"People with intellectual disabilities: rights and access to health care services in Europe"

EQUAL TREATMENT Report

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

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Abstract

This final report showcases a summary of three analysis implemented by the project consortium of Equal Treatment: collecting good practices on access of persons with intellectual disabilities to secondary and tertiary healthcare; a literature review and a stakeholder analysis. Providing a framework of related global and European policies, this report develops policy recommendations aiming at improving the access of persons with intellectual disabilities to secondary and tertiary healthcare.

In order to elaborate this study, both the project consortium and the project's Policy Advisory Board were involved by providing their feedback expertise.

Introduction to the Project Equal Treatment

Equal Treatment is an ERASMUS+ funded project with the aim to improve the access of people with intellectual disabilities to secondary and tertiary health care through inclusive European policies in healthcare services; training of healthcare staff on interacting with patients with intellectual disabilities and; stronger collaboration between healthcare staff and professional supporters.

The project cycle goes from 2022 to 2024. It focuses on one main topic: **supported rights and access of people with intellectual disabilities to secondary and tertiary healthcare services.**

The expected results of the project are:

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

The target groups and project beneficiaries are: Doctors, Nurses, Administrative staff in secondary and tertiary healthcare services (Healthcare Staff); Educators, Psychologists, Social workers, etc. supporting people with intellectual disabilities (Professional Supporters).

Aims of the study

Persons with intellectual disability have a high prevalence of mental and physical health problems. Health screening, mental and physical health interventions, inclusion of people with intellectual disability in health policy and improved health care are necessary to meet the needs of this population. This Project, through the results of a research based on three products such as the collation of good practices, the stakeholders' analysis and the literature review, highlights the main challenges faced by people with intellectual disabilities in accessing secondary and tertiary healthcare.

This study aims to highlight the results from this research analysing why, despite many EU policy recommendations on people with disabilities' health and their rights to accessing health care services, people with a learning disability die, on average, 16 years younger than the general population, and are over four times more likely to die from causes that were amenable to good quality healthcare. The study conclusions are formulated in policy recommendations addressed at policy makers, healthcare managers and professionals working in this field and aiming at improving healthcare services delivered to people with an intellectual disability.

The recommendations from this Study will support the Equal Treatment Project consortium in the development of “Online self-learning e-modules for healthcare staff” across Lithuania, Finland, Greece and Spain. This training will then be shared amongst the networks of the project partners and disseminated at European level. The expected impact is that all the above-gathered good practices will be adapted to each participant country in order to improve the access to and the rights of people with intellectual disability in secondary and tertiary healthcare.

Methodology

To elaborate the study and to develop the policy recommendations, the Project’s partnership carried out a series of analysis to identify the main issues to be highlighted and addressed at policy makers. In order to do so, firstly a literature review was prepared by analysing scientific articles and textbooks about people with intellectual disabilities in Europe and the world, in order to gain a better understanding of the disability and its current standing in global and European legal and policy documents. Starting from the framework of knowledge set by the **literature review**, a good practices analysis and a stakeholder needs analysis were carried out giving the project consortium an understanding of the situation addressed by the project in the countries under scope of the Equal Treatment project. Four key domains for change (practice, education, policy and research) are explored and some practical strategies for achieving change are identified.

The methodology following the good practices collection was structured as follows: a questionnaire was created to collect good practices in equal treatment of people with intellectual disabilities in secondary and tertiary healthcare. Partners provided relevant feedback to improve it and the last version was approved and later transposed into a Google form.

The questions are divided into five sections. The first four reflect the areas of good practices to be explored by the study: 1) Good practices of effective policies on people with intellectual disabilities inclusion in Health Care 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. The fifth section focuses on impact evaluation and the transferability of the good practices illustrated in the questionnaire.

The stakeholder needs analysis followed a similar procedure. Firstly, questionnaires were drafted and circulated by project partners in their countries among two target groups: healthcare staff and professional supporters. Secondly, interviews were conducted with people with intellectual disabilities by project partners, after the collective formulation of the interview guides. The answers from all the above were then transcribed, collected and analysed in a report. The aim was to gather information about the experiences and challenges of both people with intellectual disabilities accessing hospital services and of professionals working with them, with questions about accessibility of services, interaction between staff and the patients, examination procedures and training.

The project foresaw the collaboration of experts by having a Policy Advisory Board that reviewed the study and contributed to the sign off of the recommendations proposed by this study.

Taking the main results from the three pieces of research mentioned above, this study was developed including a policy framework and drafting recommendations that were addressed at a later stage to different target groups.

Below there is a table with the keywords of the study and their definition in the framework of the project. This table aims to help clarifying the meaning behind the terms used in the purpose of this study as agreed by the partnerships of the Project.

Term in English	Definition in the framework of the Equal Treatment project
Person with disability	A person with long-term impairments (physical, sensory, mental, intellectual) that may prevent them from fully and effectively participating in society on an equal basis with other persons[1]
Healthcare professional	A professional who belongs to the health care sector, such as doctors, nurses, paramedics.
Supporters	Professional and informal carers supporting a person with intellectual disability, such as family members, friends, educators or social workers
Person with an intellectual disability	A person "with a state of arrested or incomplete development of mind, which means that can have difficulties understanding, learning, and remembering new things, and in applying that learning to new situations"[2]
Reasonable accommodation	Necessary and appropriate modification and adjustments needed in a particular case to ensure that persons with disabilities enjoy and exercise on an equal basis with others

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[1] UN General Assembly (2007). *Convention on the Rights of Persons with Disabilities*. Resolution adopted by the General Assembly, 24 January 2007, A/RES/61/106, available at: https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

[2] World Health Organization & World Bank. (2011). World report on disability 2011. https://apps.who.int/iris/handle/10665/44575

	all human rights and fundamental freedoms, including education, employment and access to healthcare[3]
Easy-to-read	A form of communication adapted to persons with intellectual disability with the aim to improve their ability to have access to and understand information[4], including information about medical treatments or diagnosis. It can be used for written documents, media and learning materials, among others.

The policy and legal framework

At a global level

In recent years, both the global and European policy frameworks have strengthened their focus on the health of people with disabilities and their right to access health care services.

Starting from the global level, the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) is the first binding international human rights instrument specifically related to disability. Its purpose is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, as well as promote respect for the inherent dignity of these persons." [5] The UN CRPD affirms on Art. 5 on “Equality and non-discrimination” that “States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds”, while Art. 9 on “Accessibility” calls on State Parties to take appropriate measures to “ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, and other facilities and services open or provided to the public, both in urban and in rural areas”, including medical facilities[6]. The most essential article of the Convention for this study is Art. 25 on “Health”, which states that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.”[7] This articles also calls on State Parties to provide “the same range, quality and standard of free or affordable health care” to persons with disabilities, prevent discriminatory denial of health care and require professionals to provide “care of the same quality as to others” and based on free and informed consent[8].

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[3] Ibid.

[4] UN. Disability-Inclusive language guidelines. https://www.ungeneva.org/sites/default/files/2021-01/Disability-Inclusive-Language-Guidelines.pdf

[5] UN General Assembly (2007). *Convention on the Rights of Persons with Disabilities*. Resolution adopted by the General Assembly, 24 January 2007, A/RES/61/106, available at: https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

[6] Ibid.

[7] Ibid.

[8] Ibid.

The World Health Organisation addressed the issue of health of people with disabilities on several occasions. In 2021 it adopted Resolution WHA74.8 on the highest attainable standard of health for persons with disabilities. The Resolution recognizes that people with disabilities are still more likely to be unable to get access to essential health services, medicines, and treatment due to environmental, financial, legal and attitudinal barriers in society, including discrimination and stigmatization. It stresses that "disability-sensitive, quality, basic and continued education and training of health professionals, including effective communication skills, are crucial to ensure that they have the adequate professional skills and competencies in their respective roles and functions, to provide safe, quality, accessible and inclusive health services"[9]. It also reaffirms the need to enable patients with disabilities to make informed decisions and express their consent, emphasizing the importance of transmitting the relevant information in a reasonable, accessible, and understandable way.

At the EU level

Focusing on the European policy and legislative framework, there are two relevant legal instruments which affirm the right of persons with disabilities to healthcare. The first one is the EU Charter of Fundamental Rights, a legally binding document in which the fundamental rights of citizens of the European Union are enshrined. Article 35 of the Charter on Healthcare states that "everyone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices"[10], while Article 26 focuses on the right of persons with disabilities to "benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community"[11].

The other treaty is the European Social Charter of the Council of Europe, which is a pan-European legal document that guarantees fundamental social and economic rights, with a special focus on vulnerable groups including persons with disabilities. Part one of the treaty states that "everyone has the right to benefit from any measures enabling him to enjoy the highest possible standard of health attainable"[12].

The European Union launched a key policy initiative on people with disabilities, the European Strategy for the Rights of Persons with Disabilities 2021-2030. The Strategy includes health as one of its areas of action. Chapter 5 on "Equal access and non-discrimination" states that people with disabilities have the right to equal access to all health services and high-quality healthcare, pointing out that in the EU people with disabilities report unmet healthcare needs four times more than people without disabilities. The Strategy recognizes that persistent inequalities and discrimination underline the need for further

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[9] World Health Organisation (2021). *The highest attainable standard of health for persons with disabilities.* Resolution adopted by the World Health Assembly, 31 May 2021, WHA 74.8, available at: https://apps.who.int/gb/ebwha/pdf_files/WHA74/A74_R8-en.pdf

[10] European Union (2000). EU Charter of Fundamental Rights. https://www.europarl.europa.eu/charter/pdf/text_en.pdf

[11] Ibid.

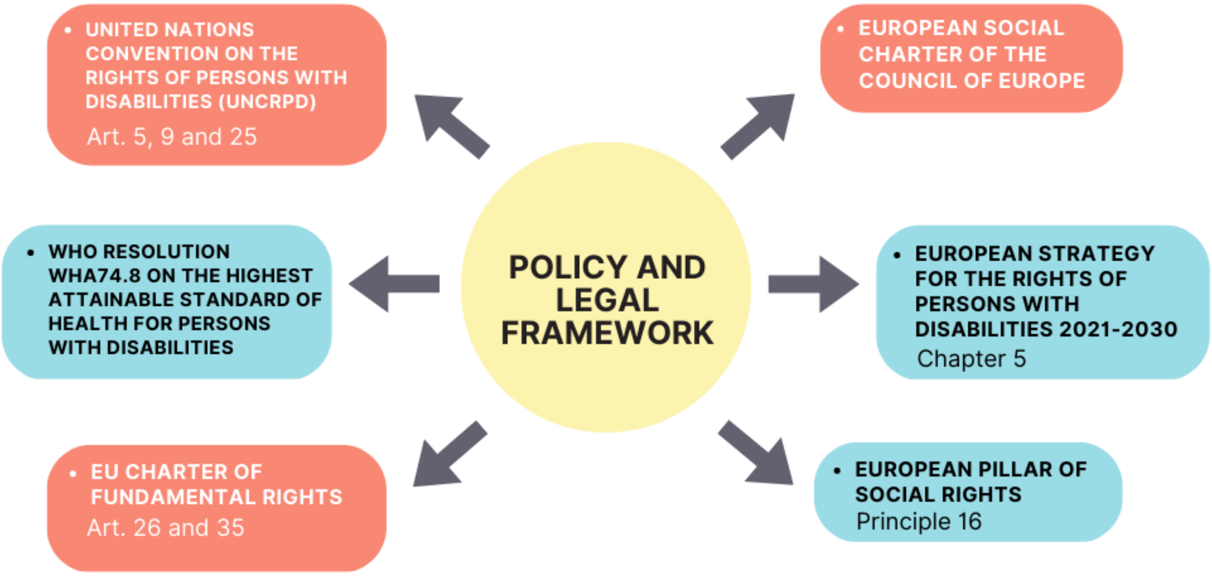
[12] Council of Europe (1961). European Social Charter. https://rm.coe.int/168006b642

progress in EU legislation and calls on Member States to improve access to the “entire healthcare portfolio” and make healthcare inclusive, accessible, and person-centered[13].

The EU is also a party of the aforementioned UN CRPD and as such it must work towards its full implementation in its Member States, which are responsible for promoting, implementing and monitoring of the Convention at the national level. This process of implementation can be monitored via multiple organizations, such as national equality bodies, ombudsmen, human rights institutions and monitoring committees including organizations representing people with disabilities.

Another important initiative is the European Pillar of Social Rights, which was launched in 2017 and includes 20 principles to promote and protect social rights in the EU with long-term perspective. Among these, principle 16 on healthcare states that “everyone has the right to timely access to affordable, preventive and curative health care of good quality”[14]. The Pillar and its Action Plan call for stronger efforts at national, regional, and local level to combat stereotypes in all fields of society, including health. The Action Plan includes a direct reference to the barriers people with disabilities face in accessing health services and the need for progress in the EU on this area.

Below there is a summary of the key policy and legal frameworks on the right to health and access to quality healthcare for people with disabilities.



The boxes in red indicate legally binding international/European documents

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[13] European Union (2021). *Union of Equality. EU Strategy for the Rights of Persons with Disabilities 2021-2030.* Available online at: https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8376&furtherPubs=yes

[14] European Union (2017). *The European Pillar of Social Rights in 20 principles.* https://commission.europa.eu/strategy-and-policy/priorities-2019-2024/economy-works-people/jobs-growth-and-investment/european-pillar-social-rights/european-pillar-social-rights-20-principles_en

Overview of findings

Background: Situational Analysis

Analysis of existing policies and regulations at EU and national level

Despite these policy initiatives being a sign of the efforts made by the EU so far, the data shows that there is still a lot to do to ensure respect for the rights of people with disabilities and their full access to healthcare. People with a learning disability have a lower quality of health than the average, are exposed to high levels of risk and die, on average, 16 years younger than the general population and are over 4 times more likely to have died from causes that were attributable to bad quality healthcare, meaning that their deaths could have been avoided through better healthcare.

Furthermore, Covid-19 has brought to light, and in some cases exacerbated, persisting inequalities and discriminating practices on access to and delivery of healthcare services to persons with intellectual disabilities in many EU countries. A review of policies from 15 European member states published in 2020 identified several barriers for accessing Covid-19 services for autistic people, such as a lack of accessibility to testing, including failure to prioritize and provide reasonable adjustments, a lack of access to outpatient and inpatient treatment due to communication issues, the use of triage protocols that may be directly or indirectly discriminating and abrupt interruptions to standard health and social care[15]. These findings have been supported by several reports and studies conducted by organisations representing persons with disabilities at European level. Persons with intellectual disabilities were often considered as “second-class patients” and victims of discriminatory approaches to life-saving procedures[16].

Key barriers to inclusive health systems remain in the fields of governance, data about people with intellectual disabilities and healthcare workers, including knowledge and communications skills.

Analysis of the data reported by articles, medical and social research

The literature review showed that there is still little research on adults with intellectual disabilities and in particular on the preparation and challenges of healthcare professionals working with them. There is a chronic lack of data about this group in the field of healthcare, and most of the research gathered focuses on missing elements or recommendations for improvements rather than evidence-based implementation of measures or procedures.

Most of the existent research and academic articles on persons with disabilities underline that this is a vulnerable population group in Europe, systematically exposed to discriminatory behaviours, high levels of poverty and social exclusion, with adverse effects on their health and well-being. Studies highlight that social inclusion is in fact associated with

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[15] Oakley B, Tillmann J, Ruigrok A, et al. (2021). *COVID-19 health and social care access for autistic people: European policy revie*w. BMJ Open 2021;11:e045341. doi:10.1136/bmjopen-2020-045341

[16] Inclusion Europe (2020). *Neglect and discrimination. Multiplied. How Covid-19 affected the rights of people with intellectual disabilities and their families.* https://www.inclusion-europe.eu/covid-report-2020/

an improved well-being and quality of life for everyone including people with intellectual disabilities[17].

The literature review shows that people with intellectual disabilities are more likely to be hospitalised, but at the same time they experience poorer health and healthcare access issues[18]. Studies show that people with intellectual disabilities are also at a higher risk of dying of respiratory and circulatory diseases at a younger age than the general population in high-income countries, although the disease in some cases are likely to be preventable[19]. The lack of adequate prevention measures in place and the vulnerability of these population groups are related to risk factors such as ageing, medication, obesity, demographics, but also non-participation and specifically the lack of face-to-face appointments with clinicians. Existing Managed Long-Term Care (MLTC) strategies and programs include several services such as home care or adult day care however are not always applicable to this population group (people with intellectual disabilities) and, as a consequence, may increase health inequalities. Other barriers can stem from a lack of competences or training, communication issues and stigmatizing attitudes.

Analysis of good practices collection

The analysis of good practices showed that positive practices on equal treatment of people with intellectual disabilities do exist, but are still not a common feature in hospitals across Europe[20]. There are still deep regional and even local differences, and when good practices exist, they might not be well disseminated yet or professionals might not be fully aware of them. In many cases, these practices are still informal and are implemented as something that the professional does regularly out of habit or routine rather than enshrined in a protocol[21]. Therefore, it's important to raise awareness of the availability of these programmes and measures among healthcare professionals through materials, meetings or training sessions such as workshops or seminars.

Analysis of stakeholders' needs

The findings from the stakeholders needs analysis carried out among healthcare professionals, people with intellectual disabilities and professional supporters reinforced the points already raised by the previous research activities. On the one hand, people with intellectual disabilities show varying levels of literacy across countries, including awareness of their insurance number, which is a key instrument to identify themselves when access secondary and tertiary healthcare services[22]. They are also often unaware of how to schedule an appointment and to engage in hospital procedures and visits due to orientation and communication barriers[23].

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[17] O'Leary L, Cooper S-A, Hughes-McCormack L. (2017). *Early death and causes of death of people with intellectual disabilities: A systematic review*. J Appl Res Intellect Disability, 00:1–18. https://doi.org/10.1111/jar.12417

[18] Equal Treatment (2022). Literature review. Conclusion report.

[19] O'Leary L, Cooper S-A, Hughes-McCormack L. (2017). *Early death and causes of death of people with intellectual disabilities: A systematic review*. J Appl Res Intellect Disability, 00:1–18. https://doi.org/10.1111/jar.12417

[20] Equal Treatment (2022). Analysis of good practices. Conclusion report.

[21] Ibid.

[22] Equal Treatment (2022). Needs Analysis. Conclusion report.

[23] Ibid.

On the other hand, findings from the analysis of healthcare professionals' needs underlines the difficulties in communicating with a patient with intellectual disability and in dealing with behavioural issues or refusal to cooperate. These challenges were shown to be directly linked to the lack of healthcare staff's skills and education on intellectual disabilities.

The findings show professional supporters were seen as key facilitators between healthcare staff and patients. Supporters pointed out the lack of standardised procedures to ask for information, the lack of reasonable adjustments for patients with intellectual disabilities and a lack of staff training and communication materials. All these issues limit the possibility of persons with intellectual disabilities to take the initiative and have autonomy while accessing secondary and tertiary health services. Supporters pointed out the need to train not only healthcare professionals, but also people with intellectual disabilities in accessing the healthcare system, better interacting with staff and managing fear.

Main challenges to full access of people with intellectual disabilities in secondary and tertiary healthcare services

People with intellectual disabilities continue to have specific challenges and barriers to access healthcare and to be adequately treated by healthcare professionals. These challenges and barriers were identified in the literature review and the analysis of professionals' and patients' experiences, and help us understand why change in the way secondary and tertiary healthcare is delivered to people with intellectual disabilities is required. Gaining awareness about this need is fundamental to achieving such change.

Identification of intellectual disability

There is still no single definition that directly describes people with intellectual disabilities. Deficits in intellectual functioning and difficulties in social skills and socialisation are the main features that characterize individuals with intellectual disabilities, but the causes are varied and often unclear. Legal documents often emphasize persons with mental health issues or physical disabilities, while missing the focus on the needs of people with intellectual disabilities. In some other cases, there are policies in place for patients with "special needs" but not for people with intellectual disabilities specifically. Insufficient legal regulation of the provision of health care services to persons with intellectual disabilities in the countries participating in the project.

There is no standardised system in place to identify and flag patients with intellectual disabilities and to possibly share these data among hospitals in the region or at national level. In the United Kingdom, Ireland and in a part of Finland, the hospital passportis a valid alternative that could be easily adopted in other countries, however it is still not widely known. Some ethical and privacy issues can arise also during the initial interviews with the patient.

Staff training

One of the main challenges to full access of people with intellectual disabilities to healthcare services is the lack of specialised knowledge of practitioners and healthcare professionals about intellectual disabilities.

Very few hospitals have an intellectual disabilities-informed figure trained to facilitate communication with intellectual disabilities. This in turn is the result of a lack of specific training, both at the level of universities and of professional development opportunities. All European countries nursing and medical education still lack courses on this specific patient group. The lack of training causes professionals to report anxiety and stress when treating intellectual disabilities, mainly due to a major difficulty in communicating with these patients.

It's essential that professionals are trained to use the different modes of communication according to the patient they are treating. Without a proper preparation, they often struggle to communicate in an accessible way, which reduces the quality of the treatment and the access to the services. In the stakeholders needs analysis, formal education was significantly correlated (p=0.001) with the level of difficulty in interacting with people with intellectual disabilities, and the respondents who had not received training were more than twice more likely to find communicating with or collecting information from people with intellectual disabilities very or extremely difficult[24].There is a need to prepare and publish guidelines for health care specialists, on proper diagnosing, treatment and nursing of persons with intellectual disability, with the focus of their special needs.

Communication barriers

Academic research shows that people with intellectual disabilities may interact better through different means of communication such as pictograms. However, poor knowledge of disability and communication skills with people with intellectual disabilities have been identified among healthcare staff both in the literature review and in the stakeholders needs collection and they contribute to a higher risk of misdiagnosis, poorer health and increased incidences of hospital visits and stays of patients with intellectual disabilities. The majority of healthcare professionals who responded to the needs analysis 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%)[25].

The struggle to communicate, sometimes coupled with a negative and stereotypical attitude of healthcare staff towards people with intellectual disabilities, is a reason why often medical professionals prefer to communicate with the support person instead of the patient. The needs analysis showed that 83.1% of respondents who had obstacles to communicate preferred to ask the supporter for help[26]. This practice can lead to the exclusion of the intellectual disabilities from making informed decisions about exams and treatments.

Involvement of people with intellectual disabilities in the design process and training

The analysis highlighted the need to involve more people with intellectual disabilities, their supporters and the organisations representing them in the design of measures and professional training in order to promote collaborative working. Capacity building and improving the knowledge of service providers is a way of improving access and quality of services. Advocacy work can be difficult as the health systems can be quite rigid when it comes to introducing change to the way of working.

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[24] Equal Treatment (2022). Needs Analysis. Conclusion report.

[25] Equal Treatment (2022). Needs Analysis. Conclusion report.

[26] Ibid.

The good practices analysis in particular stressed the lack of evidence about the actual evaluation of reasonable adjustments and other measures implemented by the hospitals for people with intellectual disabilities.

It would be useful to offer training also to supporters and people with intellectual disabilities themselves. 82.4% of the supporters who responded to the questionnaire would like to be trained in the healthcare system of their country in general. Moreover, almost all of them (95.9%) answered that it would be helpful if people with disabilities received training in accessing the secondary and tertiary healthcare system, as well as in interacting with healthcare staff in order to be better prepares and better manage their fear[27].

Lack of technology use

Technology is still not fully used to support the equal access of people with intellectual disabilities in secondary and tertiary healthcare services. One responder pointed out that artificial intelligence could be useful to provide speech recognition, for example. Mobile and digital services could be used more, for example in some home services. On the other hand, in this case, people with intellectual disabilities may remain hidden in homes and thus the feeling of isolation can grow.

Key barriers to full access of people with intellectual disabilities to secondary and tertiary healthcare services

- Identification of intellectual disability
- Lack of training of healthcare staff
- Communication
- Lack of involvement of persons with disability and supporters
- Limited use of technology

Good practices to address the challenges – what seems to be making a difference?

The analysis of good practices showed that several successful programmes exist in different parts of Europe and contribute to improving the experience of people with intellectual

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[27] Ibid.

disabilities in secondary and tertiary healthcare. There are still deep regional and sometimes local differences, with places where indeed there are no programmes, projects or measures in place to improve services for people with intellectual disabilities, however, the examples analysed offer relevant insights into the measures that could help to improve the experience of people with intellectual disabilities at the hospital. Most of them consist of forms of individualised services for people with intellectual disabilities, with some of the most common interventions including granting priority access in emergency, reducing waiting times, ensuring quick dismissals, enabling a dedicated and well-equipped space for waiting, letting caregivers access the hospital room, offering longer reception times and double appointments, and coordinating medical appointments and examinations[28].

The use of sedation or anaesthesia for procedures which might be potentially painful for the patient can be especially helpful for people with intellectual disabilities, since they often have a lower threshold for pain compared to the general population and might experience more discomfort and anxiety during examinations. This measure makes it possible to combine exams, thus reducing the duration of their stay or the number of accesses to the hospital. Because people with intellectual disabilities experience pain differently, it’s important to pay particular attention when evaluating it, since it can often be a symptom difficult to interpret and manage. Visual support can be used to better define the level of pain of the patient with intellectual disabilities.

The use of questionnaires or a “hospital passport” to easily identify and flag people with intellectual disabilities is an important good practice which enables doctors, nurses and therapists to improve their preparedness[29]. By accessing the patient’s medical history and specific information related to the type of disability, behaviour and method of communication preferred prior to the visit, healthcare staff knows better how to deal with the patient on a case by case basis and to provide reasonable adjustments before any examination or treatment. The information and data collected is always saved in an online hospital database, so that all professionals and staff are informed about the patient’s needs and it is easier to flag the patient with intellectual disability on future occasions. It also helps family relatives and supporters to communicate to the hospital staff crucial information about their relative in a safe way, as they sometimes might forget to mention everything due to stress.

To facilitate effective communication with people with intellectual disabilities during initial contact with the hospital, it is useful to improve access to online information through accessible websites and to simplify phone communication, for example by providing a phone contact specifically for people with intellectual disabilities and their families or by providing staff specialised in communication with this patient group. Once in the hospital, visual aids, pictograms, social narrative and easy-to-read information can be used. Recommendations to staff on how to interact with people with intellectual disabilities are essential and the most common ones include addressing the patient normally, using clear and simple language, a soft tone of voice, and avoiding excessive medical jargon when explaining procedures. Showing empathy and paying attention to the needs, opinions and feelings of the patient is also important to facilitate fruitful interaction. Staff should make an effort to talk directly with the patient, addressing the supporter only when the latter is truly needed to facilitate the interaction and overcome barriers.

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[28] Equal Treatment (2022). Analysis of good practices. Conclusion report.

[29] Ibid.

Families can be supported as well in interacting better with healthcare professionals and in preparing the patient to access the hospital. Information about the medical procedures can be provided through dedicated webpages, videos and easy-to-use material. Another useful but more rarely implemented measure is to let families borrow medical tools to help the patient with intellectual disabilities to familiarise with them ahead of the examination[30]. Communication tools and a contact point for families such as a "case manager", have both the ultimate aim of enabling the patient with intellectual disabilities to be obtain, process and understand information related to their health, condition and upcoming examinations.

It is important to point out that the provision of good practices' examples was regarded by 68.5% of healthcare respondents as the best means of education for healthcare staff, together with videos and an online platform to exchange experiences with colleagues[31].

Barriers	Examples of good practices
Identification of intellectual disability	• Hospital passport • Questionnaires on specific needs of the patient • Online hospital database
Access to hospital/initial contact	• Accessible websites • Simplified phone communication e.g. phone contact specifically for people with intellectual disabilities and their families • Staff specialised in communication with people with intellectual disabilities as contact point • Priority access in emergency room
Navigating the hospital	• Easy-to-read information • Dedicates signage
Reasonable accommodation	• Reducing waiting times and ensuring quick dismissals • Offering longer reception times and/or double appointments • Coordinating medical exams • Offering a dedicated and well-equipped space for waiting • Letting caregivers access the hospital room • Using sedation or anaesthesia for potentially painful procedures
Communication	• Visual aids, pictograms • Easy-to-read information • Recommendations to staff to use

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[30] Ibid.

[31] Equal Treatment (2022). Needs Analysis. Conclusion report.

	clear and simple language, avoid medical jargon
Support to families and supporters	• Providing dedicated webpages, videos and easy-to-use material with information about the medical procedures. • Letting families borrow medical tools to help the person with intellectual disabilities to familiarise with them ahead of the examination • Offering a contact point for families such as a “case manager”

Policy and practice recommendations

Key policy and practice recommendations have been drawn from this report. While developing them, the need to tailor these actions to different authorities, healthcare settings and professionals was taken into account. This point has been raised also in a study analysed during the literature review, which however recognised that sometimes it might be unclear whose responsibility it is to initiate such actions, also due to country differences[32].

The key policy and practice recommendations that have been drawn from this report are:

1. Guidelines or decision-making protocols should be put in place on access to care and treatment in secondary and tertiary healthcare, which should prevent discrimination and ensure that clinical decisions and pathways are not discriminatory and enable equal access to hospital care and treatment for everyone. To do so, **policies and procedures specifically for persons with intellectual disabilities** and not only and generally people with disabilities or people with “special needs” **should be developed and guaranteed** by both the EU and national authorities. To help inform these protocols, existing **good practices should be mainstreamed** among professionals **and disseminated** at local and regional level through materials, meetings or training sessions such as workshops or seminars.

Addressed to: EU INSTITUTIONS, NATIONAL HEALTHCARE SYSTEMS/AUTHORITIES, ASSOCIATIONS OF DISABILITY SECTOR

2. Patients with intellectual disabilities should be flagged during the initial contact with secondary and tertiary healthcare services through a **system of identification that allows to collect, codify and store data about people with intellectual disability in a hospital database**. In this way, all hospital staff and professionals can be aware of the patient’s needs, provide the adequate adjustments and flag the patient more easily on future occasions. The **hospital passport** following the model of the UK, Ireland or Finland, is a

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[32] McConkey, R., Taggart, L., DuBois, L., Shellard, A. (2020). *Creating Inclusive Health Systems for People With Intellectual Disabilities: An International Study*. Journal of Policy and Practice in Intellectual Disabilities, Vol 17, No. 4.

good practice that can be easily implemented for this purpose, as it provides all the necessary information for the staff to be able to work well with the patient, while also helping the family carers and/or professional supporters to communicate crucial information about the patient in a safe and structured way.

Addressed to: COMPETENT AUTHORITIES

3. **Reasonable adjustments should be implemented to remove barriers that may affect people with intellectual disability, adapting or changing the way services are delivered to meet an individual's needs**. The main interventions include:

- priority access to receive services in an emergency and thus reducing waiting time;
- granting access to caregivers, providing a dedicated and adapted to their needs space during waiting time;
- offering longer appointments and coordinating, if needed, multiple medical examinations to optimise the time spent by the **person with intellectual disability** in the hospital.

Addressed to: PUBLIC AUTHORITIES, HEALTHCARE SERVICES AND INSTITUTIONS, HOSPITAL MANAGEMENT

4. **Effective staff–patient communication** is essential in the treatment of **people with intellectual disability** and to make sure that the patient is well-informed about the medical examinations that must be undertaken. Key recommendations include:

- using short sentences and avoiding medical jargon when alternatives can be found;
- checking whether the patient has understood the information using easy-to-read materials, pictograms or objects – including diagnostic tools – so that the patient can become acquainted with the materials and procedures of the test they may take in advance.
  In order to implement all these measures, appropriate time should be allocated to the patient with intellectual disability by allowing longer appointments.

Addressed to: HEALTHCARE PROFESSIONALS, SOCIAL SERVICES, EXPERTS IN EASY-TO-READ FORMAT

5. Supported decision making **to all types of care or treatment must be ensured**. Often the patient knows more about their disability or illness than the doctor, and knows better than anyone else how to deal with their problems. Furthermore, when persons with disabilities come with a personal assistant, medical practitioners tend to forget about the person with disabilities and go directly to the assistant. It is true that it is often quicker to address the assistant. However, it is essential to take the person into account.

Addressed to: COMPETENT AUTHORITIES, HEALTHCARE PROFESSIONALS, PROFESSIONALS OF THE DISABILITY SECTOR

6. **Healthcare professionals need to develop their skills and knowledge in order to better support the health literacy and communication needs of patients with intellectual disabilities**. Developing the competencies of health care workers is a necessary precondition for the provision of quality health care services to disabled patients and the performance of effective professional functions. **Developing and delivering training programmes** that address intellectual disability and capacity building of staff at all

levels in secondary and tertiary health services can improve access and the quality of services. Medical training should include how to best support people with intellectual disabilities in terms of proper diagnosing, treatment and nursing, with the focus of the special needs of patients with intellectual disabilities, as well as how to communicate with them even in complex situations where the patient has behavioural issues or refuses to cooperate.

Addressed to: ASSOCIATIONS IN THE HEALTH SECTOR, HOSPITAL MANAGEMENT, PUBLIC HEALTH AUTHORITIES, DISABILITY SECTOR

7. **Training** should be provided also **to people with intellectual disabilities and their supporters**. This would enable people with intellectual disabilities to better know how to access secondary and tertiary healthcare services, for example how to schedule an appointment and follow the most common hospital procedures. Training would also play a key role to improve and facilitate the interaction of both patients and supporters with healthcare staff, their preparation and ability to manage fear or anxiety.

Addressed to: ASSOCIATIONS OF DISABILITY SECTOR, SUPPORTERS TO PEOPLE WITH INTELLECTUAL DISABILITY

8. **Promote the appointment of intellectual disability nurses** or a “disability/inclusion champion” with a clear definition of their role in supporting people with an intellectual disability, their families and other healthcare professionals across the full extent of secondary and tertiary healthcare provision.

Addressed to: COMPETENT AUTHORITIES, HOSPITAL MANAGEMENT

9. Promote a **co-production approach** in the design of healthcare services to people with intellectual disabilities that engage users, their families, professional supporters and service providers with expertise in developing the best framework including the above reasonable adjustments that to meet their individual needs.

Addressed to: ASSOCIATIONS OF THE DISABILITY SECTOR, SOCIAL SERVICES, PUBLIC AUTHORITIES

10. **Consistent and long-term funding** from the EU and national and regional level is needed to put the above recommendations in place and support the **sustainability** of projects aiming at more inclusive secondary and tertiary healthcare practices to become part of the hospitals procedures and protocols at a later stage. Funding is strongly needed to enable hospitals to implement the reasonable adjustments mentioned in recommendation 3, taking into account the financial impact that they could have, but also to ensure training to healthcare professionals. Increased **involvement of stakeholders and cooperation with social services** is needed to ensure that adequate funding is allocated.

Addressed to: EU INSTITUTIONS, COMPETENT REGIONAL/LOCAL AUTHORITIES, SOCIAL SERVICES

On the next page you can find a table summarising the ten key recommendations and the main actors involved.

	WHAT?	WHO?
1	Develop and mainstream policies and procedures specifically for persons with intellectual disabilities	European Institutions National healthcare systems or authorities Associations of disability sector
2	Introduce a system of identification to collect, codify and store data about patients with intellectual disability in a hospital database	Competent authorities
3	Introduce reasonable adjustments to remove barriers that may affect people with intellectual disability	Public authorities healthcare services and institutions Hospital management
4	Support and implement measures to ensure effective communication between healthcare staff and persons with intellectual disabilities and their supporters	Healthcare professionals Social services Experts in easy-to-read format
5	Ensure supported decision making to all types of care or treatment	Competent authorities Healthcare professionals Professionals of the disability sector
6	Develop and deliver training programmes for healthcare professionals to develop their skills and knowledge of intellectual disabilities	Associations in the health sector Hospital management Public health authorities Disability sector
7	Develop and provide training for people with intellectual disabilities and their supporters on access to hospital services and interaction with healthcare staff	Associations of disability sector Supporters to people with intellectual disability
8	Promote the appointment of intellectual disability nurses or disability champion	Competent authorities Hospital management
9	Promote a co-production approach in the design of healthcare services to people with intellectual disabilities	Associations of the disability sector Social services Public authorities
10	Increase long-term funding and strengthen cooperation between stakeholders and social services	European Institutions Competent regional or local authorities Social services