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

EQUAL TREATMENT Policy Recommendations Report

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

Erasmus 2027 program project “EQUAL TREATMENT“ No. ERASMUS-EDU-2021-PCOOP-ENGO-101049115

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

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Abstract

This report highlights the policy recommendations developed by the project consortium of Equal Treatment from the analysis of research findings from:

- **the collection of good practices** on access of persons with intellectual disabilities to secondary and tertiary healthcare;
- **a literature review** on the rights and access of persons with intellectual disabilities to secondary and tertiary healthcare and;
- **a stakeholder needs analysis** on access of persons with intellectual disabilities to secondary and tertiary healthcare.

Providing a framework of the 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 the development of the policy recommendations, both the project consortium and the project's Policy Advisory Board were involved by providing their feedback and 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 report on policy recommendations

The Policy Recommendations developed from the research findings during the first phase of the Equal Treatment Project are formulated to improve the rights and access to secondary and tertiary health care services across Europe for people with intellectual disabilities. These policy recommendations are addressed to 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 will assist the stakeholders in furthering the goals of an accessible health system as it is described in Article 25 of UNCRPD. These recommendations function as suggestions to address and attend certain issues identified throughout the implementation of the project.

Furthermore, the recommendations from this report 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 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 development of 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 research findings and contributed to the sign off of the recommendations proposed by this report.

Below there is a table with the keywords of the report 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 all human rights and fundamental freedoms,

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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

	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.

Overview of findings

Background: Situational Analysis
Analysis of existing policies and regulations at international and EU levels

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.

At 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, please see specific articles below, with the aim 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]

- Art. 5 on Equality and non-discrimination 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”,
- 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].
- 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]

These articles 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

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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.

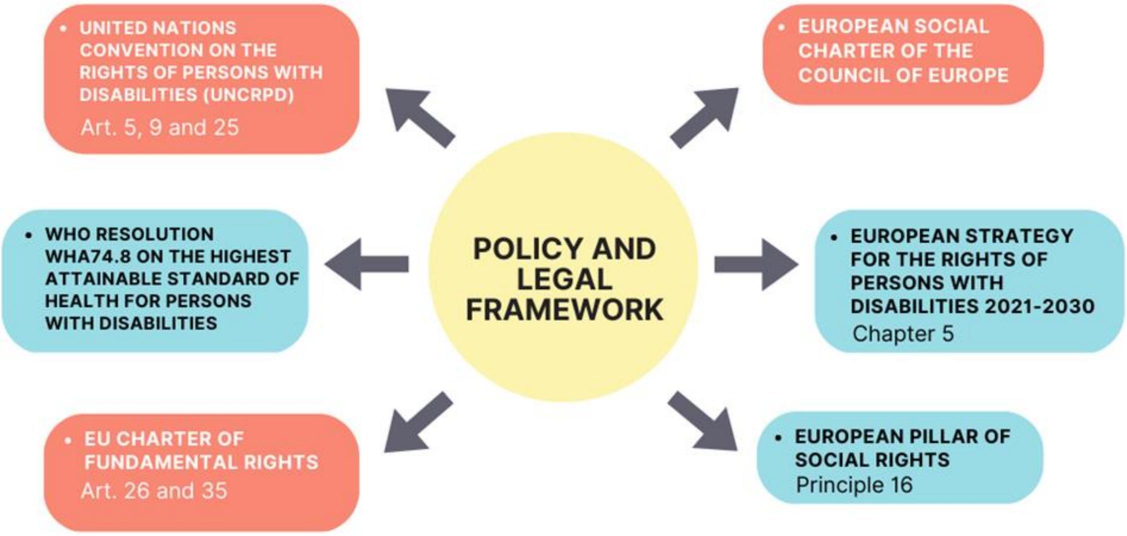
care and require professionals to provide “care of the same quality as to others” and based on free and informed consent[8].

At European level, there are two relevant legal instruments which affirm the right of persons with disabilities to healthcare

- **EU Charter of Fundamental Rights**: Article 35 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”[9]; 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”[10].
- **European Social Charter of the Council of Europe**, this pan-European legal document 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”[11].

Additionally, 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 recognizes that persistent inequalities and discrimination underline the need for further progress in EU legislation and that in the EU people with disabilities report unmet healthcare needs four times more than people without 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.

Here 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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[8] Ibid.

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

[10] Ibid.

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

Despite the above legal frameworks and policy commitments at international and European level, 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[12]. 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[13].

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

The literature review highlights that people with intellectual disabilities are more likely to be hospitalised, but at the same time they experience poorer health and healthcare access issues[14]: Most academic articles researched underline that persons with disabilities are a vulnerable group in Europe and noticeably, there is very little information or data about this group in the field of healthcare, with most of the research gathered focusing on missing elements or recommendations for improvements, rather than evidence-based implementation of measures or procedures.

There is evidence that people with intellectual disabilities are systematically exposed to discriminatory behaviours, high levels of poverty and social exclusion, with adverse effects on their health and well-being for example they experience. For example, data shows that they are at higher risk of dying of respiratory and circulatory diseases at a younger age than the

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[12] 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

[13] 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/

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

general population in high-income countries, although the disease in some cases are likely to be preventable[15].

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[16]. 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[17]. 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[18]. 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[19].

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

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[15] 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

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

[17] Ibid.

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

[19] Ibid.

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.

1. **Identification of intellectual disability**: there is still no single definition that directly describes people with intellectual disabilities which means they sometimes fall within the general category of patients with "special needs" which does not address their specific needs. In the countries participating in the project, it was found that there is insufficient legal regulation on the provision of health care services to persons with intellectual disabilities. In addition, no standardised system is in place to identify and flag patients with intellectual disabilities and to possibly share the data among hospitals at regional or national levels.
2. **Staff training:** practitioners and healthcare professionals having insufficient specialised knowledge and understanding of intellectual disabilities is a key challenge to full access of people with intellectual disabilities to healthcare services. 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.

3. **Communication barriers:** academic research shows that people with intellectual disabilities may interact better through different means of communication such as pictograms. However, the literature review and the stakeholders needs collection highlight that healthcare staff generally tend to have:
    - poor knowledge of disability and as a result, lack adequate communication skills with people with intellectual disabilities which can contribute to a higher risk of misdiagnosis, poorer health and increased incidences of hospital visits and stays of patients with intellectual disabilities;
    - a propensity to view people with intellectual disabilities negatively and with a stereotypical attitude which can lead to the exclusion of the intellectual disabilities from making informed decisions about exams and treatments.
4. **Involvement of people with intellectual disabilities in the design process and training:** the analysis of stakeholders' needs highlighted the importance of involving 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. The project's research also highlighted the need to train supporters and people with intellectual disabilities themselves.
5. **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.

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 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.

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 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

From the analysis of research carried out by the partners of the Equal Treatment Project, the following policy recommendations have been developed to improve the rights and access to secondary and tertiary health care services across Europe for people with intellectual disabilities.

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.

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.

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.

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.

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. It is essential to take the person with intellectual disabilities 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 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.

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

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.

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

Conclusion

The policy recommendations are included in a published final Study paper that draws together in more detail, all the research findings and how they have led to the development of the policy recommendations.

Furthermore, the Study with policy recommendations has been translated in to all the languages of the countries of the partnership: Spanish, Greek, Lithuanian and Finnish.

The Study with policy recommendations will be shared amongst key stakeholders including, WHO Europe and the European Commission and regional/national stakeholders, with the aim of raising awareness of the key challenges and good practices in order to influence change to ensure equal access and rights for people with intellectual disabilities to secondary and tertiary healthcare.

In summary, these are the key policy recommendations developed from the research undertaken by the Equal Treatment Project Consortium.

	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

The Equal Treatment Project consortium would like to thank members of the Policy Advisory Board for their guidance and advice in the development of these policy recommendations.