



Inclusive health and people with intellectual disabilities

Position Paper

Position Paper of Inclusion Europe

- As adopted by the 2012 Annual General Assembly of Inclusion Europe -

Health is of paramount importance for all, not alone to preserve physical and mental health status, but to increase human capabilities and to buffer the impact of poverty and to widen participation.

People with intellectual disabilities have long been sidelined by mainstream healthcare – a historical hangover from the institutional care they used to receive. As highlighted in several studies, persons with intellectual disabilities often experience difficulties in accessing the mainstream health care system.

They are more likely to have:

- poor health compared with other people;
- greater difficulty in accessing services others use; and
- more negative experiences of using health services.

Among the most often collected reasons, we can identify negative attitudes of the medical staff, reluctance to provide services to persons with intellectual disabilities and poorly trained health care workers. Cost seems to be a less important factor in accessing mainstream health care systems, although there is a difference in Central and Eastern Europe, where financial difficulties are reported¹ for persons with intellectual disabilities in accessing mainstream healthcare.

People with intellectual disabilities also have increased health needs, whilst receiving poorer health care. *People with intellectual disabilities have a different pattern of health need. For example, epilepsy, gastro-oesophageal reflux disorder, sensory impairments, osteoporosis, schizophrenia, dementia, dysphagia, dental disease, musculoskeletal problems, accidents, and nutritional problems are all much more commonly experienced. Conversely, health problems related to smoking, alcohol, and use of illegal drugs are uncommon².*

However, disability is a complex phenomenon, reflecting an interaction between features of a person's functioning and features of the society in which he or she lives. **Social circumstances** characterised by low income, social isolation, vulnerability, reliance on others to initiate health care; **environments** that are physically inaccessible, or that promote inactivity, poor nutrition and **individual behaviours** based on poor knowledge of healthy lifestyles are all factors that contribute to health disparities.

Some of these health disparities are health inequalities: that is, they are avoidable and may in fact be unjust.

¹Inclusion Europe and Inclusion International, Poverty and Intellectual Disability, Brussels, 2005, pages 25-26.

²Cooper et al., 2004, page 414

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Article 25, UN CRPD

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;*
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;*
- c) Provide these health services as close as possible to people's own communities, including in rural areas;*
- d) 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 by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;*
- e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;*
- f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.*

In addition, in our recently published research "Children's right for all!"³ the authors commented in particular on the lack of **mental health services** for children with intellectual disabilities in many countries.

Therefore, mental health problems faced by children with intellectual disabilities tend to be considered as an integral part of their disability when it is not the case, and, as a result, they do not receive any treatment for them. Indeed, people with intellectual disabilities, both children and adults, are more likely to suffer mental ill health but there is a shortage of mental health professionals skilled to treat patients with intellectual disabilities.

One of the other recurrent problems in the area of health is **dental care** as people with intellectual disabilities do not cooperate easily during dental treatment. Dental services are regarded as a particular problem, for example orthodontists consent to treat children with intellectual disabilities only with full anaesthesia in some countries.

People with intellectual disabilities are also more likely to be **over or underweight** – but they are not getting healthy eating messages. Finally, research suggests 14-24% of people with intellectual disabilities are affected by **epilepsy**. For people with profound and multiple intellectual disabilities, this rises to 50-82%, but too often epilepsy medication is not properly administered when people are taken into hospital.

Health prevention programmes and programs for positive health behaviour as well as access to information and programs to avoid health risk behavior for people with intellectual disabilities is lacking. This aspect of health is central in order to strengthen the **empowerment** of young people and adults with intellectual disabilities.

Where health care needs are greater, the response should be greater, but this is not the case. Instead discrimination and ignorance is increasing the risks for people with intellectual disabilities accessing health care.

The United Nations Convention recalls that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability.

³Latimier C. and Šiška J (2011), *Children's rights for all! Implementation of the Convention on the Rights of the Child for children with intellectual disabilities*, Brussels, Inclusion Europe, October 2011.

⁴Information presented by David Congdon, Head of Campaigns & Policy at Mencap, Bridge 2011, Health care for all in the UK.

Article 25 requirements include:

Equal access to mainstream health care, in the sense of **geographical** access (e.g.: rural/urban inequalities and in relation to **payment systems** (e.g.: health insurance)

Health care services must be **close to home**

Health care as well as **health services**

A particular aspect of health care are **sexual and reproductive health**: people with intellectual disabilities are entitled to the same quality and standard of information and programmes

Importance of **education for health professionals**

Ethical standards for health care

State investment in **family support**, especially early identification and intervention

Prohibition of discrimination, including in the provision of health insurance

People with intellectual disabilities have explicit rights to health services – especially for those required because of the presence of their impairment/s – that are of equal quality.

Obligation of reasonable accommodation also applies in the field of health care. The State has to make adaptations in a health-care facility in order to remove the barriers that prevent a person with a disability from receiving health care services on an equal basis with others.

In addition, the **Council of Europe Disability Action Plan** in its **line 9 about health care** emphasizes on consultation and involvement of people with disabilities in the decision-making process regarding their personal care plan⁵, as “*this approach places disabled people at the centre of the planning process and service provision design and empowers individuals to make informed decisions about their health.*”

The objective of the Action Plan line n°9 is

to ensure that all disabled people, regardless of gender, age and origin, nature or degree of impairment:

have equal access to all health care services;

benefit from access to available specialised services, as appropriate;

are as fully involved as possible in the decision-making process of their personal care plan;

to ensure that the needs of people with disabilities are included in health education information and public health campaigns

Inclusion Europe and its members support the following recommendations in order to facilitate access to mainstream health care for people with intellectual disabilities.

To guarantee **uniform access to health care** throughout the country, including developing mobile teams of specialist and ensuring transportation facilities from remote areas

To ensure the **full coverage of expenditures** by the health insurance system for medication and specific therapies for children and adults with intellectual disabilities, in order to ensure their equal opportunities and prevent further health complications

To **invest in research**, including at European level, to understand health disparities as well as inequities and discrimination - which are preventable and unfair.

Routinely collected health data rarely disaggregated to identify people who have disabilities and/or social

⁵Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015, pages 22-23 available at: http://www.coe.int/t/e/social_cohesion/soc-sp/integration/02_council_of_europe_disability_action_plan/Council_of_Europe_Disability_Action_Plan.asp#TopOfPage

disadvantage. Relatively few studies to date have applied health indicators to persons with intellectual disabilities. Health indicators can contribute to **knowledge about health and healthy ageing** of people with intellectual disabilities.

To **survey health experiences** of people with intellectual disabilities in order to listen to their views and needs and those of their families and to compare health of populations within or between countries, or over time.

To **ensure that people with intellectual disabilities are specifically identified in health information surveys in Europe** in order to include an especially disadvantaged group with evident health disparities people with intellectual disabilities.

To **review legislation and policies relevant to equal citizenship** in relation to the right to health in order to fulfil the non-discrimination principle of the UN CRPD Article 25.

To improve access to professional skills in **early diagnosis and treatment**, including regular health checks

To develop and to make accessible **health prevention programs and programs for positive health behaviour** for all ages from youth until old age. Access to this information should be available at doctors' offices and should be published in easy to understand language.

To widen **awareness and commitment and skills in health promotion** among those who support/work with people with intellectual disabilities

To **provide specific training to health professionals** Investing in practitioner and staff training for inclusive practice

To require **better professional education and disability awareness** for health professionals and to reform curriculum with disabled people as educators

To **empower** with age, gender and disability appropriate tools children and adults with intellectual disabilities **to contribute to decision-making about their health**

To **improve awareness/information/advocacy for public, professionals, families, disabled people.**

To **simplify health care procedures** for people with intellectual disabilities who usually require, throughout their lives, regular personalised special treatments (e.g. occupational therapy, psychological therapy, special training, etc.), medication and frequent medical tests.

To **involve people with intellectual disabilities and their families**

Providing easy to understand health information

Offering individual Health Care Plans

Strengthening two-way communication with people with intellectual disabilities and their families

Developing protocols for health care professionals to enable them to communicate properly with children and adults with intellectual disabilities and their parents.

To **improve the links and communication between health professionals** to facilitate follow-up and coordination of health care, rehabilitation and **social care professionals** who are supporting children with intellectual disabilities

To **provide tools for better communication** between health care professionals and people with intellectual disabilities and their families, like Health Passport or any other communication supporting tool

To **listen to the views of people with intellectual disabilities and their families** through:

- Supporting health advocacy
- Engaging people with intellectual disabilities in staff training and quality-based evaluation