Inclusion Europe
The European Association of Societies of
Persons with Intellectual Disabilities and their Families

Inclusion Europe

Un-equal healthcare?

Study on equal access to healthcare for people with intellectual disabilities

Contents

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This report was funded by the European Union. The EU bears no responsibility for the contents of the report.

1. Introduction

Inclusion Europe has received an increasing number of reports from its membership in all of Europe about difficulties of people with intellectual disabilities to access health services on an equal basis than other citizens. It is difficult to quantify these issues since personal health data is protected and procedures that were not carried out are not at all registered.

This study represents a starting point for further research, discussions and advocacy work. We are aware of its limits in scope or representativeness, and we intend to build on the issues highlighted here to produce more research and more evidence.

2. Methodology

Due to the lack of statistical data, we rely on individual stories as evidence. The significance of individual stories was highlighted for example but the UK report "Death by Indifference"[1] that to date documented 74 deaths[2] of people with intellectual disabilities due to lack of accessible health care. In a similar framework, this study relies on reports and opinions of experts rather than trying to get access to statistical data. What we found is described in detail on the following pages.

There seems to be a lot of neglect, indifference and discriminatory treatment. It is a merit of the Mencap studies in the UK to clearly document that these are not minor problems, but that this can ultimately lead to the death and suffering of many people.

This study covers 14 out of the 32 EU and EFTA countries: Bulgaria, Croatia, Denmark, Estonia, France, Germany, Greece, Iceland, Ireland, Netherlands, Portugal, Spain, Switzerland and the United Kingdom. Unfortunately, the replies from Central and Eastern European countries were not really sufficient. However, the responses cover 330 Million of the total of 524 Million people [3] living in EU and EFTA countries.

The data collection for this study has started in 2016 via an online questionnaire. The reports covering each country were provided by national experts who have long-standing expertise and experience in healthcare accessibility for people with intellectual disabilities.

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[1] Mencap: Death by indifference. https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf

[2] Mencap: Death by indifference: 74 deaths and counting. A progress report 5 years on. https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf

[3] Eurostat: Population and population change statistics. Data extracted in July 2017.

3. The right of access to health care without discrimination

According to CRPD Article 25, persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability[4]. In this context, health is defined as “a state of complete physical, mental and social well-being and not merely the absence of disease or illness”[5]. The CRPD also establishes that disability is not necessarily a medical condition. While persons with disabilities may at times need to access health services for medical conditions related to their disabilities, this should not be presumed to be their primary need for health services.

Persons with intellectual disabilities have the same general health care needs as everyone else. They have the right to access mainstream health care services on equal basis. It is crucial that health care services and facilities are developed and accessible to all persons with disabilities.

The obligation to guarantee non-discrimination under the CRPD imposes “an immediate obligation to guarantee that economic, social and cultural rights are enjoyed without discrimination. Accordingly, measures towards the progressive achievement of rights must at all times be guided by, and comply with, the basic requirement of non-discrimination”[6]. The Committee on Economic, Social and Cultural Rights highlighted already in 2000 that **non-discrimination in access to health care is an immediate obligation for all States,** because “many measures, such as most strategies and programmes designed to eliminate health-related discrimination, can be pursued with minimum resource implications through the adoption, modification or abrogation of legislation or the dissemination of information.”[7]

The CRPD requires that States Parties “take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.”[8] Persons with disabilities face a range of barriers in accessing health care services, including communication, attitudes, cost, accessibility, stigma and discrimination. The Committee on Economic, Social and Cultural Rights (CESCR) states in its General Comment 14 on the right to health that the four components of accessibility are non-discrimination, physical accessibility, economic accessibility, and information accessibility[9]. Without equal access to health care, “people with disabilities are at serious risk of delayed diagnoses, secondary co-morbidities, persistent abuse, depleted social capital, and isolation.”[10]

Physical barriers to accessing health care include both environmental and infrastructural barriers as well as geographical barriers, such as access to rural health centres. The CRPD also focuses on geographical access to health care, establishing in Article 25(c) that States parties must “provide these health services as close as possible to people’s own communities, including in rural areas.” Provision of health care facilities to individuals in rural areas ensures that everyone is able to physically reach health care facilities.

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[4] United Nations General Assembly, *Convention on the Rights of Persons with Disabilities*, A/RES/61/106, Art. 25 (2006). http://www.ohchr.org/EN/HRBod- ies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx.

[5] World Health Organization, “Definition of Health.” http://www.who.int/about/definition/en/print.html

[6] United Nations Economic and Social Council (2007). “Report of the United Nations High Commissioner for Human Rights”, E/2007/82, 25 June. http:// ap.ohchr.org/documents/alldocs.aspx?doc_id=15584

[7] UN Committee on Economic, Social, and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, E/C.12/2000/4 (Aug. 11, 2000). http://www2.ohchr.org/english/bodies/cescr/comments.htm.

[8] United Nations General Assembly, Convention on the Rights of Persons with Disabilities, A/RES/61/106, Art. 25(a) (2006). http://www.ohchr.org/EN/HR- Bodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx

[9] UN Committee on Economic, Social, and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health, E/C.12/2000/4 (Aug. 11, 2000). http://www2.ohchr.org/english/bodies/cescr/comments.htm.

[10] World Health Organization, World Report on Disability (2011). http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf

The CRPD provides in Article 25 that States parties must “provide persons with disabilities the same range, quality and standard of free or affordable health care and programmes as provided to other persons. States parties must “prohibit discrimination against persons with disabilities in the provision of health insurance [...] which shall be provided in a fair and reasonable manner.” However, persons with disabilities have lower rates of employment, making it more difficult for them to afford health insurance or are less likely to be covered if health insurance is usually provided by the workplace. Those persons with disabilities who are provided health insurance may be denied coverage due to their pre-existing conditions or discriminatory coverage policies.

Research demonstrates that persons with disabilities receive poorer health care services and consequently experience poorer health outcomes**. Persons with disabilities are also more vulnerable to deficiencies in health care services, which increase their risk of secondary conditions, co-morbid conditions and age-related conditions.** Persons with disabilities are also vulnerable to violence, abuse and exploitation, especially when they have to rely on others for support and care. Persons with disabilities are susceptible to violations within their home and by family members, caregivers, health care professionals and community members[11].

Access to information is crucial for patients with intellectual disabilities to receive and understand relevant health information and to communicate with health care professionals. Access to information is also important for navigating the health care system. The form or the content of information can thus serve as barrier to accessing information for many persons with disabilities[12]. Using easy-to-read language[13] or using pictures and communication symbols are different methods for changing the content of information to make it more accessible.

In addition, States parties must “require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent”. This requirement of article 25 is crucial for people with intellectual disabilities. Informed consent cannot be limited to the acceptance of a medical intervention, but has to be a voluntary and informed decision on the basis of accessible information. Violations of informed consent may, in some instances, amount to torture. The UN Special Rapporteur on torture states clearly that the “United Nations treaty bodies have established that involuntary treatment and other psychiatric interventions in health-care facilities are forms of torture and ill-treatment.”[14] Persons with disabilities have the right to provide or withhold consent to any medical intervention or health service. Health professionals should speak directly with the individuals about their health matters and not only to their carers, support persons or relatives

The Special Rapporteur against Torture affirms that involuntary and forced medical treatment in, as well as involuntary commitment to health-care facilities and institutions are forms of torture and ill-treatment. He writes that “in the context of health care, choices by people with disabilities are often overridden based on their supposed “best interests”, and serious violations and discrimination against persons with disabilities may be masked as “good intentions” of health professionals.”[15] The report explains that violations cannot be justified by claims of “medical necessity,” and emphasizes the fundamental need for free, full, and informed consent by patients for any medical procedures.

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[11] United Nations General Assembly, Note by the Secretary General on Torture and other cruel, inhuman or degrading treatment or punishment, A/63/175 (July 28, 2008).

[12] Office of the High Commissioner for Human Rights, Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors (2010), pg. 58. http://www.ohchr.org/Documents/Publications/Disabilities_training_17EN.pdf

[13] See www.easy-to-read.eu

[14] Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53 (Feb 2013). http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

[15] Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment*, A/HRC/22/53 (Feb 2013). http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

The Special Rapporteur against Torture notes that the following practices are banned under the CRPD:

- Forced and non-consensual medical interventions including forced administration of psychiatric medication
- Medical experimentation or medical treatments without consent including abortion, sterilization, electroshock treatment and psycho-surgery.
- The use of restraints or seclusion for both long and short-term application. Over-medication may also be considered a form of chemical restraint.
- Deprivation of liberty through involuntary commitment to psychiatric hospitals or institutions

The CRPD thus prioritizes health care training and awareness for health professionals. Health care education on disability should include a range of topics including clinical information, communication strategies and an introduction to a human rights approach to disability. Training beyond clinical information for professionals to understand not just disease, but also the experience of living with disability, is important. Health care professional training on the rights of persons with disabilities combats stigma and equips providers with the awareness necessary to provide persons with disabilities quality health care.

The CRPD establishes in Article 25 that States parties must provide persons with disabilities the same sexual and reproductive health care and programmes as provided to other persons. Sexual and reproductive rights must be guaranteed for persons with disabilities and yet persons with disabilities often experience gross violations of their rights and cannot access sexual and reproductive services.

4. Equal access to health care in European Union policies

Health policies in the European Union are mainly a remit of the Member States. The EU has the competence to carry out actions to support, coordinate and/or supplement the actions of Member States regarding to the protection and improvement of health of European Union citizens. Complementing national actions, the EU can be active in the areas of research, health information and education, monitoring and combating serious cross-border threats to health.

In the framework of the implementation of the CRPD, ‘health’ constitutes one of the eight areas for action under the EU Disability Strategy. One focus point is to ensure equal access to health care for people with disabilities, mainly by combating discrimination and enhancing accessibility. The EU also supports the development of early intervention and needs assessment services.

The CRPD Committee states in its recommendations to the EU:

> “62. The Committee is concerned that discrimination on the grounds of disability is not explicitly prohibited in the field of health care. It notes the barriers faced by persons with disabilities in accessing health care in different member States.
>
> 63. The Committee recommends that the European Union explicitly prohibit discrimination on the grounds of disability in the field of health care and take measures to ensure access to quality health care for all persons with all types of disabilities. It also recommends that the European Union evaluate the impact of the European Parliament and the Council of the European Union Directive 2011/24/EU on patients’ rights in cross-border health care with regard to gaps in access

for persons with disabilities, including accessible information, reasonable accommodation and training of professionals."

The 2009 Commission Communication on "Solidarity in Health - reducing health inequalities in the EU"[16] highlights that disability is a factor which increases the risk of health inequality. The third Health Programme for the period 2014-20 aims inter alia to contribute to reducing health inequalities.

The Fundamental Rights Agency has conducted in 2013 a study on multiple discrimination and healthcare in 14 Member States[17] which identified several barriers, including financial access, the right to consent or withhold consent, and involuntary treatment. SILC statistics found that, in 2011[18], 13.4% of persons with disabilities indicated that they needed to consult a medical doctor but were unable to do so, compared to only 4.4% for persons without disabilities.

However, unfortunately there are several issues that limit the scope and focus of EU actions for the improvement of access to health for people with intellectual disabilities. First and foremost, this is the limit to household survey data in most European studies. Since even today a large number of people with intellectual disabilities are living in residential institutions, these are systematically excluded and remain below the radar of most studies. In addition, most health information is data protected, under the control of health care providers, and not disaggregated enough to come to serious evidence-based results and recommendations. Because of these facts and on the basis of individual reports and anecdotal evidence, we estimate a much higher prevalence of discrimination in access to health services because of an intellectual disability as is known today.

5. Results of the Inclusion Europe study

While the reports in our study show quite a lot of national differences, two main aspects of accessibility seem to be very prevalent and common in all countries:

- **Healthcare staff find it difficult to communicate directly with people with intellectual disabilities about their situation.** Many speak thus only with the accompanying support person or simply do not explain procedures or medication.

- **People with intellectual disability are not respected and treated as other patients by the health professionals.** Expressions of pain or discomfort are not taken seriously, when sexual and reproductive health is not accessible, or when certain procedures are not made available because of the disability.

5.1 Availability of information

Most respondents reported that in their country there is little reliable research published on the access to health of people with intellectual disabilities. Because of the unavailability of reliable data, some organisations had done their own research into the extent of the problem.

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[16] Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions - Solidarity in health: reducing health inequalities in the EU {SEC(2009) 1396} {SEC(2009) 1397} /* COM/2009/0567 final

[17] FRA: Inequalities and multiple discrimination in access to and quality of healthcare. 2013. http://fra.europa.eu/sites/default/files/inequalities-discrimination-healthcare_en.pdf

[18] EU-SILC UDB 2011

There is published scientific research available on this topic	23 %
The topic of access to health care has been discussed at some conferences or in some publications.	46 %
The information available to us is based on individual stories and anecdotal evidence.	24%
We have done our own studies into the extend of the problem.	7 %

These findings still correspond with the conclusions of the EU Pomona study from 2002: “Overall, the activities of the Pomona project indicated that there is no systematic monitoring of the health of people with intellectual disabilities in the EU Member States. Accordingly, there is no foundation for monitoring the health of this sector of the population, for making comparisons across Member States or for tracking trends over time.”[19]

The Academic Network of European Disability Experts (ANED) has published in 2015 a series of Country Reports on the accessibility of healthcare as well as a comparative report[20]. ANED still recommends that “the European Commission (and Eurostat) might usefully play a role in supporting the design and development of effective systems for monitoring accessibility in healthcare. [...] there is an urgent need for the development of such systems.” [21]

However, there seem to be some important resources available at national levels, such as:

- Pomona project Spain: http://www.saludpublica.mx/index.php/spm/article/view/8201/11284
- Scottish Government. The keys to life: Improving quality of life for people with learning disabilities, 2013. http://www.gov.scot/Resource/0042/00424389.pdf
- IDS_TILDA: The intellectual disability supplement to the Irish Longitudinal Study on Ageing. Compares ageing of persons with intellectual disabilities against general population of older people. http://www.idstilda.tcd.ie/

5.2 Accessibility of specific health services for people with intellectual disabilities

As literature already suggested, **sexual and reproductive health services were identified as not accessible in many countries.** This may be the result of preconceptions of health professionals, family members or carers who assume that people with intellectual disabilities do not have sexual relationships, do not want to have or are incapable of having children.

Access to dental and oral hygiene and care, as well as to ophthalmology was considered on average rather good. This, however, contradicts frequent reports about dental problems of people with intellectual disabilities and would need some further investigation. However, there seem to be significant difficulties in some countries: Spain, Denmark, Estonia and France.

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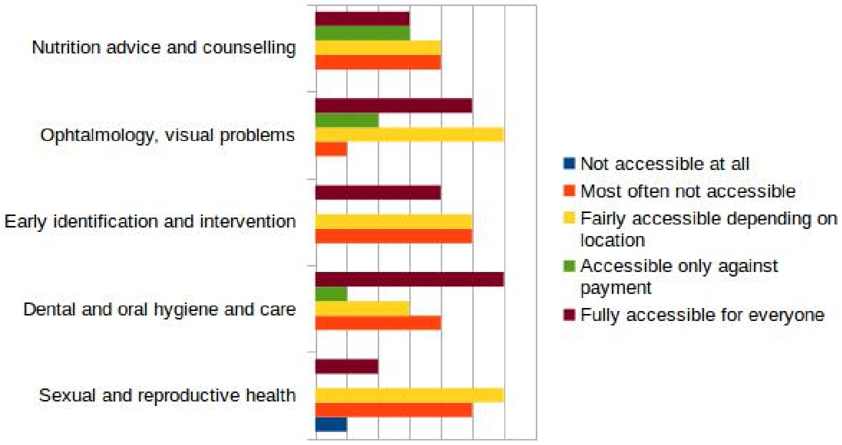
[19] POMONA - Status of Health Monitoring for Adults with Intellectual Disability in the Member States. http://ec.europa.eu/health/ph_projects/2002/monitoring/fp_monitoring_2002_frep_05_8_en.pdf

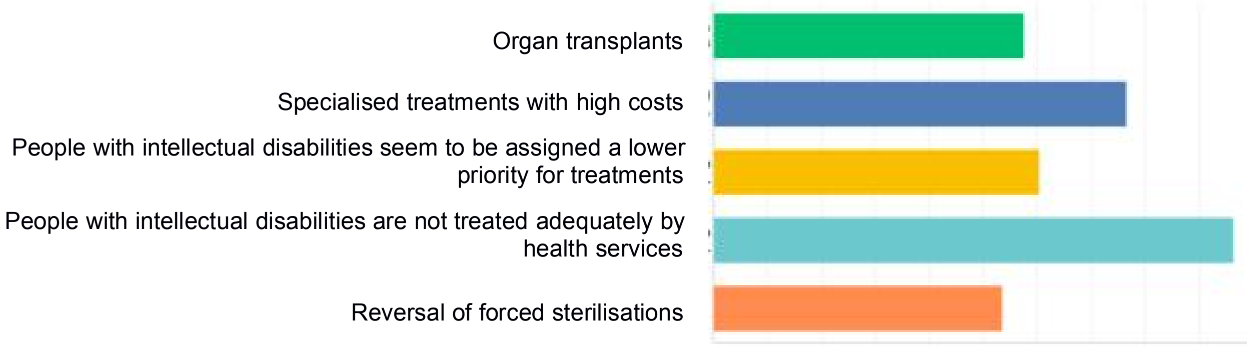
[20] See: http://www.disability-europe.net/theme/health

[21] Ibid.

Spain, Denmark, France, Bulgaria and the Netherlands report significant problems in access to early identification and intervention

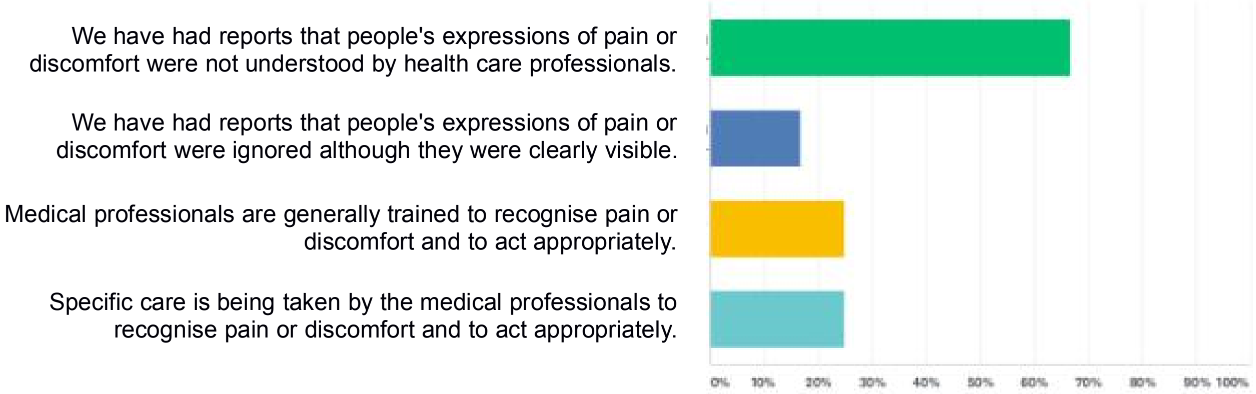


We also asked if some medical procedures may be denied to or are more difficult to access for persons with intellectual disabilities. The issue with this question is that information of this kind is generally not available and thus the rate of respondents who answered that no information was available was very high. Those who responded provided insight where the main problems may be:



5.3 Pain and discomfort

Direct neglect of visible pain or discomfort seems to happen rather seldom, whereas the issue seems to be communication and understanding by health care professionals. However, one respondent remarked that some medical professionals are trained to recognise pain, but the problem would be if people who perform daily care activities recognise pain. France reported that more and more professionals in France are trained to recognize pain or discomfort and to act appropriately. Furthermore, some existing tools are developed to facilitate communication between professionals and people with intellectual disabilities.



5.4 Mistreatment and abuse by medical professionals

The experts did not report criminal abuse, and only rarely experimental medical procedures, forced organ donations or experimental drug testing.

Forced sterilisation is reported in about 1/3 of the responding countries as happening very seldom. However, three countries reported that the forced implant of long-term contraceptives is a frequent issue, whereas in most others, this happened seldom.

Bad treatment and sexual or emotional abuse were reported by almost all respondents. Spain, Ireland and the Netherlands reported bad treatment as a regular issue, and Croatia even as a very frequent problem.

5.5 Treatment of patients with intellectual disabilities who have also other health problems

The experts were asked about the treatment of patients who have an intellectual disability combined with some health problems that can be challenging for practitioners. Not surprisingly, they responded that health services are least prepared to deal with an addiction to drugs or alcohol. The majority found the treatment of additional mental health problems, or of dementia and other age-related degenerative diseases in their country rather acceptable. Best scored services for patients with epilepsy.

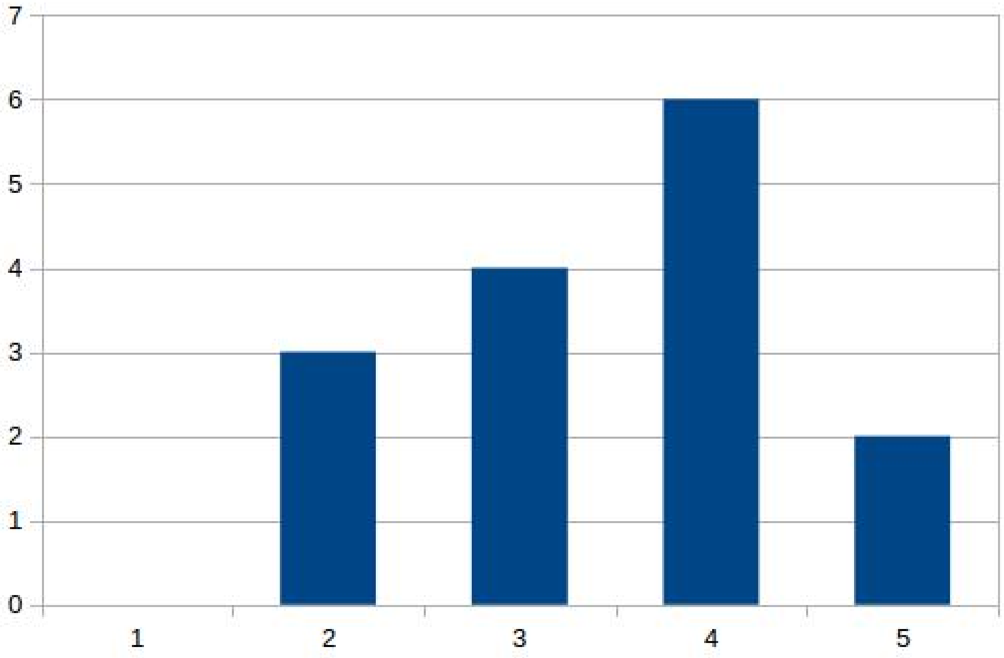
5.6 Legal capacity and communication

Despite of the CRPD having been adopted by all EU countries, in 2/3 of the responding countries adults with intellectual disabilities are mostly under guardianship and thus cannot give their legally valid consent. This contravenes the CRPD; and it raises questions in relation to treatments without consent amounting to torture or degrading treatment as outlined above.

Many medical professionals often do not accept the consent of a person with intellectual disability. **50% of the respondents knew about examples of medical procedures that were done against the clearly expressed will of the patient.**

In terms of communication and information, 80% of the respondents rated the information about medical procedures as difficult to understand. In only 1/3 of the countries, medical professionals learn to communicate adequately with patients with intellectual disabilities.

A large majority of the respondents thus sees in communication difficulties one of the major obstacles in access to health care of people with intellectual disabilities. When compared with other barriers to their access to health care, only attitudes of health care professionals ranked equally high, whereas e.g. regional differences were not identified as a major barrier.



Communication Difficulties are ...	Not important	Not much important	Somewhat important	Very important	Extremely important

A striking **100% of the responding countries reported that medical professionals often prefer to communicate with the support person instead of directly with the patient with intellectual disability.**

Only very few hospitals seem to have social service staff which are trained to facilitate communication with people with intellectual disabilities and also most medical professionals are not trained in communicating with patients in an accessible and understandable way. It is thus mainly up to the patients with disabilities themselves to organise communication support if they need it. This is most often provided by family members, but also by disability organisations or local social services.

This underlines the importance of training medical professionals in communicating with people with intellectual disabilities as has been frequently recommended by research studies[22]. Inclusion Europe will further investigate, how such training can be systematically integrated into academic or vocational courses for medical professionals.

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[22] For example in the Austrian POMONA II Study: Brehmer, Barbara; Zeilinger, Elisabeth and Weber, Germain (2009). Abschlussbericht des POMONA II – Projekts (2005-2008). Die Gesundheit von erwachsenen Menschen mit intellektueller Behinderung. http://bidok.uibk.ac.at/library/brehmer-pomona.html

5.7 Prevalence of potentially discriminatory practices in access to the public health system and private health insurances and their benefits because of intellectual disability

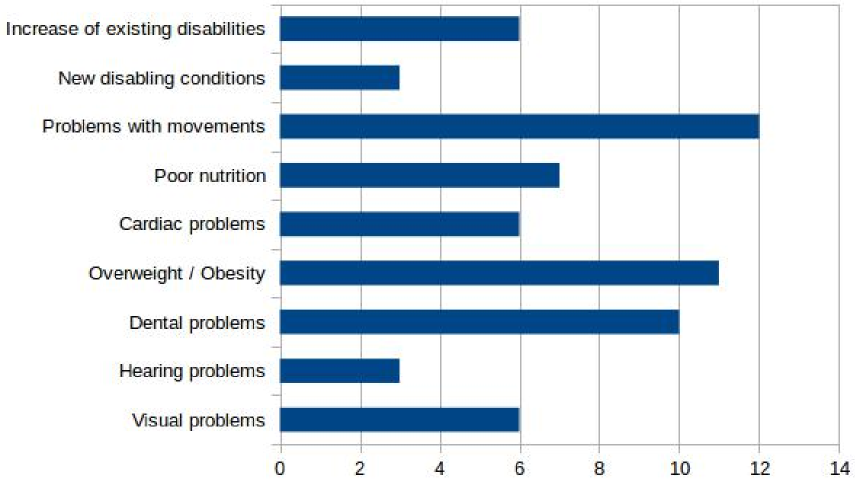
We tried to get an impression about the effects of health care financing systems on the access by people with intellectual disabilities. As expected, acceptance in the public health system was generally not seen as a problem and also the premiums to be paid do not serve as a barrier. In most countries, discrimination in this area is prohibited by law; only Bulgaria reported this as a regular issue.

In the public health systems, patients with intellectual disabilities also seem to have in most countries access to the same health services under the same conditions than non-disabled people. Only Estonia reported that exclusion of some health costs is a very frequent problem. However, differences were reported in the area of access to prevention programmes: more than 50% of the responding countries reported this as an issue. As example, the exclusion from prevention of cervical cancer was mentioned, as health professionals assume that women with intellectual disabilities do not have sexual relationships until older ages than other women.

In the private health insurance sector, the main barrier to access seem to be prohibitively high premiums. This may reflect the economic situation of people with intellectual disabilities, although we did not ask if the intellectual disability as such leads to higher premiums. Exclusion of some health costs and exclusion from some prevention programmes are more frequent in the private sector than in the public health system.

5.8 Consequences of bad access to health care

Disability is not a disease or illness. However, there is a proven link between certain health conditions and impairments. Consequently, bad access to health care leads to long-term consequences for people with intellectual disabilities. The following table shows the estimated additional conditions when compared to people without intellectual disabilities of the same age groups:



The effect on the life expectancy of people with intellectual disabilities is, however, rather different. While the Netherlands, Greece and Estonia report an equal mortality from preventable causes than for people without disabilities, other countries report an up to 3 times higher mortality. Unfortunately, this information is based only on the estimation of experts. Only Scotland has some reliable published data on this issue[23].

5.9 Activity of organisations of people with intellectual disabilities and their families

About 50% of the responding organisations reported that they had done own campaigns or other activities in the area of access to health. They range from the publication of information to family members, health discussions and programmes with people with intellectual disabilities, to the organisation of conferences and other events.

6. Policy recommendations

Based on the literature research carried out by Inclusion Europe and the answers of our membership to the questionnaire, we can identify five policy strands that we will pursue in the future to improve access to health services by people with intellectual disabilities.

6.1 Monitoring and reporting

Difficulties in access to health care services for people with intellectual disabilities seem to be rather frequent in all European countries. However, this situation is difficult to monitor since personal health data is protected and many discriminatory practices are not reported.

Inclusion Europe thus supports the call of the Academic Network of European Disability Experts to the European Commission to support the “design and development of effective systems for monitoring accessibility in healthcare”[24]. Such monitoring systems would have to combine quantitative as well as qualitative components in order to be able to provide sufficient information.

One component could be outcome-oriented, i.e. figures on the prevalence of different indicator health conditions and causes of death disaggregated by type of disability. This would allow to accurately determine accessibility problems in the healthcare systems of different Member States.

In terms of input indicators, for persons with intellectual disabilities the availability of adequate information and the training of medical professionals are crucial determinants. Monitoring of the practical availability of accessible, easy to understand information material in all medical establishments would provide important data, as would compliance checks of the training curricula of medical professionals regarding their information about intellectual disability.

This “hard” information needs to be complemented by an active management and monitoring of independent patients complaints mechanisms. In this area, the European Commission could invest in actions that would improve the collaboration between patients organisations and intellectual disability organisations as well as statistical information about complaints disaggregated by type of disability.

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[23] Scottish Government, The keys to life: Improving quality of life for people with learning disabilities, 2013: http://www.gov.scot/Resource/0042/00424389.pdf; Health Scotland, Health Needs Assessment Report – Summary: People with learning disabilities in Scotland, 2004: http://www.healthscotland.com/uploads/documents/1676-LD_summary.pdf

[24] See: http://www.disability-europe.net/theme/health

6.2 Communication, coordination and information sharing of health services

Health care staff finds it often difficult to communicate directly with people with intellectual disabilities about their situation. Many speak thus only with the accompanying support person or simply do not explain procedures or medication. In terms of accessible information and communication it is thus essential to further develop good practices in this area.

The first obligation of States would be to ensure that general health information or communication is accessible for people with intellectual disabilities. General health information is aimed at the general public and not at one specific person. It also includes generally the information about available medical treatment and services. While this is often ensured for people with other kinds of disabilities, there seems to be a marked shortage of this general information in easy to understand language and a lack of awareness about the availability of such information if it has been produced at local or national level. Governments should focus on the dissemination of such accessible health information through centralised websites that allow direct and easy access.

At European level, Directive 2016/2102 on the accessibility of the websites of public sector bodies[25] provides an important instrument to improve as well the accessibility of people with intellectual disabilities to general health information. Inclusion Europe and our members will accompany the implementation of this Directive also in the health sector in the coming years. It is especially important to focus on the implementation of the accessibility directive in the area of “e-medicine”.

In addition, there is the issue of communication of medical professionals with the individual patient. While the training of medical professionals is addressed below, there are a number of structural issues that can also be improved. Our study demonstrated that support for patients with intellectual disabilities has often to be organised by the patients themselves and often comprises family members or staff of disability services. Patients often do not have a choice of independent support which compromises their rights to privacy.

Governments must ensure the choice of independent support in medical services for all patients with intellectual disabilities. Hospitals could be the base stations for such independent supporters who then could support patients within the hospital, but also in ambulatory practices. These supporters could also be specifically trained in alternative communication methods and have access to the appropriate materials or technologies.

Many patients, not only those with an intellectual disability, feel in many countries somewhat lost and left alone with the coordination of different health professionals and health interventions that they may need. Inclusion Europe thus promotes the availability of trained facilitators in mainstream health services who support patients in organising their individual health care plans. The availability of personal health passports in accessible language or the possibility to sign up for regular health assessments can also improve access of people with intellectual disabilities to health services.

6.3 Training and awareness-raising of health professionals

The CRPD emphasizes especially the importance of training and awareness-raising for health professionals. This should include not only medical information, but also communication strategies and an introduction to a human rights approach to disability. The training of health care professionals

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[25] Directive (EU) 2016/2102 of the European Parliament and of the Council of 26 October 2016 on the accessibility of the websites and mobile applications of public sector bodies

on the rights of persons with disabilities combats stigma and equips providers with the awareness necessary to provide persons with disabilities quality health care.

Inclusion Europe is thus committed to support medical schools and other medical training institutes in integrating an intellectual disability awareness training in their courses. For this purpose, we will identify and train people with intellectual disabilities in several countries to be able to deliver short training courses to different kinds of medical professionals. Our objective is to make this issue a compulsory component of medical training. We hope for support for this initiative under the European Disability Strategy which wants to "promote awareness of disabilities in medical schools and in curricula for healthcare professionals".

In the framework of accessibility of higher education for people with intellectual disabilities, Inclusion Europe also explores the possibilities to involve them as students in medical courses. Since not everyone who studies medicine needs to become a doctor, we want to explore different possibilities in this innovative field.

Finally, informed consent is an important area for the training of health professionals, since "involuntary treatment and other psychiatric interventions in health-care facilities are forms of torture and ill-treatment."[26] Medical professionals must know that persons with intellectual disabilities have the right to provide or withhold consent to any medical intervention or health service. Inclusion Europe will continue to actively pursue good practices for dealing with informed consent in health services.

6.4 Involve people with intellectual disabilities and their families in the planning of health services

Direct participation of people with intellectual disabilities, their families and their civil society organisations in the planning and quality assessment of health care services is an important consideration that is also stipulated by the CRPD. Inclusion Europe is committed to support skills training of people with intellectual disabilities and their families in order to improve their capacities to engage in dialogues with policy-makers or service providers on the planning and improvement of health services.

Experiences in the area of quality evaluation of specific disability services have demonstrated that user-led evaluation systems can provide important new insights. It would be useful to explore the potential of this approach also in the area of health services and their accessibility. This could also include the assessment of the effectiveness and efficiency of reasonable accommodations in heath services.

6.5 Cross-cutting issues

There are three cross-cutting issues that concern all health and support services: legal capacity, accessibility for people with complex support needs, and the protection from violence and abuse.

The full legal capacity of all people with disabilities to decide and to act is one of the core achievements of the Convention on the Rights of People with Disabilities. In many European countries, it is however not fully implemented and thus cannot be exercised by some people with intellectual disabilities. It is absolutely essential to align national legislation and practices fully with

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[26] Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, A/HRC/22/53 (Feb 2013). http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf

the rights stipulated in Article 12 of the CRPD and its General Comment[27]. Inclusion Europe and its members will continue to work for its full implementation in all areas of life.

Meeting the health needs of people with severe and/or multiple impairments can be very challenging and complex. People with complex support needs need a very individualised approach that carefully considers the interaction between their health needs, their impairments and their social network in order to avoid negative impacts on their inclusion in society. Since communication issues as well as the question of informed consent are rather frequent, it can be necessary to involve a circle of persons in decisions and treatment who know the person well. Most important is, however, that no treatment is withheld from this group of patients because of their disability.

Persons with intellectual disabilities are also vulnerable to violence, abuse and exploitation, especially when they have to rely on others for support and care. They are susceptible to violations within their home and by family members, caregivers, health care professionals and community members[28]. Especially “women with disabilities are at a heightened risk of violence, exploitation and abuse compared to other women.”[29] Research shows that women with disabilities experience violence (physical, psychological and sexual) at significantly higher rates, more frequently, for longer, and by more perpetrators than other women and compared to men with or without disabilities[30].

Health care services and professionals need to be aware of and alert to this issue. Patients with intellectual disabilities may not talk by themselves about instances of violence or abuse, but medical professionals should look for signs that this may have happened. It is very likely that a patient with intellectual disability has suffered from violence or abuse at some time in his or her life. Medical professionals should be aware that their patients may have developed behaviours or coping strategies to protect themselves from these experiences. This can affect communication and cooperation with medical professionals as well.

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[27] CRPD, General comment No. 1 (2014): Article 12: Equal recognition before the law. https://documents-dds-ny.un.org/doc/UNDOC/GEN/G14/031/20/PDF/G1403120.pdf

28 United Nations General Assembly, Note by the Secretary General on Torture and other cruel, inhuman or degrading treatment or punishment, A/63/175 (July 28, 2008).

29 CRPD, General Comment No 3 Article 6: Women and girls with disabilities (Adopted 26 August 2016), para 29. http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx

[30] See Life after Violence at www.life-after-violence.eu

7. Policy Publications, information and websites

- Bulgaria: Health and Sports Project: 'Active Life for People with Intellectual Difficulties'. It consists of: Yoga schemes; 2. Gymnastics; 3. Interest clubs in various sports such as zumba, table tennis, darts etc.
- Bulgaria: http://mariasworld.org/en/more-projects-1/579-project-active-life-for-people-with-intellectual-difficulties.html
- Bulgaria: http://mariasworld.org/en/programi/351-healthcare-and-health-education-programme.html
- Bulgaria: https://www.facebook.com/MariasWorldFoundation/posts/920717051376843
- Denmark: http://www.lev.dk/media/1702/konference-annonce-med-program.pdf
- Denmark: http://www.lev.dk/nyheder/2016/august/sundhedsprojekt-i-roskilde-dokumenterer-massivt-behov-for-sundhedstjek
- Denmark: http://www.lev.dk/nyheder/2017/februar/budskabet-fra-roskilde-sundhedstjek-nu
- France: Contribution to the following report: http://solidarites-sante.gouv.fr/IMG/pdf/rapport-pjacob-0306-macarlotti.pdf
- France: http://www.unapei.org/Livre-blanc-Pour-une-sante.html
- Ireland: http://www.inclusionireland.ie/sites/default/files/attach/basic-page/1110/inlcusion-ireland-submission-ageing-may-2017-2.pdf
- Ireland: http://www.inclusionireland.ie/sites/default/files/attach/basic-page/1110/patient-advocacy-submission-website.pdf
- Spain: Guidelines for admission to a hospital for people with intellectual disabilities. http://www.plenainclusion.org/informate/actualidad/noticias/2017/dia-mundial-de-la-salud-plena-inclusion-solicita-las-autoridades
- Spain: http://www.plenainclusion.org/informate/publicaciones/discapacidad-intelectual-y-salud-derechos-desigualdades-evidencias-y
- Spain: http://www.plenainclusion.org/informate/publicaciones/indicadores-de-salud-en-personas-con-discapacidad-intelectual
- Spain: http://www.plenainclusion.org/informate/publicaciones/salud-mental-y-alteraciones-de-la-conducta-en-las-personas-con-discapacidad
- Spain: http://www.plenainclusion.org/que_hacemos/apoyamos-a-las-personas/calidad-de-vida/salud
- Spain: Some good practices can be found (in Spanish) at http://elhuertodeideas.org/, some of them are related to health promotion.
- Switzerland: www.vbmb.ch