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NEEDS ANALYSIS

EQUAL TREATMENT

Supporting rights and access of people with intellectual disabilities to secondary and tertiary healthcare services

Erasmus+ 2021-2027 Project "EQUAL TREATMENT"
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Institutions participating in the project:

European Platform for Rehabilitation, Belgium

Kaunas University of Applied Sciences, Faculty of Medicine, Lithuania

Tampere University of Applied Science, Finland

Vocational Training Center MARGARITA, Greece

Research Center of Biopolitics from Panteion University, Greece

Girona Biomedical Research Institute (IDIBGI), Spain

Fundació campus Arnau d' Escala (FCAE), Spain

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Contents

List of tables and figures

Tables

Figures

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Introduction

The study was designed for the purposes of the ERASMUS+ project called "Equal Treatment", which is funded with the aim to improve the access of people with intellectual disabilities to secondary and tertiary healthcare system through inclusive European policies in healthcare services, training of healthcare staff in interacting with patients with intellectual disabilities and, stronger collaboration between healthcare staff and professional supporters. The project's duration 30 months, starting from March 2022 and will focus on one main objective: **supported rights and access of people with intellectual disabilities to secondary and tertiary healthcare services.**

Results

1. More effective policies on people with intellectual disabilities inclusion in healthcare services.
2. Lower barriers for people with intellectual disabilities to access healthcare services.
3. More effective training of healthcare staff to interact with people with intellectual disabilities.
4. Stronger and better collaboration between healthcare staff and other professional supporters.

Target Groups and project beneficiaries: Doctors, nurses, administrative staff in secondary and tertiary healthcare services (healthcare staff); Educators, psychologists, social workers, etc. supporting people with intellectual disabilities (professional Supporters); People with intellectual disabilities.

Core deliverable of the project is the creation of self-learning e-modules addressed to healthcare staff aiming at improving their capacities to provide more optimized services to people with intellectual disabilities and thus facilitate our project's main objective, meaning supporting people's with intellectual disabilities access in the secondary and tertiary healthcare system.

In this context, needs analysis for people with intellectual disabilities, healthcare staff and professional supporters was implemented in order to

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secure the inclusion of each beneficiary in the procedure, as well as that educational material will reflect their actual needs. For the people with intellectual disabilities, qualitative study was conducted through interviews. As for the other two groups, questionnaires were disseminated, collected and statistically analyzed. The results of the analysis can provide valuable content for policy recommendations.

The partner responsible for the needs analysis is the Research Center of Biopolitics (RECEBI) from Panteion University of Greece, and the researchers that conducted it are:

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1. Needs of People with Intellectual Disabilities

1.1. The study and the methodology

Beginning with our first group of beneficiaries, meaning people with intellectual disabilities, a separate study was conducted with the aim to explore their experiences and needs when accessing the secondary and tertiary healthcare system, while being treated in its context, as well as regarding the continuity of treatment after exiting the system to some extent. Thus, interviews with people with intellectual disabilities were undertaken.

All project partners participated in the preparation of the study through both constant online meetings and communication, and a physical two-day kick-off meeting in which they were all present. The number of interviews to be conducted was predetermined, thus saturation of data while conducting the interviews was not considered. The sampling criteria were the person’s own desire to participate in the study, having mild or moderate intellectual disability and being over 18 years old.

Moreover, all project partners, except from the one responsible for the analysis of the data (RECEBI) and the project’s coordinator (EPR) conducted the interviews in their countries. Thus, interviews took place in multiple settings and during different time periods (see Table 1), starting from July 2022 to October 2022.

Table 1: Interviews' conduction settings

	Number of informants	Time period of conduction	Setting of conduction
Project partners			
Kaunas University of Applied Sciences	16	One and a half month – July 2022 to August 2022	Organization where informants live or from which they receive services
Fundació campus Arnau d’ Escala	15	One day – September 2022	Ramon Noguera foundation
Girona Biomedical Research Institute	15	Two months –July to September 2022	Office of the Institute
Tampere University of Applied Science	12	One month – October 2022	Half conducted online, half in the lobby of the housing facility “unit Kuussalonki residents” or in informants’ house or private room
Vocational Training Center MARGARITA	60	Three months – July to October 2022	“Margarita’s” facilities
TOTAL	**118**	-	-

Furthermore, the interviews conducted were semi-structured yet contained some closed-ended questions. This decision was based on the final aim of the project, which is the creation of educational material for healthcare professionals on treating people with intellectual disabilities, for the formulation of which specific information needed to be extracted. Nonetheless, in many parts of the interviews, participants were given the chance to freely express their experiences and feelings while being treated by healthcare staff inside the hospitals, and some elements of interpretation were included in the analysis when it was necessary. For the process of the data,

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thematic analysis was implemented, combining a deductive and semantic approach. Finally, the analysis took place from mid-October to early-December of 2022.

1.2. Limitations and strengths

Considering that the current research was implemented for the purposes of a European program, many (seven) partners from multiple countries (Greece, Spain, Lithuania, Finland and Belgium) and different entities (i.e., universities, research institute (NGO), and vocational training center) participated in the preparation of the research, as well as the collection and analysis of the data. Five out of seven partners conducted the interviews, which were then sent to be analyzed from RECEBI. This separation between the collectors and the analyzer of the data may have caused some limitations with regards to the clear overview of them, increasing the possibility of misinterpretation of the interviews collected. Also, not taking account of the saturation of themes may have been problematic.

Moreover, the interviews (firstly the interview guide and then the transcripts) were doubly translated from English to the language of each participating partner for facilitating the research subjects, and then back to English in order to be analyzed. Especially for the interviews, the interchange between languages may have resulted in missing meanings that could be important for the analysis and the final narrative.

Furthermore, conducting interviews with people with intellectual disabilities raised some difficulties to the interviewers, since some of the informants needed the questions to be repeated or rephrased in order to be fully understood. Also, they were asked to describe experiences from the secondary and tertiary healthcare system that may have taken place long time ago, increasing the possibility of recall bias. Adding to this, some interviewers reported that interviewees were afraid to provide answers as if they were taking an exam (IDIBGI).

Some of the above may have limited the validity and reliability of the data. To ameliorate any relevant problems, in the preparation phase of the research the interview guide was produced after thorough discussions with all the consortium partners and disseminated to each of them to be evaluated before its final dissemination to the research subjects. Additionally, specific guidelines were given to each data collector from RECEBI (e.g., the interviewers were asked to take notes of informants' nonverbal expressions during the interviews), so as to secure as much as possible the uniformity of the deliverables. Similarly, a document was disseminated to each partner that conducted the interviews, through which valuable information was provided regarding the settings and procedures followed, as well as the difficulties and opportunities they faced, all of which were taken into account in the analysis phase.

Finally, despite the diversity of the organizations, all of them had a scientific group, aware of and experienced in conducting research and in interacting with people with intellectual disabilities. Thus, clarifying questions during the interviews was effectively implemented when needed, as well as comforting the interviewer. Likewise, easy-to-read information was provided, since questions were generally simply stated and images displaying emotions were used to help the informants regulate and express their feelings.

Image 1: Easy-to-ready images displaying emotions that were used during the interviews.

After analyzing the data, four main themes emerged with regards to our study's informants' experiences with the secondary and tertiary healthcare system: a) awareness, health literacy and access, b) systems' responsiveness: the hospitals' environment, c) system's responsiveness: interaction with healthcare staff, and d) the role of the supporter.

1.3. Awareness, health literacy and access

Following the pathway of accessing a hospital, participants were asked to describe their experience step by step depending on each individual case, i.e., scheduling an appointment with a doctor for tests/surgery/hospitalization etc., going directly to the emergency department, and finally accessing the hospital area. The particular concern was with the people’s with intellectual disabilities awareness and literacy on the procedures, the decision-making process and whether it was undertaken independently, as well as the supporting or undermining elements intermingled with these activities.

As Saurman (2015, p. 3) states “awareness is more than knowing that a service exists, it is understanding and using that knowledge”, including all the aspects of this service, such as to whom it is addressed and for which reason, as well as the dimensions of “when, where, how and why”. Health literacy is conceived as a “content and context specific” embraced by the concept of awareness, critical in making health decisions and described as the result of effective communication.

Under this definition, people with intellectual disabilities in the study showed varying levels of health literacy, depending on the issue at stake and with significant differences among countries. In general, significant limitations were the case for informants from Greece, in contrast with interviewees from Finland that appeared to be highly literate. Notwithstanding, not a few health awareness issues appeared in general, which may influence people with intellectual disabilities effective access in the secondary and tertiary healthcare system, yet useful proposals for future improvements emerged too.

Beginning with the *awareness of the insurance number*, as a prerequisite to identify oneself when accessing the many levels —in our case, the secondary and tertiary— of the healthcare system, all but Greek people with intellectual disabilities of the study presented more or less high literacy when insurance number was approached conceptually at first. Thoroughly, almost all the informants from Lithuania and Finland, and more than half of

Spain knew what an insurance number is in general, in spite of providing, in a few instances, some ambivalent clarifications (e.g. “a lot of numbers” or “numbers” with their date of birth included). On the contrary, results from Greece were strikingly differential, with more than half reporting not having relevant knowledge. Likewise, most of the interviewees seemed to be aware of in which circumstances the insurance number is needed, at times quoting additional occasions besides the ones pertained to the healthcare system. Results from Greece were vaguer, since more than half of the informants did not answer that question. Yet the few who did, similarly, covered a wide range of instances when the insurance number is of use.

Regarding the knowledge of their own insurance number and where it can be found, as well as having it with them when visiting the doctor, a core issue relevant to accessing the healthcare system, results were more ambiguous. Although Finnish participants overwhelmingly gave positive feedback, the case was not the same for other countries’ informants. Only half of the Lithuanian interviewees seemed to have literacy regarding their own insurance number, who also reported having it written in their ID card, which they carried with them in their medical appointments. Otherwise, supporters provided it for them. In like manner, less than half of people with intellectual disabilities from Spain were literate when it came to their own insurance number, albeit most of them used to have it when they visit the doctor, as they declared. Again, in other cases, they relied upon their supporters. In addition, as before, the majority of the Greek participants were unaware of which and where is their insurance number, while only a few mentioned having it written somewhere. Inevitably, their supporters provide it in medical visits, or else some mentioned not bringing it at all. It should be noted that in case some respondents had no knowledge of their own insurance numbers, this could be attributed to the fact that the later consist of many digits, which generally cannot be learnt by heart irrespective of intellectual disability.

Beyond outlining the situation of our study’s informants, one emergent observation that may be proven handy, is the *need for written provision of* *relevant information* to people with intellectual disabilities, to facilitate their independent access in the healthcare system.

Continuing with *scheduling an appointment* as one of the first steps needed in order to access the secondary and tertiary healthcare system, the majority of participants from all countries mentioned being unaware of how to engage in this procedure and/or had never tried to do so. Nonetheless, it is important to mention that more than half of the people with intellectual disabilities of the study from Finland and Spain did not indicate facing difficulties when they were asked directly. Probably, in the case of Finland, more clearly than in that of Spain, it seemed that the reason why the participants reported no challenges was the underlying recognition that the supporters or the counselors from the residential care home were the ones that made the procedure (appear) easy for them when undertaking the task to implement it for them.

Among the *most reported obstacles* were:

- the complexity of the procedure of scheduling an appointment (Lithuania, Spain, Greece)
- navigation issues (Lithuania),
- unawareness of doctor’s or hospital’s phone number (Lithuania),
- adversities in contacting hospital’s reception, due to missed calls and difficulties in explaining their needs (Lithuania and Spain),
- long wait for requests to be approved, raising difficulties in keeping up with them (Spain),
- large amount of information available on the internet and detecting the correct ones being a time-consuming activity (Lithuania),
- intricacy of the online registration system (Lithuania),
- identification issues with online application (Finland), and
- troubles in describing their feelings via online application (Finland).

On the contrary, *what seemed to facilitate making an appointment* with the hospital was:

- supporters (all countries),
- primary healthcare professionals, like General Practitioners, providing a referral in countries where it is standardized (e.g., Lithuania and Spain),
- familiarity with the procedure due to repetition (Lithuania),
- phone or online application, where all the information is concentrated and easily found ("Rioja Salud" in Spain and "Omaolo" in Finland, yet easy language for the latter was suggested as an improvement).

Furthermore, in cases when the informants had to visit the *emergency department* of a hospital, all but Greek people with intellectual disabilities of the study appeared to have adequate relevant literacy, citing knowing the emergency phone number, even if few of them evidently mentioned a wrong one. In particular, as a *good practice*, interviewees from Lithuania said that their *supporters* have transmitted this knowledge, or that they *wrote down and displayed the emergency number somewhere visibly in the house*.

Notwithstanding being aware of how to call an ambulance, in almost all instances when visiting the emergency department was needed, it was the people's with intellectual disabilities supporters that took the decision to call the ambulance or directly transferred them to the hospital by their own means. Contrarily, the few participants of the study that went to the emergencies independently, especially in the case of Lithuania, were the ones that previously showed having an insight into scheduling an appointment, suggesting a more general literacy in how to access the secondary and tertiary healthcare system.

Likewise, supporters accompanied most people with intellectual disabilities of the study to the *hospital area*, with a few exceptions emerging mainly from Lithuania and Spain. What was reported by these informants as *helpful in accessing the hospital independently*, was —again—*familiarity with the procedure because of previous experiences* and the *hospitals' proximity to their own house*.

Controversies among countries arose from the extent to which participants knew how to navigate themselves after entering the hospital, i.e., where to find their doctor or relevant information, as well as whether they understood the instructions given to them. Apart from interviewees from Lithuania, who did not answer the relevant questions, almost all informants from Greece were unaware of where to find their doctor and, with a few exceptions, did not know where to ask for such information. Conversely, most Spanish and Finnish participants described hospitals as easily accessed and/or seemed to comprehend these procedures. In detail, as they cited, *things that enabled them to orientate themselves inside the hospital* were:

- their habitual engagement with the hospital environment (Spain),
- having the room number already noted or writing it down after asking the reception (Spain),
- supporters (all countries)
- information boot and other patients (Lithuania and Spain),
- automatic machines in the entrance lobby where they can scan their health card and obtain information about their appointment, e.g., room number, floor, etc. (Spain and Finland),
- signs inside the hospital (Finland), and
- the provision of short answers (Finland).

On the contrary, the use of “medical language” was reported by a participant from Spain as a deterrent against understanding instructions, while another from Finland depicted large number of hospital rooms as confusing.

1.4. Systems’ responsiveness: the hospitals’ environment

After mentally “arriving” at the hospital area and discussing relevant accessibility issues, people with intellectual disabilities of the study were asked to describe their experience inside this environment. What was captured by this discussion was the secondary and tertiary healthcare system’s “responsiveness”. Even though “responsiveness” is not equal to “access”, it is associated with dimensions of the system such as “dignity, communications, autonomy, prompt services, access to social support during care, quality of basic services and choice of provider” (Smith et al., 2008, p.8), all of which constitute, to a significant extent, what this project seeks to improve, i.e., “equal treatment” of people with intellectual disabilities. In this chapter, we will focus on attributes of the hospitals’ environment per se, dedicating later an autonomous chapter for the interaction and communication between people with intellectual disabilities and healthcare staff.

Responses from each participating country vary significantly not only in the overall representation of interviewees’ experiences as positive or negative, but also in the reasons which accounted for them, yet some similar patterns emerged too. Overall, participants from Spain and Finland reported having a generally pleasant experience in the hospital area. It is noteworthy that, although satisfied, some of the informants from Finland highlighted some observed problems or generally issues that need to be taken into consideration (see below). Ambivalent descriptions were illuminated by people with intellectual disabilities from Lithuania and Greece, with more upsetting situations emerging a little more frequently, albeit together with some enjoyable ones and a few circumstantial (the latter will be discussed in the next chapter).

Some of the reasons why interviewees felt unpleasantly seemed to not be related to the healthcare system itself, such as being homesick or in pain, as well as the evident worry of their familiars. Even so, all the above probably can be alleviated inside the hospitals, in order to upgrade patients’ overall experience.

On the one hand, *among the most highlighted causes of dissatisfaction* were:

- other people:

  a) the presence of many, unknown, moving and starring individuals, causing discomfort (Lithuania),

  b) the view of their suffering, provoking sadness or fear (Spain and Greece),

c) presence of diverse kinds of patients in a ward (Lithuania), such as substance abusers (Finland),

d) random interactions (e.g., yelling at them for walking across a freshly washed floor) (Lithuania),

- the long wait (Lithuania, Spain and Greece) and shortage of staff (Finland),
- the inability to undertake desired activities (e.g., eating, having nothing to do and feeling boredom because of that) (Lithuania and Greece),
- negative stimuli (e.g., disturbing-triggering images, causing fear (e.g., surgery room) (Spain), and noise in the environment, like screams and the sound of ambulances’ siren (Spain and Greece)),
- other hospitality issues (dissatisfactory food and clothes) (Finland).

On the other hand, informants said that some *aspects of the hospital as a setting made them feel enjoyment* inside of it, such as:

- the view of other people, both staff and patients, perceived as funny (which before was a cause for distress to other patients) (Lithuania and Spain),
- positive stimuli (e.g., seeing and being occupied with many different devices available in the area, the smell of the environment (Lithuania) and a TV (Greece)),
- familiarity with the environment (Spain),
- fast provision of services (Spain), which were received as good (Finland),
- the upcoming procedure and the excitement of it (Finland), and
- the support of their family members (Finland).

The *adaptations suggested* by the study’s informants *for improving the hospitals’ environment* and thus their stay in it were:

- installing a TV in the waiting room (which may distract them from unpleasant stimuli),
- complete omission of wait both before and after seeing the doctor,

- shorter waiting time,
- not having to encounter other patients, and
- waiting in a room with less noise.

1.5. System’s responsiveness: interaction with healthcare staff

Having its “special place” when people with intellectual disability are at stake and due to responses received during the interviews, communication and interaction between healthcare staff, people with intellectual disabilities and their supporters became a distinct theme of our analysis. For people with intellectual disabilities of all countries involved, this aspect of their experience was fundamental in their overall view of being involved in the secondary and tertiary healthcare system.

As before, when participants were asked whether their general experience inside the hospital was pleasant or dissatisfactory, healthcare staff’s behaviour and their own (i.e., people’s with intellectual disabilities) ability to communicate with them as they wanted, appeared frequently as a reference, accounting for the whole spectrum of experiences. For instance, informants from Spain reported that facing difficulties in communicating with doctors caused feelings of nervousness and this factor was recalled as the reason why they generally left with negative perceptions when being in a hospital. On the contrary, Finnish and Lithuanian interviewees attributed their positive experience to their own ability to communicate effectively with healthcare staff, as well as being understood by them. The same goes with cases when healthcare staff was described as helpful (Finland) or attentive (e.g., asking many questions) and friendly (e.g., providing candy or allowing the patient to choose the colour of their cast) (Lithuania).

Delving into the issue of interaction with healthcare staff, three dimensions of this topic occurred, such as: a) healthcare staff’s actions related to communication, b) whom they addressed while doing that, and c) how the study’s people with intellectual disabilities felt about healthcare staff’s aforementioned choices or omissions, as well as which their preference if not satisfied.

In detail, throughout the interviews, participants described whether healthcare staff paid attention to them, whether they or, in case they were escorted, their supporters addressed more frequently them, if they felt attention was paid to them, as well as their feeling arising from the above. Moreover, the experience of being treated by a healthcare professional was examined, together with the possibility of doctors and nurses trying to comfort their patients in case of need. Finally, the adequacy of providing explanation regarding examinations and after-treatment instructions was another subject investigated.

To briefly display descriptively the general picture, in terms of to whom doctors and nurses addressed when treating patients with intellectual disabilities, results were mixed. The majority of Finnish interviewees solely conversed with healthcare professionals, in comparison with half of Spanish and a few Greek and Lithuanian participants. In other circumstances, supporters were mainly addressed either exclusively or together with people with intellectual disabilities, especially if the latter did not effectively communicate with doctors or nurses. If healthcare staff talked merely and directly with the patient or both with him/her and his/her supporter, almost all informants reported feeling pleasantly, comfortably and happily, interpreting that sometimes as a sign of interest, or as a necessity. To the opposite site, in few instances when the doctor or nurse communicated alone with the supporter, or when the latter did not allow the patient to express himself/herself, a sense of neglect and disregard, as well as feelings of irritation and unsatisfaction were articulated by the participants of the study.

The same goes with the perceived attention given to the study’s people with intellectual disabilities by healthcare staff, with most of them from all countries reporting receiving adequately. With that justification in mind and reminiscing their whole interaction, mostly positive feedback was provided by the interviewees regarding feeling comfortably when being treated by doctors, nurses or paramedics, representing them with positive characterizations. Notwithstanding, some interviewees highlighted the circumstantial dimension of this topic, meaning that it is dependable on each professional’s character each time. It is noteworthy that some interviewees showed understanding towards staff's limited attention or preference to communicate more with their supporters, justifying these in light of staff's limited time available and overload, as well as due to their own difficulties in understanding and expressing themselves as much as they would want. Yet some complaints emerged for all of the professional categories, as well as when attention to the patient was the issue at stake, asking for more.

In relation to comforting the patient in case of need, most informants expressed their worries to the healthcare staff which, as they reported, usually did actually try to alleviate their negative feelings. Nonetheless, some Greek participants seemed to hesitate communicating this to doctors and nurses. Among the deterring factors were feelings of shame about sharing the problem or of fear and anxiety to not get in conflict with the personnel and then react in an angry manner, as well as supporter's prohibition. Moreover, in the case of Lithuania, even if some healthcare staff did not remained silent and tried to make the patient feel better, it seemed sometimes as if they mostly tried to persuade them to calm down, than actually fully explain the issue at stake in order to make them understand the situation and relax.

Regarding offering clarifications in how the tests were to be conducted, even though more than half of the healthcare staff was depicted doing that, some informants, especially from Greece and Lithuania, seemed unsatisfied. In some cases, this deficiency was a cause of great unpleasantness, fear and anxiety for some people with intellectual disabilities. In addition, some of them explicitly cited preferring to know more about their health condition and the procedures that they were about to undertake. Only a few of these participants did not declare preferring further clarifications, which in one instance was interpreted by the participant on the grounds of not being understood by the healthcare staff.

Furthermore, with regards to instructions provided when the patients were to leave the hospital, answers vary to some extent. In the case of Lithuania, half of the instructions were directly given to the patients in a written form and rarely only verbally, and were understood completely by them.

Nonetheless, for the other half of our study’s people with intellectual disabilities, supporters were the receivers of doctors’ guidance, in which case only them were depicted as understanding the instructions. Similar was the situation for Greek and Spanish people with intellectual disabilities of the study, who otherwise mentioned comprehending all or at least most of the instructions, which were offered by doctors either verbally and written or merely verbally. In contrast, healthcare staff from Finland in most instances directly instructed people with intellectual disabilities mainly verbally, most of which were understood. It is worth noting that some informants from Finland and Lithuania declared being non interested in these issues.

Finally, when medications were prescribed, the dose of the medicine and the time when it needs to be taken was explained to people with intellectual disabilities of all participating countries. In contrast, how and when medicines start having effect were articulated in half or less than half of the cases. With regards to side effects, very few or almost none such references were made by doctors.

In total, as *core barriers in communication* between patients with intellectual disabilities of the study and healthcare staff reported by all study’s participants, as well as basic reasons for their relevant dissatisfaction were:

- showing indifference in patients’ needs, opinion and feeling, as well as prohibiting their free expression either by not addressing them or by interrupting them, causing feelings of disregard, irritation and unsatisfaction,
- uncertainty of the patient regarding their health condition or the upcoming examination and therapeutic procedure, thus inadequate elaboration by healthcare staff, causing fear and anxiety,
- use of medical terminology,
- displaying indecisiveness together with other colleagues, thus confusing the patient,
- limited time dedicated to the patient,
- strictness and display of negative feelings (anger and worry) by healthcare staff,

- rejection of patients’ needs, feelings and viewpoint, as a deterring factor for future self-advocacy,
- fear of medical procedures themselves, especially injections (not directly correlated to interaction).

Study’s participants’ *most reported suggestions for the improvement of their collaboration with healthcare staff* were:

- the need for mutual communication, avoiding merely counting on patient’s initiative,
- non-discrimination and equal treatment of all patients,
- use of short and plain answers, short-paced speech, and native language, use of images, as well as avoid using medical terminology,
- shortening the instructions and providing easy language versions, especially for the names of the medication, which he/she described as difficult,
- provision of “space” to the patient to express oneself, with the supporter interfering only when needed, to avoid misunderstandings,
- need for receiving effectively articulated and clear explanations for their condition, the procedures and the instructions.

Lastly, in accordance with the previous proposals of the interviewees, what emerged after the description of their own experience was that the *main facilitators of interacting with healthcare staff* were:

- actively showing interest in patients’ own feelings and perceptions, through, for instance, carefully listening and asking questions, which was welcomed by the informants in all cases and enhanced their overall experience in the hospital,
- allowing the patient to express himself/herself as much as he/she needs,
- explaining their health condition and what is upcoming in a clear way (e.g., how the tests are conducted), which was always represented in a

positive way, making people with intellectual disabilities of the study feel comfortable and relaxed,
- written provision of instructions and short verbal answers,
- prioritization of the people with intellectual disabilities as the first subject of communication and interaction with the supporter collaboratively with the patient and/or only if necessary,
- the friendly, calm and supportive behaviour of the healthcare professionals.

1.6. The role of the supporter

Moving to our final theme, it should be obvious after reading this analysis that supporters of people with intellectual disabilities are present and valuable through the whole pathway of accessing the secondary and tertiary healthcare system. We should note from the very beginning that when referring to "supporters" we mean not only professionals but also the family members of the people with intellectual disabilities, especially their mothers and sisters, who more than usually were mentioned by the informants as the ones accompanying them in the hospital. From undertaking activities such as scheduling an appointment or taking on decision making procedures like calling an ambulance, to standing as intermediaries between patients with intellectual disabilities and healthcare staff, supporters were playing a key role in every step of our interviewees' narrations, yet in various ways.

In terms of awareness and literacy in how to access the system, in some cases it appears that the reason why some participants reported no challenges was the underlying recognition that their supporters were the ones that made the procedure (appear) easy for them when undertaking the task. Not only that, but in other instances supporters seemed to facilitate independent access for people with intellectual disabilities, through, for example, writing down the emergency phone number or the number of the room they had to visit inside the hospital. On the contrary, absence of this support system may have accounted for limited literacy for other informants or even be presented negatively by them. As one person with intellectual disability from Greece stated when asked whether he/she knew how to orientate himself/herself inside the hospital:*“…no one has taught me yet. They think it’s self-evident that we should know it. Unfortunately, not all families are so helpful”*.

When it comes to communicating with healthcare professionals, some contradictions emerged. Frequently, if the supporter was the one mainly discussing with the doctor, nurse or administrative staff instead of the patient, informants might seem to accept this situation, probably since supporters were depicted by them as well-informed on their needs or even more skilled in communicating, and thus justified intermediaries between them and the healthcare professionals. Nonetheless, many people with intellectual disabilities of the study showed great dissatisfaction when only their supporters were addressed by hospital’s staff or if their supporters did not allow them to interact with them, at least as much as they wanted.

Despite the fact that interviewees’ emotional reactions on this issue vary to some extent, to draw our conclusions and recommendations for the future, it may be important to view the situation in reverse: None of the informants from any participating country displayed negative reactions when the healthcare staff conversed directly or more frequently with them. Of course, this does not stand as proof that in all cases when supporters conversed more with healthcare staff, participants that reported feeling positively or neutrally with that, would have the same reaction if they were solely addressed by doctors or nurses. Supporters’ role appears crucial and necessary. Thus, what could be more helpful for the sake of people with intellectual disabilities is to prioritize them as the main subjects of communication. Supporters could interact with healthcare staff collaboratively with the patients and only if necessary or in a way that again is inclusive for the people with intellectual disabilities (e.g., putting an effort to clarify doctors/nurses instructions instead of taking over completely the role of the patient).

2. Needs of Healthcare Staff of secondary and tertiary healthcare services

2.1. The study and the methodology

The second target group of our project is healthcare professionals, meaning doctors, nurses, paramedics, and administrative staff, working in the secondary and tertiary healthcare system. A survey was designed to investigate some of their possible difficulties when providing services to people with intellectual disabilities (only with mild or moderate level of intellectual disability), as well as their preferences for future improvement, with particular concern in issues of communication and collection of information, interaction during clinical and paraclinical tests, and comprehension of instructions. Moreover, educational topics were taken into consideration, to help formulate more suitably to healthcare staff’s preferences our e-modules later on in the project. In this context, questionnaires were distributed to and completed by them.

All project partners participated in the preparation of the survey through both constant online meetings and communication, and a physical two-day kick off meeting in which they were all present. Four out of seven project partners (Kaunas University of Applied Sciences (Lithuania), Tampere University of Applied Science (Finland), Vocational Training Center MARGARITA and Research Center of Biopolitics (Greece - collaboratively)) sent and collected the questionnaires to healthcare staff in their own countries and in multiple time periods (see Table 2), starting from August 2022 to October 2022.

The sampling methodology followed was that of convenience, yet with some criteria included as being employed in a hospital, as well as geographical and cross-occupational (specialties and job position) inclusion. The sample was approached in many ways: personal contacts with healthcare staff were made directly or by email sent via contact persons. Otherwise, questionnaires were sent to the hospitals in order to be then internally

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disseminated. Additionally, call for participation was announced through social media.

Answers not accompanied by approval of the terms of participation in the research or with many missing values were excluded from the final analysis. The same goes for respondents reported that they have never encounter patients with intellectual disabilities during working in a hospital.

Table 2: Healthcare staff’s questionnaires dissemination and collection procedures

	Sample (n)	Time period	Way of filling questionnaires
Project partners			
Kaunas University of Applied Sciences	76	One month –August 2022	Online (google form) and few in paper version
Tampere University of Applied Science	37	Two months – August to October 2022	Online (google form)
Vocational Training Center MARGARITA and Research Center of Biopolitics	66	Two months – August to October 2022	Online (google form)
TOTAL (N)	**179**	-	-

Since all our survey’s variables were either nominal or ordinal, and in line with our research questions, we presented our findings by displaying the frequencies of the answers received. Moreover, chi-square analysis was opted as the most suitable test in order to investigate any possible correlations between our sample’s a) country, b) profession, c) frequency of treating a patient with intellectual disability, and d) previous acquisition of formal education on treating people with intellectual disabilities (independent variables), with their difficulties and preferences, as well as the levels of them (dependent variables). Some open-ended questions were also included in the research, which were then analyzed via content analysis. Finally, the analysis was conducted between November and December of 2022 (approximately one month duration).

2.2. Strengths and limitations

Discontinuity between partners collected and analyzed the data is one important issue to be taken in account with regards to control over the process. Although in contrary to the study of people with intellectual disabilities, this time RECEBI, which was responsible for the data analysis, also participated in the collection phase, yet not alone.

One of the most significant limitations of the current study is the small sample size (N=179), which is not representative of the population of healthcare staff in each participating country, and the sampling methodology (convenience). Similarly, the sample is not equally distributed among the participating countries, as well as among professions, with nurses being over-represented (51.1%). For these reasons, difficulties emerged to find statistically significant outcomes and correlations.

Moreover, the questionnaires and answers provided were doubly translated from English to the language of each participating partner for facilitating the research subjects, and then back to English to be analyzed. Especially for the case of answers retrieved from open-ended questions, the interchange between languages may have resulted in missing meanings that could be important for the analysis and the final narrative.

For all the above reasons, the validity and reliability of the data is questioned. Key strength in this study was the involvement of all project’s partners in the preparation phase. Additionally, a document was disseminated to each partner that disseminated and collected the questionnaires, through which valuable information was provided regarding the settings and procedures followed, as well as the difficulties and opportunities they faced, all of which were taken into account in the analysis phase.

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2.3. Sample’s characteristics

Almost half of the respondents were from Lithuania (42.7%), while 36.5% and 20.8% were from Greece and Finland respectively. As reported previously, nurses were over-represented accounting for half of the total sample, followed by doctors (23.6%), paramedics (12.9%) and administrative staff (10.7%). Furthermore, the majority of the subjects mostly rarely or only once per month (71.4% combined) encounter/treat patients with intellectual disabilities, while others a few times per week or (almost) every day. Frequency of treating/encountering patients with intellectual disabilities was significantly correlated (p=<0.001) with respondents’ country, since the ones from Finland were almost nine times more likely to choose “every day/almost every day” (48.6%) than subjects from Lithuania (5.3%) and Greece (4.7%). Contrarily, only 29.7% of the Finnish healthcare staff of our study reported “mostly rarely” encountering patients with intellectual disabilities during their work, compared to 43.4% of Lithuanian and 59.4% of Greek healthcare professionals.

In addition, service provision to people with intellectual disabilities was not included in the formal education of half of the respondents (56.2%). The other percentage of our sample having been relatively educated (43.8%) regard their training as a facilitator in effective interaction with people with intellectual disabilities, yet half of them (37.1% of the total sample) consider that it needs to be upgraded. Statistically significant correlation was found between formal education and the profession of the respondents (p=0.009), as well as their country (p=<0.001). In detail, nurses (53.8%) and paramedics (47.8%) were almost twice more educated in treating people with intellectual disabilities, in comparison with doctors (26.2%) and administrative staff (26.3%). Moreover, the majority of subjects from Greece (78.5%) reported that this topic was not included in their formal education, in contrast to Lithuanian (44.7%) and Finnish (40.5%) healthcare professionals.

2.4. Challenges in providing healthcare services to people with intellectual disabilities

In general, the majority of the respondents reported facing minimum to medium difficulties when communicating with or collecting information from patients with intellectual disability (71.3%), as well as while interacting with them during clinical and paraclinical examinations (75.3%) (see Figure 1). With regards to healthcare staff’s perceptions of whether their instructions were understood by people with intellectual disabilities, almost half of them (48.9%) answered that the patients needed a lot of explanations to comprehend what they were saying, while 32% reported that patients with intellectual disabilities did not understand them at all during the provision of instructions, thus they opted for interacting with their supporters.

Figure 1: Categories and level of difficulties in treating/encountering patients with intellectual disabilities

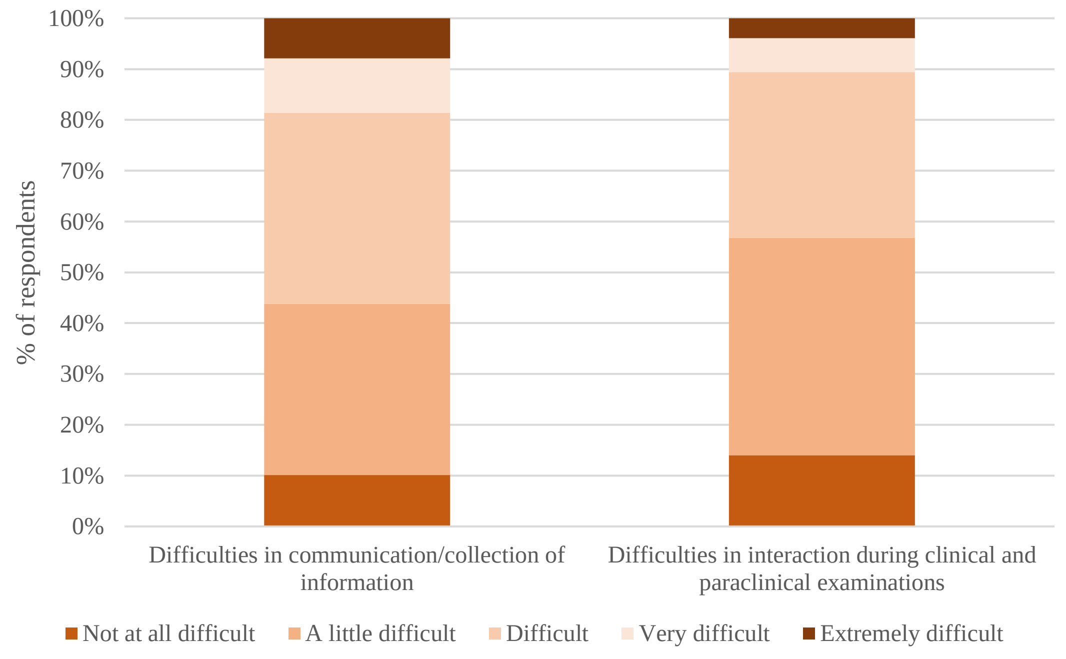
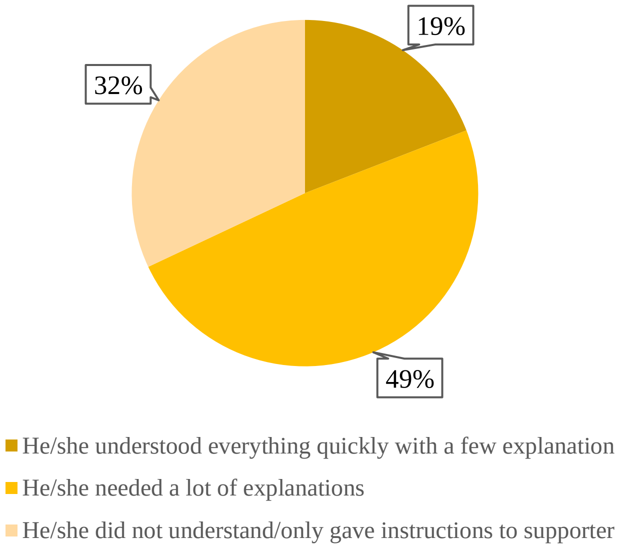


Figure 2: Perceptions of healthcare staff on whether patients with intellectual disabilities understood their instructions



No statistically significant correlation (chi-square tests) was found between these variables and the country origin or the profession of the respondents, and the frequency of encountering patients with intellectual disabilities. Nonetheless, having been formally educated on providing services to people with intellectual disabilities was significantly correlated with all the above.

To begin with, being formally educated in this issue had statistically significant correlation (p=0.007) with the level of difficulty in communicating with or collecting information by people with intellectual disabilities. In detail, in contrast with relatively formally educated respondents, the ones not having received such training were more than twice more likely to find communicating with or collecting information from people with intellectual disabilities very or extremely difficult (see Table 3). Likewise, formal education was significantly correlated (p=0.001) with the level of difficulty in interacting with people with intellectual disabilities during clinical and paraclinical examinations (see Table 3), since healthcare staff not trained in treating them scored higher or double percentages than the others in viewing it as difficult or very difficult.

Table 3: Correlation between the (level of) difficulty healthcare staff face when communicating with/collecting information from and interacting with patients with intellectual disabilities during treatment, and whether they were formally educated in providing services to patients with intellectual disabilities

			Formal education		
		Difficulty	Yes	No	**Total (N=179)**
Level of difficulty	Not at all difficult	Communication/collection of information	12.8%	8%	10.1%
		Interaction during treatment	24.4%	6%	14%
	A little difficult	Communication/collection of information	44.9%	25%	33.7%
		Interaction during treatment	6%	41%	42.7%
	Difficult	Communication/collection of information	33.3%	**41%**	37.6%
		Interaction during treatment	20.5%	**42%**	32.6%
	Very difficult	Communication/collection of information	3.8%	**16%**	10.7%
		Interaction during treatment	5.1%	**8%**	6.7%
	Extremely difficult	Communication/collection of information	5.1%	**10%**	7.9%
		Interaction during treatment	5.1%	3%	3.9%

Finally, similarly significant correlation (p=0.001) emerged in relation to the extent that the respondents found that patients with intellectual disabilities easily understood their instructions (see Table 4), with respondents not formally educated in our issue at stake being almost twice more likely to report that people with intellectual disabilities did not comprehend them, having to address their supporters. This variable was also significantly correlated (p=0.02) with the country of the respondents (see Table 5), since Greek healthcare staff were almost twice more likely (46.2%) to opt for their instructions not being understood and thus address the supporter of the patient, in contrast with Lithuanians (22.4%) and Finish (27%). Both associations may not be surprising, having in mind, as we saw previously (p. 26), that Greek respondents were the least formally educated in providing services to patients with intellectual disabilities.

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Table 4: Correlation between healthcare staff's perception of patients' with intellectual disabilities level of understanding of their instructions and whether they were formally educated in providing services to patients with intellectual disabilities

		Formal education		Total (N=179)
		Yes	No	
Healthcare staff' s perception	He/she understood everything quickly with a few explanations	25.6%	14%	19.1%
	He/she needed a lot of explanations	56.4%	43%	48.9%
	He/she did not understand – I only gave instructions to his/her supporter	17.9%	**43%**	32%

Table 5: Correlation between healthcare staff's perception of patients' with intellectual disabilities level of understanding of their instructions and their country

		Country			Total (N=179)
		Lithuania	Finland	Greece	
Healthcare staff' s perception	He/she understood everything quickly with a few explanations	25%	13.5%	15.4%	19.1%
	He/she needed a lot of explanations	52.6%	59.5%	38.5%	48.9%
	He/she did not understand – I only gave instructions to his/her supporter	22.4%	27%	**46.2%**	32%

Furthermore, another issue of investigation was the reasons why they were challenged while interacting with patients with intellectual disabilities during examinations, as well as the level of these difficulties. Among the

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proposed options were challenges usually attributed to intellectual disability, such as behavioural issues (e.g., hostility, aggressiveness, inhibition, shyness etc.), fear (e.g. of niddles, lights, darkness etc.), refusal to cooperate and inability to communicate properly or understand healthcare staff’s instructions. No statistically significant correlation was found between either the categories of challenges or the level of them opted and other variables.

Although all challenges were opted by more than half of the subjects (total range from 71.3% to 87.6%), issues of communication and comprehension of the instructions collected the highest score (see Figure 3), followed by people’s with intellectual disabilities behavioural issues, fear and lastly refusal to cooperate with healthcare staff during the examinations. Additionally, most categories of challenges were found as a little to medium difficult (total range from 79.6% to 89.3%) (see figure 4), yet problems related to communication and understanding were more likely to be considered as very or extremely difficult (20.4% in total) in contrast to other challenges.

Except for “inability to communicate properly/understand the instructions”, all other categories of problems were significantly correlated with the country of the respondents, with Lithuanian healthcare staff of our study reporting more frequently difficulties with other actions/situations of people with intellectual disabilities, and Finnish professionals less likely. Specifically, behavioural issues (p=<0.001) were opted by the 94.7% of the Lithuanian respondents, in comparison with 76.9% of the Greeks and 62.2% of the Finnish. Also, patients’ fear (p=0.02) was again found to be more challenging for subjects from Lithuania (84.2%) than for Greeks (67.7%) and Finnish (64.9%). Finally, patients’ refusal to cooperate (p=0.008) scored 78.9% for the case of Lithuania, in contrast to that of Greece (73.8%) and Finland (51.4%).

Figure 3: Reasons of difficulty in interacting with patients with intellectual disabilities during examination

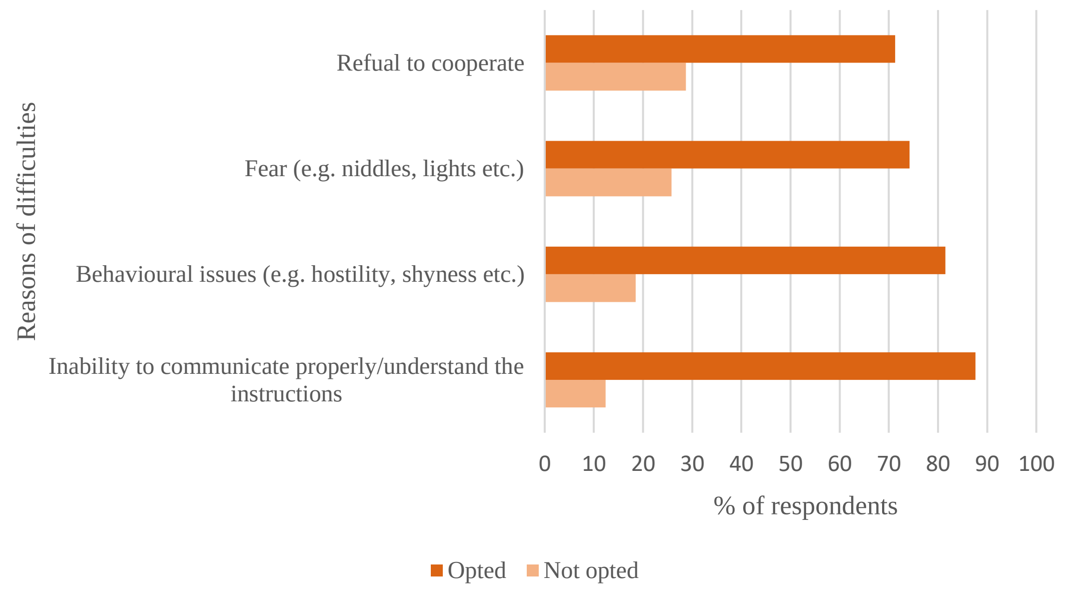
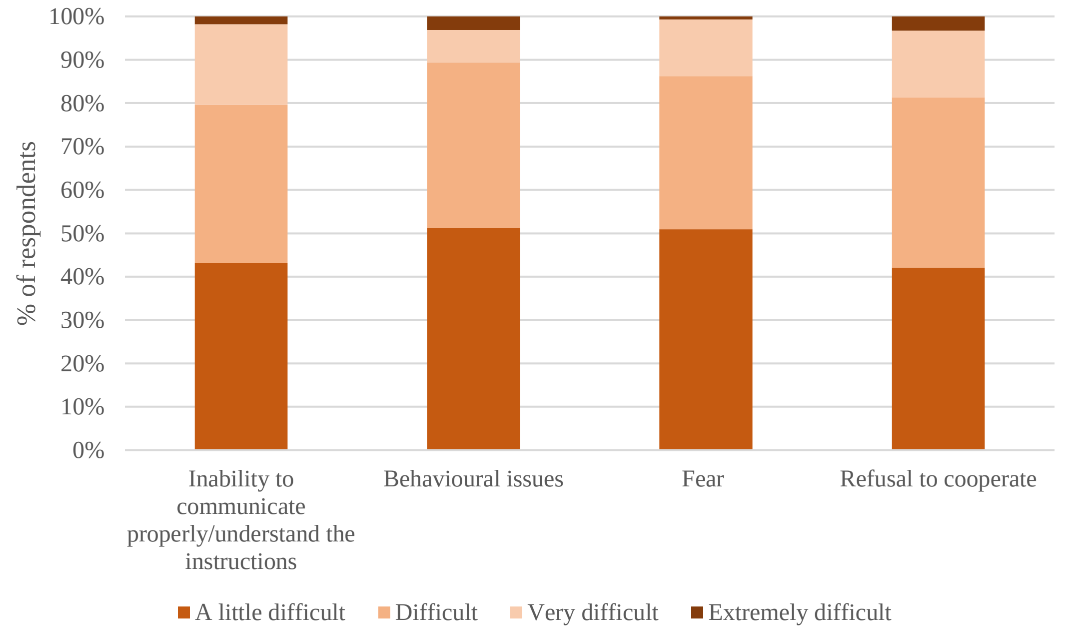


Figure 4: Level of difficulty in interacting with patients with intellectual disabilities during examinations by reason of difficulty



An open-ended option (“other”) was included in this theme to collect other possible reasons of difficulty relating to interacting with people with intellectual disabilities during examinations, yet plenty good practices instead of challenges were highlighted too. Five main categories of issues and good practices emerged after the analysis of the responses, which are related to: 1) communication, 2) education of healthcare staff, 3) interpersonal interaction, 4) emotions of people with intellectual disabilities, and 5) physical reactions of people with intellectual disabilities.

Among the collected answers (n=23), most of them were associated with communication with people with intellectual disabilities, a finding which is in accordance with our above quantitative results, providing a more in depth understanding in the relevant topic. Beginning with the problems noted, these were related to:

- inefficiency or difficulty of the patients in articulating his/her exact symptoms, making the healthcare professional, for instance, "to try to observe to find out if something is sore",
- "significantly" more attention needed to dedicate to these patients and thus more time,
- people's with intellectual disabilities characteristics like not speaking and not staying focused,
- "extreme" responsibility arising from interacting with a patient with intellectual disability, and
- non-communication with other colleagues.

Moreover, some respondents highlighted the lack of healthcare staff's skills in communicating with patients with intellectual disabilities effectively. Specifically, they were described as non-empathetic or without knowledge of particular ways to interact with people with intellectual disabilities, like the use plain language. As one respondent wrote "When we receive a patient with an intellectual disability, the staff is very stressed, we are really not prepared for it", depicting the need for further training in these situations.

A few subjects also highlighted trust issues as another important factor when treating people with intellectual disabilities, either as mutual or as directed from the patients to the healthcare professional only. Furthermore, with regards to the increased fear of patients with intellectual disabilities (e.g., in procedures), the need for tools for reducing bad reactions and redirected people’s with intellectual disabilities attention was reported. Finally, a practical difficulty was presented, meaning patients’ with intellectual disabilities difficulty in easily standing still during the examination.

Nonetheless, many respondents chose to articulate some good practices related to communication with people with intellectual disabilities during examinations, like:

- calm communication, without raising one’s voice, in order to reassure the patient,
- presence of patients “loved-ones” to facilitate peace in the environment,
- written provision of instructions (what needs to be done and when),
- provision of only the most needed information in several stages with plain language,
- asking whether further explanation of the procedures or the instructions is needed,
- use of materials to visually explain how the procedure will be implemented (e.g., use of a sponge to show how the injection will be performed).

2.5. Means of overcoming obstacles

Moving on to ways to cope with challenges related to providing services to people with intellectual disabilities, the majority of the respondents (83.1%) that had to handle obstacles relevant to communication and data collection preferred to ask for help by patients’ supporter, contrarily to 21.9% of the subjects that addressed their colleagues and 15.2% that asked for the support of the hospital’s social service/liaison psychiatry.

Statistically significant correlation (p=0.007) was observed between cooperating with a colleague and the frequency of treating a patient with intellectual disability, with the ones encountering them mostly rarely or once per month being 1.5 times more likely not to ask for help from a colleague (see Table 6). Likewise, the country of the respondents was significantly correlated ($p=<0.001$) with their preference in opting a colleague for support (see Table 7), since subjects from Greece and Lithuania showed lower probability of turning to their coworkers than Finnish respondents. Both correlations could be combined, since as we showed previously (p. 26) contrarily to Greeks and Lithuanians, Finnish healthcare staff of the study encounters more frequently patients with intellectual disabilities.

Table 6: Correlation between the frequency that healthcare staff encounter patients with intellectual disabilities and addressing a colleague to tackle with difficulties in communicating with or collecting information from people with intellectual disabilities

		Frequency of encountering patients with intellectual disabilities				**Total (N=179)**
		Mostly rarely	Once per month	A few times per week	Every day/almost every day	
Asking help from a colleague	Yes	15.8%	15.9%	41.7%	40%	23.1%
	No	**84.2%**	**84.1%**	58.3%	60%	76.9%

Table 7: Correlation between the country of healthcare staff and addressing a colleague to tackle with difficulties in communicating with or collecting information from people with intellectual disabilities

		Country			**Total (N=179)**
		Lithuania	Finland	Greece	
Asking help from a colleague	Yes	25%	43.2%	7.1%	23.1%
	No	**75%**	56.8%	**92.9%**	76.9%

Moreover, respondents were asked to choose and propose ways of enhancing interaction with patients with intellectual disabilities. According to Figure 5, all options were regarded as “very” or “extremely” helpful by half of the subjects, yet the availability of and easy access to people’s with intellectual disabilities medical history was characterized more frequently as “very” or “extremely” helpful (62.9% combined), followed by informing the professional a priori that the upcoming patient has intellectual disability (59.5%), more training to support interaction and communication (58.5%), and more time available (44.9%).

Both for data collection and interaction with patients with intellectual disabilities, respondents made some suggestions (n=5 and n=6 accordingly) for further improvement, such as:

- acquaintance with the patients, either directly or by visiting the housing unit they may accommodate in it and familiarizing with their daily activities, with the objective to gain their trust, increase the flow effect among them and facilitate communication for healthcare staff,
- devoting more time to a patient with intellectual disability to reach a common understanding,
- use of plain language, pictures and signs,
- genuine encounter,
- more aids, like Finnish icon folder for communication,
- adequacy in staff specialized in providing services to people with intellectual disabilities,
- trained supporters and social services

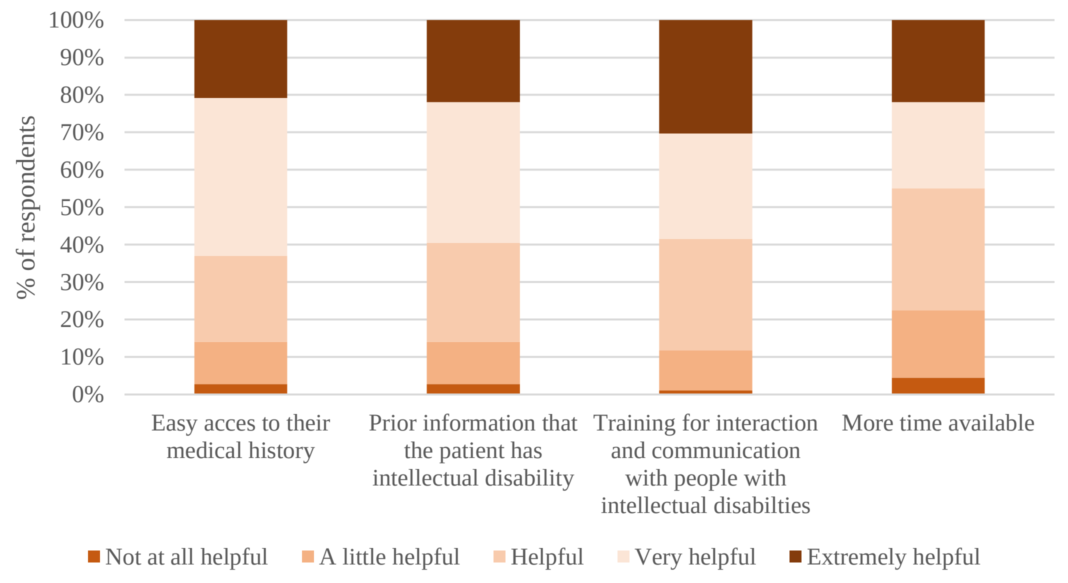


Figure 5: Facilitators of interacting with patients with intellectual disabilities

Insisting on education, being the objective of this current project, respondents were asked to evaluate whether further information and training in the provision of services to patients with intellectual disabilities within their professional framework would be helpful. Afterwards, they were invited to rank some reasons why this education would facilitate their work.

Firstly, half of the respondents (see Figure 6) considered relevant education to be “very” or “extremely” useful (57% in total). Secondly, all given causes (see Figure 7) were received as “very” or “the most” important, with the ability to cope with people’s with intellectual disabilities fears and reactions (69.7% combined), being able to understand their needs in general (68.4%) and understanding their particularities (65.7%) accumulating most relevant answers. Reinforcing their own feelings of security while treating patients with intellectual disabilities accumulated the most “not at all” or “a little” important answers (22.8% combined).

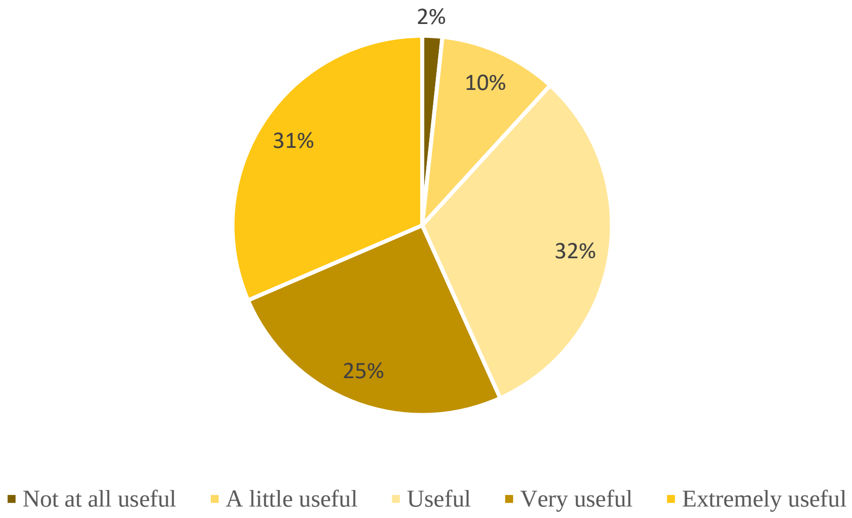


Figure 6: Level of usefulness of more education in providing services to people with intellectual disabilities within the professional framework

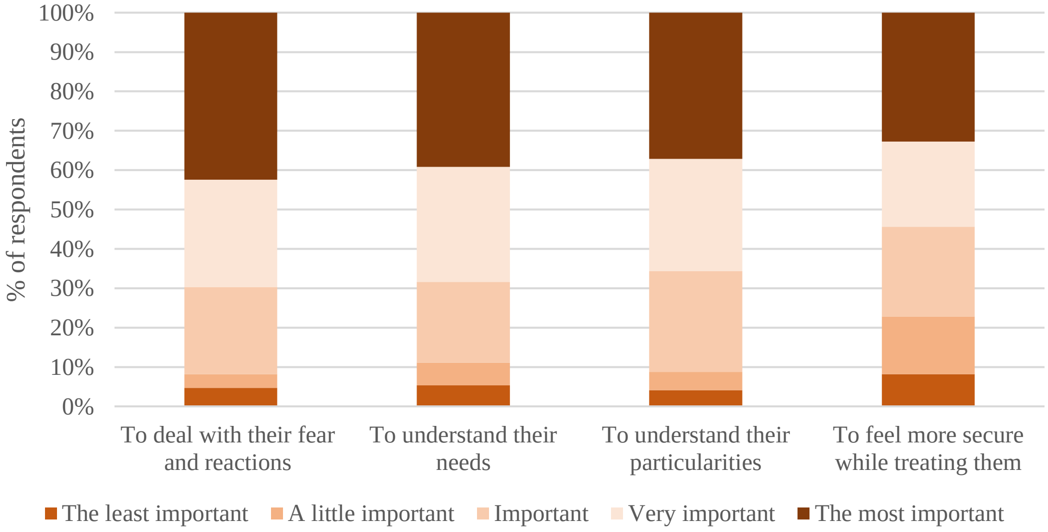
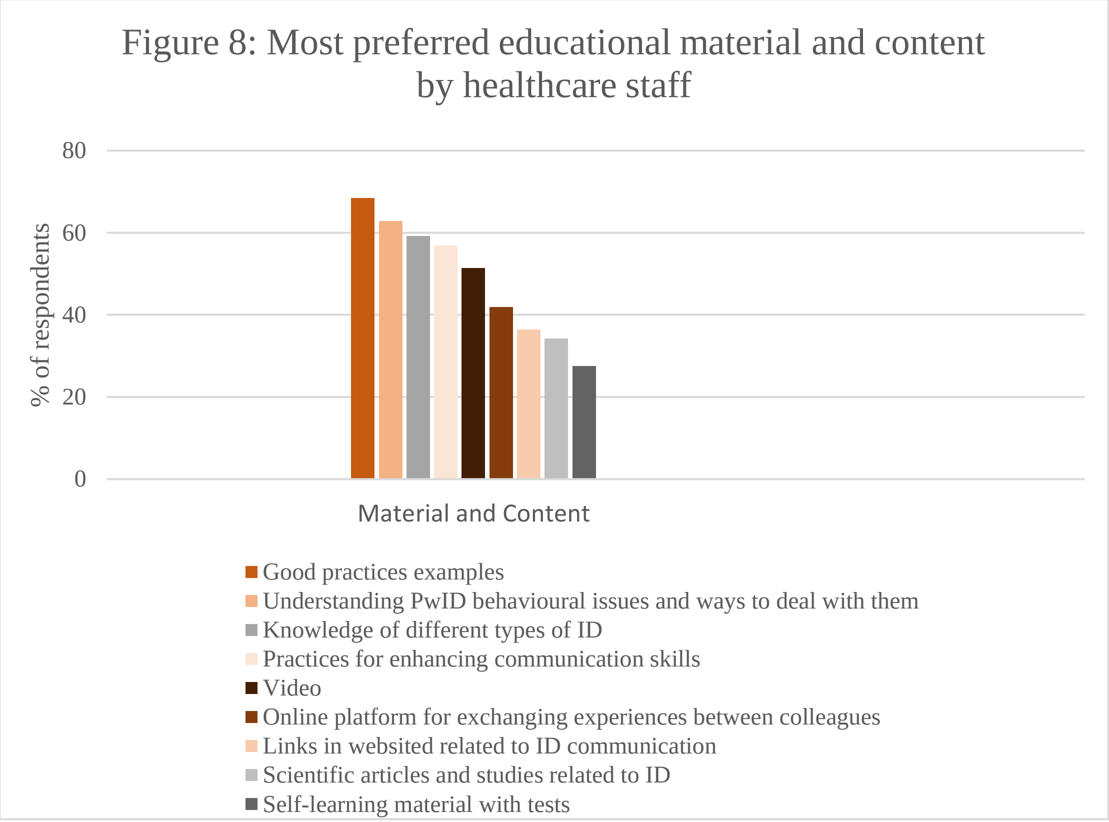


Figure 7: Prioritization of reasons why further education on provision of services to people with intellectual disabilities would be helpful

Among other reasons noted directly from the respondents (n=10) as justifying of more training in providing services to patients with intellectual disabilities were:

- the rarity and particularity of such patients, thus treating them requires specific (“unusual”) communication skills and a lot of patience,
- necessity of knowledge of the disability and patient’s condition,
- strengthening healthcare professional’s confidence,
- ensuring that communication benefits the patient,
- enhancing connection with the patient,
- improving communication with the patient’s family members and significant others.

Finally, respondents were asked to choose their most preferred educational material and content. According to Figure 8, the best means of education for the healthcare staff of our sample are the provision of good practices’ examples (68.5%), as well as videos (51.3%) and an online platform to exchange experiences with other colleagues (41.9%). All the proposed content of training, i.e., related to behavioural and communicational issues of people with intellectual disabilities, and different types of ID, scored high percentages.



2.6. Conclusions

According to our findings, communication and interaction with patients with intellectual disabilities seems to be a challenge for healthcare professionals in secondary and tertiary healthcare facilities, in view of the particular characteristics of these patients, as well as of the skills required to approach them. Yet some variations emerged in relation to the intensity of these issues, as well as the content of them and their distribution among different sample categories.

First and foremost, *communication issues* per se were considered to be the most difficult obstacle during clinical and paraclinical examinations. Not only that, but in most open-ended questions relevant to difficulties healthcare staff face in every procedure and to opportunities they may want to report, communication was again at the core of the discussion. In short, *what would further improve interacting with people with intellectual disabilities* is linguistic adaptations (plain language, use of images and visual examples, and written provision of information) and the use of tools not only to communicate with the patient but also to understand his/her situation. More interpersonal and behavioural improvements were proposed too, such as the need for healthcare professionals to be calmer and more patient than usual, devoting more time and providing further explanations, in order to reassure the patient and gain his/her trust.

Secondly, with regards to other actors involved in the interaction between healthcare staff and patients with intellectual disabilities, *supporters* (both formal/professional and informal/family members) appeared to be the primary facilitators. In cases when communicating with a person with intellectual disability while giving instructions was received as difficult by the respondents, 32% of them addressed to their supporters instead of giving more explanations to the patients themselves. Likewise, if issues emerged during collecting data from a patient with intellectual disability, instead of seeking the support of a colleague or from the social services/liaison psychiatry of the hospital, the vast majority (83.1%) of our sample opted for asking people's with intellectual disabilities supporters to help them. Furthermore, in open-ended questions informal supporters were described as key in creating a peaceful environment for the patient with intellectual disability during examinations, and formal-trained supporters as vital for enhancing data collection procedures and interaction between healthcare professionals and people with intellectual disabilities.

A third observation made from our data is the importance of *preparedness*. In detail, availability of patients' medical history and prior to their visit notification that the upcoming patient has intellectual disability accumulated the highest scores as ways for enhancing interaction with them, compared to further training of healthcare staff and time availability. Both preferences may fit under the general term of "preparedness" viewed as a need and could be interpreted under the significant adaptations needed by healthcare staff when treating a patient with intellectual disability. Moreover, preparedness emerged as a theme in the systemic level. Specifically, Finnish respondents who frequently encounter patients with intellectual disabilities were more likely to ask for the help of their colleague in case difficulties emerged in communication. We could hypothesize that this situation is representing exactly the readiness of the Finnish secondary and tertiary healthcare system in treating patients with intellectual disabilities, thus further research on this issue is needed.

Finally, preparedness is highly correlated with *education* of the healthcare staff. To begin with, being formally educated in providing services to patients with intellectual disabilities was associated with lesser likelihood of considering communicating and collecting data, interacting with people with intellectual disabilities during examinations and providing instructions to them as challenging. Thus, a more in-depth investigation of this issue is needed. Even though further training to support interaction and communication with people with intellectual disabilities for optimizing providing services to them was not the most preferred option of the respondents, half of them considered it as very or extremely helpful. Education was also frequently reported in open-ended questions and depicted as vital for their relationship with patients with intellectual disabilities. Concluding, understanding intellectual disability in general, meaning people's with intellectual disabilities needs and particularities, and its unique expression in each individual case is regarded as a genuine need by and for the healthcare staff in the hospitals and is viewed as a major opportunity for the more effective treatment of patients with intellectual disabilities.

3. Needs of Professional Supporters of People with Intellectual Disabilities

3.1. The study and the methodology

The third and last target group of our project is the professional supporters of people with mild or moderate intellectual disabilities. A survey was designed to investigate some of the difficulties they may face when trying to access the secondary and tertiary healthcare system together with people with intellectual disabilities, as well as during accompanying them to the hospital. Their views regarding their own and people’s with intellectual disabilities interaction -alone or together- with healthcare staff were of particular concern. Furthermore, their needs and preferences in further training on these issues was examined to include them effectively in our e-modules later in the project. In this context, questionnaires were distributed to and completed by them.

All project partners participated in the preparation of the survey through both constant online meetings and communication, and a physical two-day meeting in which they were all present. Three out of seven project partners (Kaunas University of Applied Sciences (Lithuania), Girona Biomedical Research Institute (Spain) and Vocational Training Center MARGARITA (Greece) sent and collected the questionnaires to professional supporters in their own countries and in multiple time periods (see Table 8), starting from August 2022 to October 2022.

The sampling methodology followed was that of convenience, yet with some criteria included as cross-occupational (profession) inclusion. The sample was approached in many ways: personal contacts with professional supporters were made directly or by email sent via contact persons. Otherwise, questionnaires were internally disseminated to professional supporters being employed by project partners. Additionally, call for participation was announced through social media. Answers not accompanied by approval of the terms of participation in the research or with many missing values were excluded from the final analysis.

Table 8: Professional supporters’ questionnaires dissemination and collection procedures

	Sample (n)	Time period	Way of filling questionnaires
Project partners			
Kaunas University of Applied Sciences	13	One month – September to October 2022	Online (google form)
Girona Biomedical Research Institute	50	Two months –July to September 2022	Paper version
Vocational Training Center MARGARITA and Research Center of Biopolitics	62	One and a half month –August to October 2022	Online (google form)
TOTAL (N)	**125**	-	-

Since all our survey’s variables were either nominal or ordinal, and in line with our research questions, we presented our findings by displaying the frequencies of the answers received. Moreover, chi-square analysis was opted as the most suitable test to investigate any possible correlations between our sample’s a) country, b) profession, and c) frequency of accompanying a person with intellectual disability to the hospital (independent variables), with their difficulties, experiences and preferences (dependent variables). No statistically significant correlation emerged between any of the above variables. Some open-ended questions were also included in the research, which were then analyzed via content analysis. Finally, the analysis was conducted between November and December of 2022 (approximately one month duration).

3.2. Strengths and limitations

Discontinuity between partners collected and analyzed the data is one important issue to be taken into account with regards to control over the process, since RECEBI, which was responsible for the data analysis, did not participate in the collection phase. Furthermore, one of the most significant limitations of the current study is the small sample size (N=125), which is not representative of the population of professional supporters in each participating country, and the sampling methodology (convenience). Likewise, the sample is not equally distributed among the participating countries, with subjects from Lithuania being under-represented (10.4%). For these reasons, difficulties emerged to find statistically significant outcomes and correlations.

Moreover, the questionnaires and answers provided were doubly translated from English to the language of each participating partner for facilitating the research subjects, and then back to English to be analyzed. Especially for the case of answers retrieved from open-ended questions, the interchange between languages may have resulted in missing meanings that could be important for the analysis and the final narrative. For all the above reasons, the validity and reliability of the data is questioned.

Key strength in this study was the involvement of all project’s partners in the preparation phase. Additionally, a document was disseminated to each partner that disseminated and collected the questionnaires, through which valuable information was provided regarding the settings and procedures followed, as well as the difficulties and opportunities they faced, all of which were taken into account in the analysis phase.

3.3. Sample’s characteristics

Almost half of the respondents were from Greece (49.76%), while almost the same proportion of subjects (40%) were from Spain and only 10.4% from Lithuania. With regards to the professions, a quarter of the sample was social workers and the other one psychologists. Additionally, 40% of the sample had various professions like nurses, physiotherapists, speech therapists etc. and only 7.2% and 6.4% were occupational therapists and special educators accordingly.

The majority of our subjects has assisted a person with intellectual disability to access the secondary and tertiary healthcare system by, for instance, scheduling an appointment (84.8%), and has accompanied one to the hospital (80.8%), the latter occurring mostly rarely (63.9%) and seldom once per month (16%) or a few times per week (16.8%).

3.4. Access and health literacy

Regarding accessing the secondary and tertiary healthcare system, almost half of the subjects (46.4%) reported understanding well enough the relevant procedures, while a similar proportion was very (21.6%) and efficiently (22.4%) aware of the issue. Afterwards, professional supporters were asked to evaluate the information about accessing the hospitals provided via the internet, the phone, or by the hospital’s reception, in terms of how easy to use they were both for them and for the people with intellectual disabilities they support.

According to Figures 8, 9 and 10, for the supporters themselves online information was mainly found to be a little (56.6%) or very easy to use/understand (32%), in contrast to phone communication which even though scored a combined percentage of 65.9% for the same answers, it was not a possible means of communication for a quarter of the subjects (27.6%) because of missed calls. Moreover, guidance provided by the hospitals’ receptions was efficient for most of our subjects (79.2%). Comparing these to respondents’ perceptions of the people with intellectual disabilities they helped, the results are highly differentiated. In detail, online information was considered to be not only almost seven times more difficult to use/understand for people with intellectual disabilities (50.4%) contrarily to them, but also was presented to be more challenging even from communication via phone

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(36.8% opted for "inadequate/difficult to understand"), although similarly missed calls was an issue at stake (24.8%). Similar to perceptions of themselves, yet to a lesser extent for people with intellectual disabilities (49.6%), guidance from the hospital's reception was the most efficient means of information.

Figure 9: Level of ease in using information to access hospitals provided via the internet

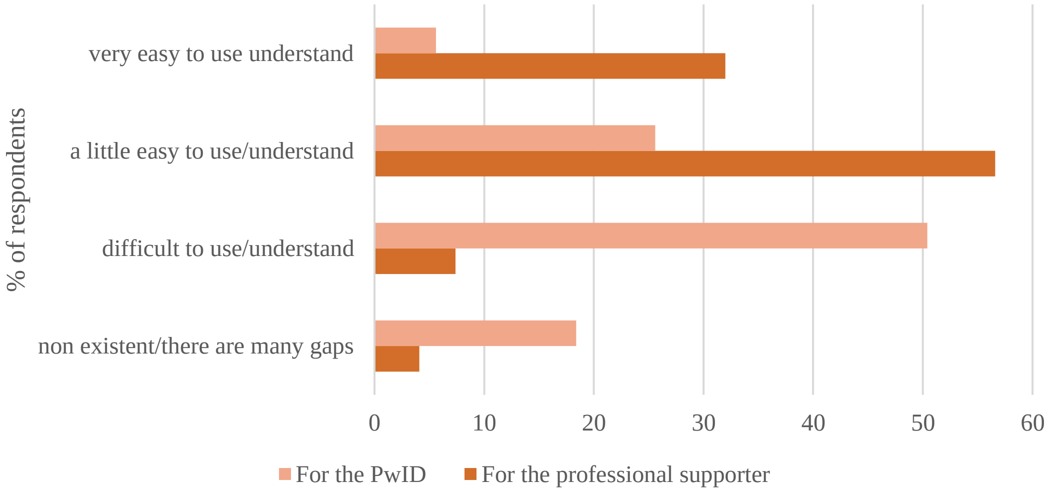
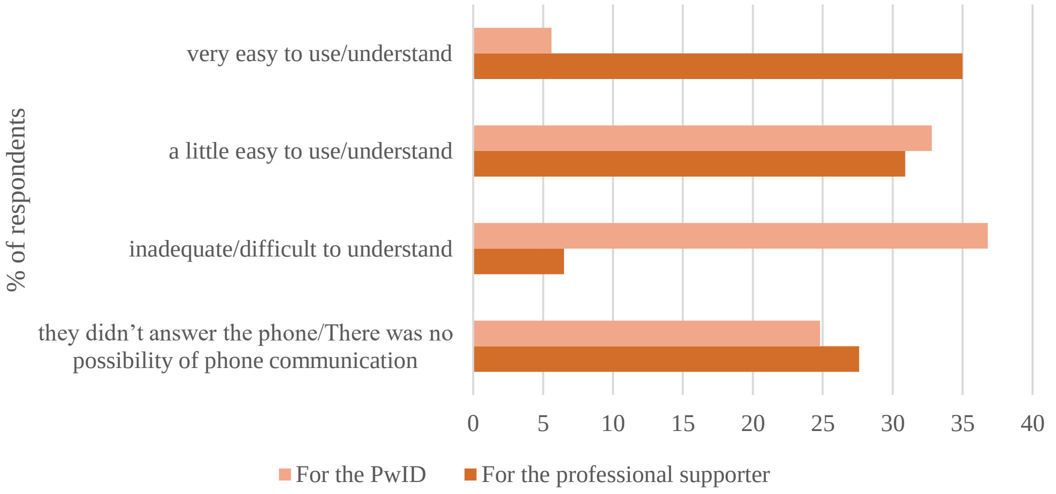
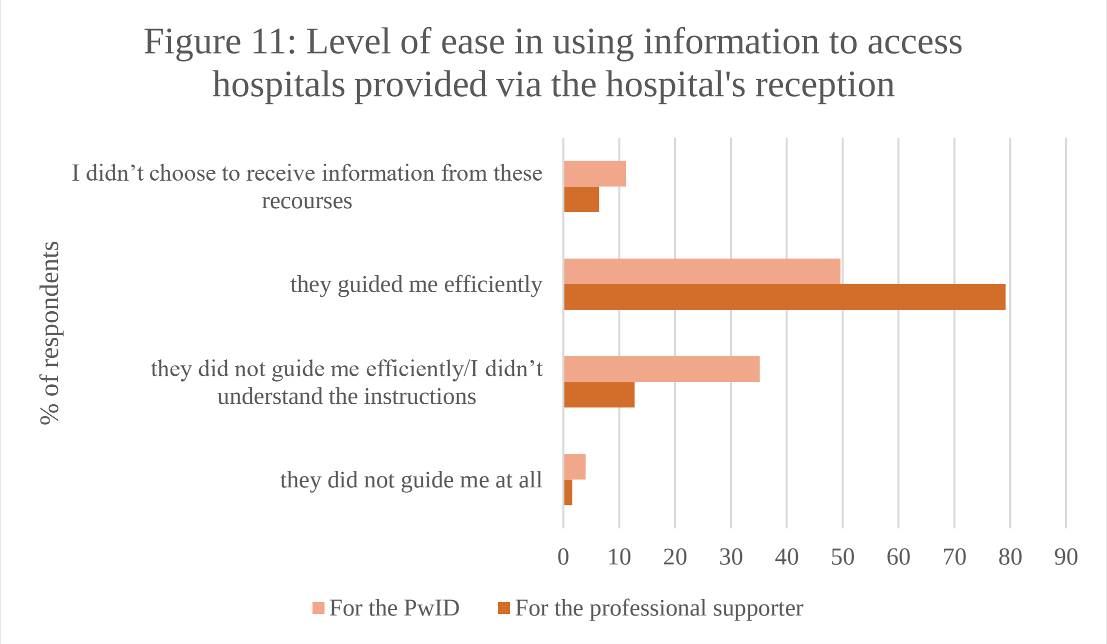


Figure 10: Level of ease in using information to access hospitals provided via the phone





Moreover, respondents were invited to propose *ways for enhancing the accessibility of people with intellectual disabilities to the secondary and tertiary healthcare system* through an open-ended question. Many proposals emerged by a significant number of respondents (n=91) which according to their topic can be divided into 1) informative and comprehension issues, 2) environmental and systemic adaptations needed, and 3) educational issues.

With regards to *improving information to be more easily understood by people with intellectual disabilities*, professional supporters suggested:

- provision of short, simple, non-technical and precise information, using symbols, visual content, pictograms and/or easy-to-understand examples,
- repeating answers when needed,
- simplify phone communication or provision of an alternative phone number especially for people with intellectual disabilities and their families, avoiding pressing buttons to reply to the answering machine and background noises, or staffed by call receivers specialized in communicating with people with intellectual disabilities,
- provision of easy-to-access online information, via making sites accessible, with easy-to-read, clear and simple instructions, using

images, symbols and vocal descriptions, while offering specialized instructions for people with intellectual disabilities in the websites and frequently updating them,

- easy-to-read information, with QR codes on leaflets inside the hospitals providing guidance and explaining both clinical and non-clinical procedures,
- prioritization of the person with intellectual disability when communicating with them, in spite of the presence of a supporter, and
- more empathetic, patient and polite behaviour by the healthcare staff.

Moving on to the *systemic adaptations suggested for offering more suitable, effective and of good quality services to people with intellectual disabilities*, these were:

- recruitment of more healthcare staff to the hospitals, in order to avoid long waits, and generally omit long waits,
- longer appointments,
- installing signs inside the hospitals for their guidance,
- complete alteration of the hospital's architecture or flexibility in adapting settings to their needs,
- provision of services by specialized healthcare staff in communicating with them and understanding their needs,
- availability of an office for civilians and/or specifically for people with intellectual disabilities inside the hospitals with trained staff, providing mediation and/or reference services, as well as personalized guidance to them,
- secured accompaniment of people with intellectual disabilities inside the hospital by supporters, not only professionals and family members, but also professionals specifically working in the hospital for faster and direct facilitation of the procedures, and
- available information in the medical record of the patients regarding their support needs.

Finally, *specialized and adequate training* not only was directly suggested by many professional supporters, but also penetrated horizontally many other of their above recommendations as a prerequisite for their implementation. Further education emerged as a necessity for all stakeholders involved in the provision of secondary and tertiary healthcare services to people with intellectual disabilities, meaning the patients with intellectual disabilities, their families, the healthcare staff and the people responsible for organizing the system in general. Especially for people with intellectual disabilities, subjects suggested that their training could be through using different scenarios and role-playing simulating interactions inside the hospital.

3.5. Initial orientation inside the hospital

Overall, most subjects of our study (66.7%) described their experience with hospitals’ reception services as pleasant or helpful, compared to a few that had opposite views (15.8%) or reported that no such services were offered (17.5%). Staggering differences were observed and noted by professional supporter between them and people with intellectual disabilities regarding the extent of comprehending how to orientate themselves inside the hospital (see Figure 12). For most of the subjects the procedures seemed to be quite or very easy (62.9% and 19.8% accordingly), while for people with intellectual disabilities, as they perceived it, they were quite or very difficult (54.9% and 22.1% accordingly).

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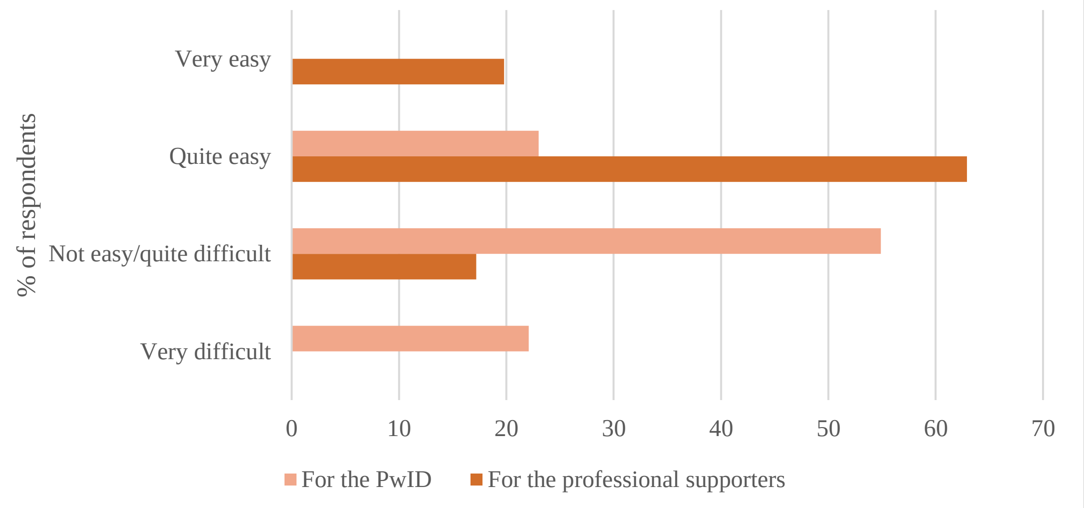
Figure 12: Level of ease in understanding orientation procedures inside the hospital



Through an open-ended question, respondents provided valuable information with regards to what impeded or facilitated theirs and patients' orientation inside the hospital. Starting from outlining the *difficulties that our study's subjects faced themselves in navigation*, they were related to systemic barriers and referred to:

- ambiguity/lack of standardized procedures regarding were to ask for information, having to address many different offices, even professionals not in charge of orienting visitors (e.g., hospital's security), being a complex and time-consuming process,
- lack of precise knowledge of the procedures that must be followed by the healthcare staff, thus providing inadequate and contradictory information, or no instructions at all,
- long wait and lack of knowledge of the actual duration they have to wait,
- overload and limited time of staff, combined with or because of shortage of staff,
- staff's unwillingness to facilitate the procedures and/or devote their time to them,

- omission of providing important information by the healthcare staff, like introducing themselves, explaining tests results and why some procedures have to be followed,
- non appropriate reception venues and vague layout of the environment, and
- unintelligible signals.

As for their views in what appeared to be *inhibitory factors for the orientation of people with intellectual disabilities,* many relevant or even similar issues were again pertained to systemic problems, yet some of their references were related to difficulties emerging from the intellectual disability itself, i.e., viewed as a personal attribution and not as a condition related to the non-adapted environment. In particular, the latter had to do with people’s with intellectual disabilities:

- limited ability to comprehend information and follow instructions, as well as to concentrate on others and retain information for a long time,
- distress, anxiety, frustration and fear caused by complex procedures in an unfamiliar environment,
- state of being in denial, making it important to find an approach to improve trust between them and healthcare staff,
- limited health literacy, and
- comorbidity (mental illness or dementia, visual impairments, lack of speech, lack of balance).

Systemic obstacles reported by professional supporters, many of which were difficult for them likewise, were:

- lack of standardized, simple, and personalized procedures in providing services to and understanding the needs of people with intellectual disabilities, combined with the involvement of various people and in different places for just one procedure, meaning the orientation of the patient,
- lack of hospital staff specialized in disability,

- long wait, causing significant distress to the patients,
- overload and limited time of staff, combined with or because of shortage of staff,
- non appropriate reception venues and vague layout of the environment (“labyrinth”),
- noisy and over-crowded environment,
- inadequate visual signs,
- provision of many, complex, non-explanatory information by staff in a fast-paced manner, described as chaotic even for the general population, especially for people with intellectual disabilities,
- lack of interest in patients’ needs by the reception,
- indirect provision of information to the patient through his/her supporter, and
- lack of resources/tools to facilitate communication and alternative/accessible means of communication for people with comorbidities, like visual impairments.

For all the above reasons and because of people’s with intellectual disabilities lack of independence, as was articulated in an open-ended question, 88.6% of the subjects did not think that the person they accompanied could have accomplished the entire process on their own. Yet a few respondents explained that this could have been accomplished in case more relevant training was provided to people with intellectual disabilities. Adding to this, the majority of the subjects (82.6%) believed that no opportunity was given to the people with intellectual disabilities in order to take the initiative and follow the instructions given on their own. From the 71.2% of the total sample that clarified the reasons why, 73% of them opted for person with intellectual disability being in danger of getting lost and feeling afraid, while 56.2% of them viewed instructions as complicated for people with intellectual disabilities and thus difficult to be independently followed. Only 19.1% of these respondents thought time limitation as the issue at stake.

Continuing with *things that helped professional supporters alone to navigate themselves inside the hospital*, among the ones mentioned were:

- familiarity/experience with escorting patients and hospital’s procedures in general, in some cases due to being healthcare professionals themselves,
- preparation regarding steps to be taken inside the hospital,
- provision of adequate, holistic, reliable and clear information by healthcare staff,
- asking in case of doubt or repeating information to confirm the instructions given were properly understood or to draw healthcare staff’s attention,
- combination of written and verbal information,
- personal contacts and other colleagues, as well as collaboration between the organization of the supporter and the health sector,
- knowledge of venues of local hospitals,
- appropriate accommodation inside the hospital, e.g., find the reception desk beside the main entrance,
- adequate signs, and
- staff’s gentle behaviour.

Finally, when it came to *what enabled people with intellectual disabilities to orientate themselves inside hospital’s facilities*, in most cases professional supporters highlighted their own contribution to the procedure. In detail, the facilitators they mentioned were:

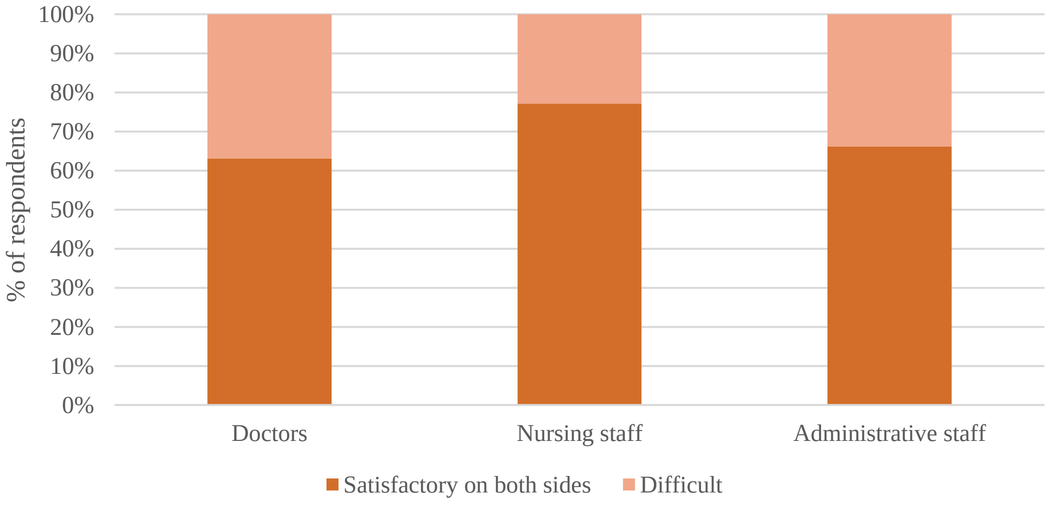
- good preparation of the supporter himself/herself or in collaboration with the patient prior to the visit,
- providing explanations to the person with intellectual disability by the supporter regarding what healthcare staff mentioned either directly or after exiting the hospital, and

- use of simple language and provision of helpful instructions by hospital’s staff and repetition of information by them as much as needed.

3.6. Communication with healthcare staff

Another issue of investigation was professional supporters’ views about their communication (either in the hospital or via telephone) with doctors, nurses and administrative staff, as well as relevant difficulties some of them may have faced. Generally, more than half of the subjects reported having a mutually satisfactory communication with all the above professional categories (see Figure 13), although doctors accumulated a little more negative answers (36.9%) in comparison with administrative staff (33.9%) and nurses (22.9%).

Figure 13: Satisfaction with communication with healthcare staff by profession



Nonetheless, reverse outcomes emerged when respondents were asked who was mainly responsible for issues in communication (i.e., the healthcare professional or themselves). Particularly, administrative staff were more likely to be blamed for this (81.4%),[1] in contrast to nurses (67.8%)[2] and doctors (53.8%).[3] Otherwise, subjects attributed miscommunication to their own limitations in expressing themselves or to other issues (e.g., social skills), which was mainly the case when facing doctors (40.6% and 28.8% accordingly), then nurses (29.4% and 14.7% respectively) and administrative staff (11.6% and 7% accordingly).

Continuing with the underlying reasons accounting for problems in communication with healthcare staff, if issues originated from doctors, nurses and administrative staff (see Table 9), their limited time available was perceived as the main cause of miscommunication by the majority of the subjects (81.8%, 85.7% and 59.5% accordingly to each profession). Even so, indifference showed from the part of administrative staff, seems to be another important obstacle in the interaction with 42.9% of our subjects facing relevant issues with them, contrarily to only a quarter of the respondents having communication problems with doctors and nurses.

Table 9: Reasons of difficulty in communication attributed to healthcare staff

		Reasons of difficulty			**Sample size as % of the total sample**
		Time inavailability	Lack of interest	Other	
Profession	Doctors	**81.8%**	22.7%	13.6%	35.2%
	Nurses	**85.7%**	25.7%	8.6%	28%
	Administrative staff	59.5%	**42.9%**	14.3%	33.6%

Furthermore, in case communication issues arose from the part of the professional supporters (see Table 10), their lack of knowledge on people's

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[1] As % of the respondents that answered the relevant question ("if your communication with administrative staff was difficult, that was because of…"), meaning as % of the 34.4% of the total sample.

[2] As % of the respondents that answered the relevant question ("if your communication with nurses was difficult, that was because of…"), meaning as % of the 27.2% of the total sample.

[3] As % of the respondents that answered the relevant question ("if your communication with doctors was difficult, that was because of…"), meaning as % of the 41.6% of the total sample.

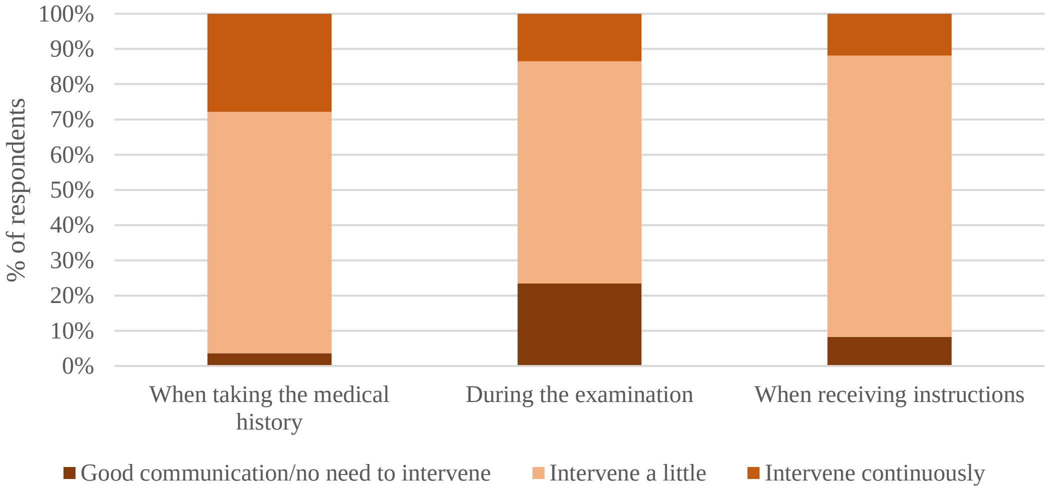
with intellectual disabilities full rights was opted by almost half of those that faced communication difficulties, irrespectively of with whom they interacted. Yet again, if administrative staff were the other subject of communication, difficulties in expressing patients' needs or symptoms was the underlying cause for 36.4% of the respondents of this answer, in contrast to doctors (28.9%) or nurses (25%).

Table 10: Reasons of difficulty in communication arising from professional supporters

		Reasons of difficulty			
		Lack of knowledge on people's with intellectual disabilities full rights	Issues in communicating patients' needs/symptoms	Other	**Sample size as % of the total sample**
Profession	Doctors	**44.7%**	28.9%	**31.6%**	35.2%
	Nurses	**60.7%**	25%	17.9%	22.4%
	Administrative staff	**54.5%**	**36.4%**	13.6%	17.6%

After depicting their interaction with healthcare staff, professional supporters of the study provided their opinions on how hospital's staff interacted with the people with intellectual disabilities in various clinical processes (see Figure 14). Effective communication was presented in the questionnaire as not having to intervene at all while healthcare staff interacted with people with intellectual disabilities, in contrast to ineffective interaction that results to the need of professional supporters' mediation. For the vast majority of the subjects, at least limited intervention was needed while healthcare professionals were taking patients' medical history (68.5%), examining them (63.1%) or providing them instructions (79.8%). As Figure 14 shows, medical history was found to be the most challenging procedure in terms of interaction, requiring professional supporters' continuous intervention for 27.9% of the subjects. To the opposite side, communication during examination accumulated most “positive” answers, meaning that for 23.4% of the respondents it could take place without their mediation.

Figure 14: Professional supporters' perceptions of the interaction between healthcare staff and people with intellectual disabilities



As for the reasons professional supporters had to intervene, the need to give clear and reliable information while healthcare staff were receiving patients’ medical history was opted by most subjects (84.9%),[4] followed by the need to focus the doctors’ attention to the patients (31.2%) and other reasons (6.5%). Two of the latter reported in an open-ended question were to calm the patient and to transfer their words to the doctor.

During examinations, almost half of the respondents that intervened did so to calm the person with intellectual disability or to give clear and reliable information (47.7% and 41.9% accordingly),[5] and only a few of them to modify doctors’ or nurses’ behaviour towards the patients (11.6%), to draw doctors’ attention to the patients (10.5%), or for other reasons (2.3%). Even though behavioural issues on the part of healthcare staff were not chosen frequently,

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[4] As % of the respondents that answered the relevant question (“if you had to intervene when taking people’s with intellectual disabilities medical history, that was because of…”), meaning as % of the 74.4% of the total sample.

[5] As % of the respondents that answered the relevant question (“if you had to intervene during the examination, that was because of…”), meaning as % of the 68.8% of the total sample.

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almost half of our total sample (44.8%) explained that in case they had to intervene because of doctors’ or nurses’ behaviour, the reason why was chiefly to ask them to further explain the medical procedures (94.6%)[6] and to a much lesser extent to be more patient with the person with intellectual disability (17.9%).

Additionally, an open-ended question was available for professional supporters that wanted to clarify whether other causes inclined them to intervene during the examinations. Among the ones reported were:

- doctor’s limited time devoted to understanding a personal with intellectual disability,
- the need to provide reliable information to the doctor, especially in relation to people’s with intellectual disabilities confusion around unfamiliar surroundings and inability to communicate coherently or clearly, or understand what is said to them,
- the need to explain to the patient what will be done and why,
- to remind to the healthcare professional to interact with the person with intellectual disability and not with the supporter,
- healthcare professionals’ unwillingness to interact with people with intellectual disabilities, and
- people’s with intellectual disabilities trust to their supporters.

Lastly, if professional supporters had to intervene while doctors were giving instructions to the patients with intellectual disabilities, the reasoning behind it for 80.4%[7] of the respondents was to explain the instructions to the person with intellectual disability and only for a quarter (25.5%) to explain to the doctors the right way of giving instructions in order to be understood by the patient.

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[6] As % of the respondents that answered the relevant question (“if you had to intervene because of the doctor’s / nurse’s behavior, it was because you tried to ask him/her…”), meaning as % of the 44.8% of the total sample.

[7] As % of the respondents that answered the relevant question (“if you had to intervene during the reception of instructions, that was because you tried to…”), meaning as % of the 80.4% of the total sample.

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With regards to the ways of intervention chosen by the professional supporters (see Table 11), most of the subjects reported that they communicated with the healthcare staff in front of the patient they escorted, both during the examination of the patient (74.7%) and when the doctor/nurse gave him/her instructions (72.4%).

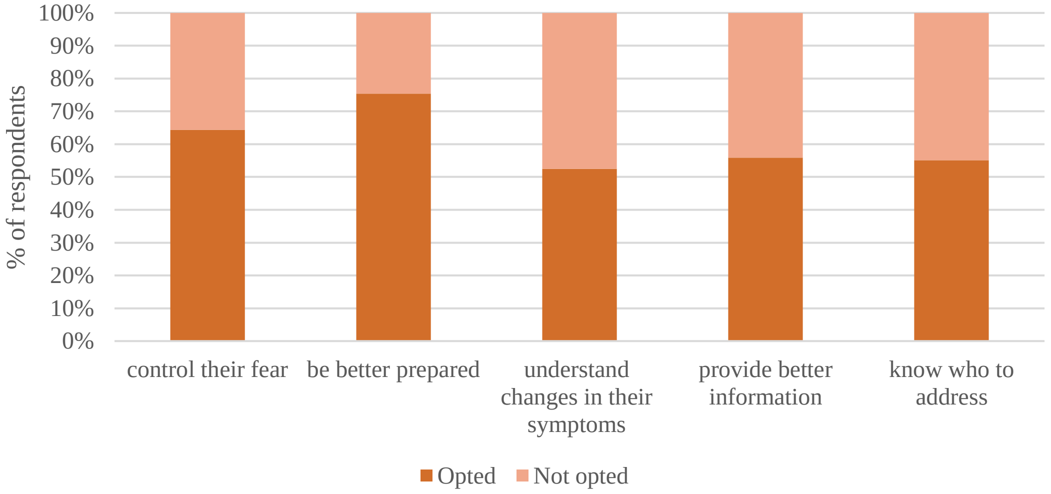
Table 11: Ways through which professional supporters intervened during the interaction of healthcare staff with patients with intellectual disabilities

		Procedure				**Sample size as % of the total sample**
		Conversed with doctor/nurse later and privately	Conversed with doctor/nurse in the presence of the patient	Interrupted the patient	Interrupted the doctor/nurse	
Procedure	Medical history and examinations	32.6%	**74.7%**	4.2%	8.4%	76%
	Instructions	26.5%	**72.4%**	2%	9.2%	78.4%

3.7. Education and training

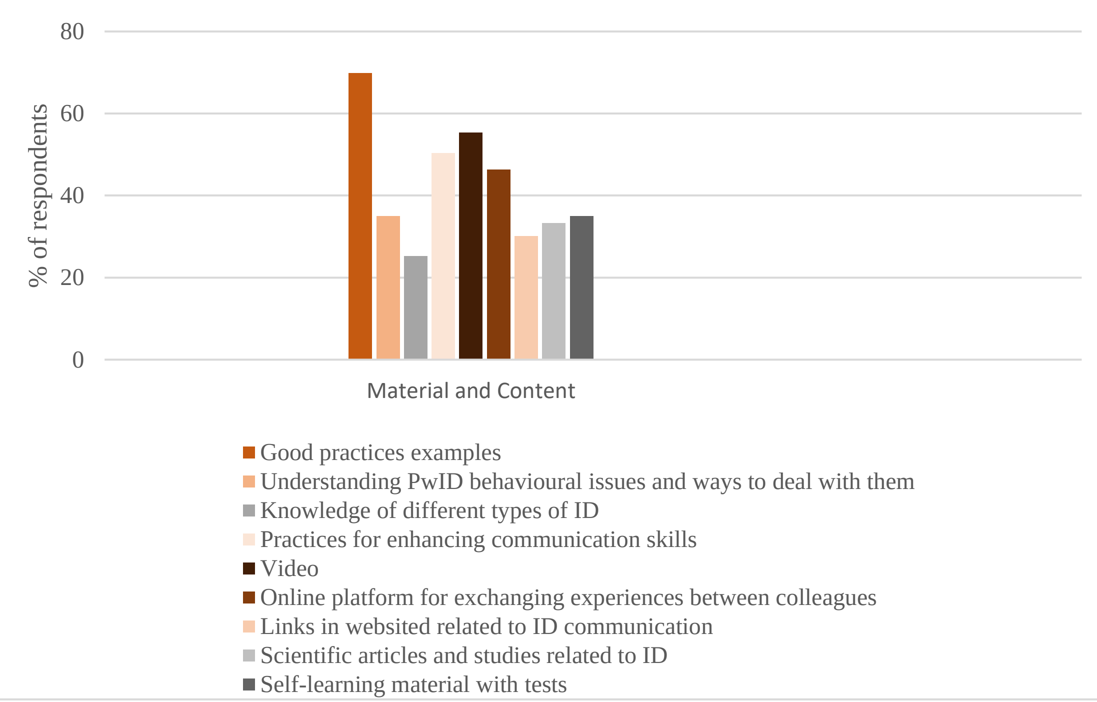
Coming to an end, professional supporters were asked whether they and people with intellectual disabilities should receive further training in issues regarding the secondary and tertiary healthcare system. In detail, 82.4% of them would like to be trained in the healthcare system of their country in general, compared to 10.4% that were not sure and only 7.2% that did not think it is necessary. As for acquiring additional education in accompanying people with intellectual disabilities to the hospitals, 64.7% of the subjects regard it as very useful and 26.1% as useful enough. Moreover, almost all respondents (95.9%) answered that it would be helpful if people with intellectual disabilities were trained in accessing the secondary and tertiary healthcare system, as well as in interacting with healthcare staff. Among the reasons why they think it’s necessary (see Figure 15), better preparation (75.4%) and the ability to manage their fear (64.4%) were mostly opted, yet all the causes seem to be important for more than half of the subjects.

Figure 15: Professional supporters' opinions about advantages gained by training people with intellectual disabilities in accessing hospitals and interacting with healthcare staff



Finally, respondents were asked to choose their most preferred educational material and content. According to Figure 16, the best means of education for the professional supporter of our study are the provision of good practices’ examples (69.9%), as well as videos (55.3%) and an online platform to exchange experiences with other colleagues (46.3%). Regarding the educational content, only practices for improving their communication skills was preferred by half of the subjects (50.4%).

Figure 16: Most preferred educational material and content by professional supporters



3.8. Conclusions

The views of professional supporters of people with intellectual disabilities regarding the secondary and tertiary healthcare system of their country may have brought to the surface that these *systems are not designed for everyone*. In detail, *access to and orientation inside the hospital* appeared to be an easy procedure for the supporters themselves, yet in a moderate level, implying that there is room for improvement. The latter was also made clear directly by the subjects, since through the open-ended questions they presented an extensive list of problems pertaining to the system, like lack of resources (especially in human force) and inconsistency/lack of organization, which every individual -irrespective of disability- may encounter.

Notwithstanding, professional supporters clarified that *difficulties are escalated for people with intellectual disabilities*, thus they could not have accessed the hospitals on their own. Particularly, through their views, it became apparent that it is by far more challenging to overcome obstacles posed by the system when issues related to the intellectual disabilities themselves (e.g., cognitive limitations and behavioural issues) are intermingled. For instance, even though the vague layout of the hospitals can be puzzling any person, without proper signs and/or staff available and trained to guide people with intellectual disabilities in an organized way, it is more likely to disorientate them and cause significantly more fear and anxiety.

Similar observations can be made in relation to *communication issues* between the professional supporters, healthcare staff and people with intellectual disabilities. Starting from our subjects’ interaction with the professional alone, even though it was viewed as mostly satisfactory, some difficulties were mentioned too. Communication with doctors was found to be the most challenging one, mainly due to professional supporters’ unawareness of people’s with intellectual disabilities full rights, but also because of doctors (and nurses) limited time available. As for administrative staff, the main communication issue with them arose from their perceived lack of interest to listen to professional supporters.

Nonetheless, interaction between them and people with intellectual disabilities seemed to be much more challenging. It is noteworthy that varying importance was attached either to patients’ difficulties in understanding or to healthcare staff’s inability to properly explain/carry the information to people with intellectual disabilities, as the underlying causes of communication issues between them. Despite this distinction, miscommunication seemed to cause significant limitations to people’s with intellectual disabilities access and orientation inside the hospital, as well as during being treated by healthcare staff. The need to give clear and reliable information, as well as to calm the patients and explain to them doctors’/nurses’ instructions, were presented as the main justifications of professional supporters’ intervention.

For all the above reasons, we could conclude that *specific adaptations can and have to be made for people with intellectual disabilities*, like the creation of an alternative phone number to schedule appointments addressed to them or the design and implementation of a mechanism for their guidance in the hospitals by respectively trained staff. Even so, the implementation of *horizontal policies* in order to improve the access of all people in the secondary and tertiary healthcare system (e.g., employment of more healthcare staff to reduce long waits and allow them to devote more time and attention to each patient) could therefore be beneficial for people with intellectual disabilities too.

Lastly, *education of all stakeholders* was highlighted throughout the study as a powerful tool to improve people's with intellectual disabilities access and quality provision of services in the secondary and tertiary healthcare system. From the part of professional supporters, education in their healthcare system in order to facilitate the access of the people they accompany was endorsed by most of them. In like manner, subjects thought that it is essential to strengthen hospitals with staff trained in providing services to people with intellectual disabilities, who would understand their needs and would be able to communicate with them in an effective way. Finally, almost all professional supporters regarded that education of people with intellectual disabilities would help them to be better prepared when accessing a hospital and to manage their own emotions in this environment. This final view could represent that people with intellectual disabilities, *if given the chance*, can enjoy the same benefits and rights in health with all other people.