-researchers. On one hand, three types of needs emerged: communication, relationships, and support. On the other hand, empowerment challenges and professional skills were highlighted.

The main finding regarding communication concerns the need to **better understand the information** shared by the medical professional. In particular, people with intellectual disability would like to have better explanations for this information and for doctors to make adjustments. As already emphasized by Howieson (2015), people with intellectual disability require the use of a simplified vocabulary free of medical jargon. In addition, slower speech was highlighted as an essential aid. These points, which reflect communication difficulties and inadequate sharing of information, are in line with what has already been shown in the literature (Ali et al., 2013; Bell, 2012; Howieson, 2015; Tuffrey-Wijne & Butler, 2010). Although this existing body of literature relates mainly to experiences of hospital services (Shady et al., 2024), it seems that, in our study, these findings can be generalized to broader healthcare experiences in mainstream services. Considering the specific context of Belgium, a study conducted in Dutch-speaking part of Belgium revealed that even general practitioners and nurses working in home or residential care settings report lacking knowledge about adapted communication for disabled patients and attribute the communication difficulty mainly to limited capacities of these patients (Storms et al., 2017). However, we do not have other study conducted in Belgium and investigating the experience of people with intellectual disability directly to compare our results with, to the extent of our knowledge.

Another important need in the relation is to be **respected and considered as adults**. This has been reported elsewhere (McCormick et al., 2021) and testifies to the wide gap between the expectations of people with intellectual disability and the attitude of doctors. To bridge this gap, people with intellectual disability ask the doctor to ask them questions so they can express themselves about their medical situation (i.e., whether their medication is effective, whether a

change in treatment is necessary, etc.). They ask to be heard and listened to and for time during the consultation to be devoted to this. It should be noted that one of the mentioned obstacles to the expression of needs was the **presence of the carer** during consultations. Indeed, people with intellectual disability criticize the fact that the doctor generally addresses the accompanying person when he/she is present, and they feel ignored. In line with what Walker et al. (2016) stated, people with intellectual disability want to be given the space to give their own opinion. It should also be noted that the presence of the accompanying person was often cited as being a real support for people with intellectual disability, both for emotional (e.g., reassurance) and practical reasons (e.g., support for explanations given by the doctor, expression of needs). Indeed, the beneficial role of carers is widely recognized (Charles, 2020; Williamson & Meddings, 2018). Among the positive aspects of relation, we found it interesting that the ability to turn quickly to one's GP was a facilitating factor for the inclusion of people with intellectual disability in healthcare because the GP adequately knows the person and his/her needs. Therefore, this proximal follow-up seems crucial for people with intellectual disability. In this respect, one recent study has shown that having contact with people with intellectual disability via employment is linked to better representations and practices in inclusive health as a result of low social distance (Lucassen et al., 2024). Already in 2010, in a systematic review, Gibson and O'Connor highlighted the important role of GP in supporting the healthcare needs of people with intellectual disabilities by recommending that doctors prioritize registering individuals with special needs, emphasizing the importance of creating a more inclusive healthcare system. It is important to note, however, that the feasibility of proximal follow-up varies from one country to another.

In terms of support needs, technical aids such as **written materials** (e.g., schema or images) partly meet the communication needs mentioned by people with intellectual disability by helping them understand the medical information provided by the doctor. People with intellectual disability are also asking to be able to return home with a written document containing the information discussed. These communication adaptations have already been the subject of studies attesting to their added value for people with intellectual disability (Phillips, 2019; Walker et al., 2016). Nevertheless, healthcare professionals should be trained in how to use them, as they are not always used appropriately (Tuffrey-Wijne et al., 2014; Walker et al., 2016). We also found that services combining technical (such as schema or images) and human support (such as a liaison person on site) were the most satisfactory for individuals with intellectual disability. Given the rarity of these services (e.g., only one hospital in Belgium

offers them), it is not surprising that this theme appears to be new compared to existing literature and could be a valuable area for further perspectives.

Regarding empowerment challenges encountered by the participants, the thorny question of the **lack of consent request** was addressed. Although some healthcare professionals believe that people with intellectual disability are not capable of giving consent (Rinaldi & Batselé, 2023), our data contradict these representations. We suggest that education programmes should make a point of stressing the importance of asking people with intellectual disability for consent, as well as the consequences of not doing so. Concerning the **difficulties in expressing their needs** and aspirations, it is important to note that it is challenging for individuals with ID due to limited opportunities to practice these skills (Pelletier & Joussemet, 2014). As highlighted in several studies (e.g., Rinaldi et al., 2022), this complexity arises from the intricate interplay among social opportunities, environments, and cognitive abilities, which significantly influence health outcomes and the identification of health-related needs. Nevertheless, the challenges that people with intellectual disability encounter with regard to empowerment could be improved if healthcare professionals were better aware of and trained in active listening and empathy skills. As already reported, people with intellectual disability confirmed the **lack of training and knowledge** of intellectual disability from physicians and nurses (Iacono et al., 2014; Rinaldi & Batselé, 2023). It has been shown that the improvement in students' attitudes occurs specifically when the education programme promotes direct contact with an expert by experience with intellectual disability (Frankena et al., 2015; Ryan & Scior, 2014; Watkins & Colgate, 2016). Therefore, involving people with intellectual disability in intervention programmes seems promising and should be further encouraged. As our study shows, they are the ones who have knowledge about the dysfunctions of healthcare systems and their own needs.

These overall results allow to draw some practical recommendations on how to take care of people with intellectual disability in medical consultation such as: talking directly to the patient to make him feel considered, integrated and respected, ensuring the presence of the accompanying person is desired by the patient, listening to the needs of the patient taking the necessary time to do so (by booking an extended consultation time if needed), speaking more slowly and using simple words, using visual aids (such as images, drawings, schemes,..), asking for consent when suggesting an examination, treatment, etc., and treating them as adults (i.e. don't be on first-name terms without asking permission). While such adjustments and accommodations are recognized in theory (see Moloney et al., 2021), their actual implementation remains limited, and many barriers still exist that prevent equal access to care

for people with intellectual disability. Significant efforts are needed to ensure that individuals with intellectual disabilities can receive the same level of care and attention as the general population, and that their specific needs are met in a consistent and supportive manner within the healthcare system. This can be encountered through training and should be included in the initial curriculum of physicians.

This study is not without its limitations. It is worth noting that, in one focus group, caregivers expressed themselves extensively, thereby limiting the speaking time of the individuals directly affected. Similarly, the presence of the institution's head nurse in another focus group may have constrained the participation of people with intellectual disability. Moreover, the participants represented a wide range of age groups. Since older adults with intellectual disabilities tend to have greater healthcare needs and require more frequent visits to their physicians (Heller & Sorensen, 2013; Wark et al., 2016) future studies should consider focusing on specific age groups to better address these differences.

5. Conclusion

This study revealed that people with intellectual disability have specific needs (in terms of communication, relationships, and support) and encounter individual and environmental difficulties in the context of healthcare. For future research direction, it would be relevant to develop education programmes in the context of healthcare that specifically consider the difficulties highlighted by people with intellectual disability in the present study. It would also seem essential to rely on their advice to draw up intervention programmes aimed at improving the skills of health professionals in dealing with them (Akbulut Zencirci et al., 2024; Morin et al., 2023; Watkins & Colgate, 2016). Finally, it is important to further develop inclusive studies and methods to highlight their added value.

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