



**European Declaration on Health of Children and
Young People with Intellectual Disabilities
and their Families**

DRAFT
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Conference Declaration
**Better health, better lives: children and young people with intellectual
disabilities and their families**

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Preamble

1. We, representatives of Member States in the European Region of the World Health Organization (WHO) together with the WHO Regional Director for Europe, in partnership with the United Nations Children's Fund (UNICEF), the European Commission, and the Council of Europe, joined by self-advocates, family representatives, social and educational service providers and representatives of nongovernmental organizations, convening in Bucharest on 26-27 November 2010, commit ourselves to improving the health care of children and young people with intellectual disabilities* in order to enhance their lifelong development, inclusion and full participation in society.
2. We welcome the progress made in recent decades towards securing the human rights and quality of life of the approximately five million children and young people with intellectual disabilities in Europe and towards improving care and support systems in many countries. We are also aware of the remaining challenges as illustrated by the deprivation of rights and incidents of neglect and abuse in both long-stay residential institutions and local communities. These demand further and stronger action.
3. We recognize that people with intellectual disabilities are often disadvantaged in their health care from childhood onwards. They have greater health needs yet they encounter major barriers in gaining access to appropriate and effective health promotion and care.
4. Children and young people and their families are at risk of discrimination due to intellectual disabilities, and at an additional risk on the grounds of

* **Disability** depends not only on the child's health conditions or impairments but also crucially on the extent to which environmental factors support the child's full participation and inclusion in society.

Intellectual disability includes:

- a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence)
- with
- a reduced ability to cope independently (impaired social functioning)
- which
- started before adulthood, and has a lasting effect on development.

The use of the term "intellectual disability" in this Declaration includes children with autism who have intellectual impairments.

For the purposes of this Declaration, the term also encompasses children who have been institutionalized because of a perceived disability or family rejection and who acquire developmental delays and psychological problems as a result of their institutionalization.

ethnicity, gender, religion, economic status, physical or neurological impairments, and stigmatization due to obsolete and degrading terminology. This leads to even greater inequalities in their health and development and ultimately to their exclusion from society.

5. We recognize that children and young people with intellectual disabilities have the right to grow up in a family environment. However, families often receive little or no support from responsible agencies. Community-based services should be developed and expanded in order to improve their health and well-being and their inclusion in society and to eliminate institutionalization.
6. We also recognize that the health of children and families and their quality of life are strongly influenced by poverty and inequality in our societies and that families with disabled children need the resources to access services and care. It remains essential that poverty reduction programmes pay special attention to the inclusion and needs of disabled children and their families.
7. We therefore reaffirm our support for enforcement of the relevant United Nations instruments. We refer particularly to the Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, and the International Bill of Human Rights which consists of the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, and the International Covenant on Civil and Political Rights.
8. We also welcome recent European initiatives on further action to secure the rights of people with disabilities, which draw upon the Council of Europe Disability Action Plan 2006-2015, the European Union Disability Action Plan 2003-2010, and the WHO Disability and Rehabilitation Action Plan 2006-2011.

Purpose

9. On the basis of these conventions and commitments, we state unequivocally that children and young people with intellectual disabilities are equal citizens. They have the same rights to health and social care, education, vocational training, protection and support as other children and young people. They should have equal opportunities to live

stimulating and fulfilling lives in the community with their families, alongside their peers. Our purpose, therefore, is to achieve the optimal quality of life for these children and their families by:

- promoting and supporting good physical and mental health and well-being*;
- eliminating health and other inequalities and preventing other forms of discrimination, neglect and abuse;
- providing support that prevents family separation and allow parents to care for and protect children and young people with intellectual disabilities;
- supporting children and young people in the development of their potential and the successful transitions through life.

Priorities for action

10. We have identified the following ten priority areas which need to be addressed as a matter of urgency, in order to realize our vision that children and young people with intellectual disabilities and their families are able to live healthy and full lives. We will:

1. Protect children and young people with intellectual disabilities from harm and abuse.

All children and young people with intellectual disabilities, wherever they live, must be guaranteed lives free from bullying, harm or abuse and should not live in fear or neglect.

2. Enable children and young people to grow up in a family environment.

Promoting secure attachments and improving family functioning limits the impact of intellectual disability. Ongoing support to families is essential.

3. Transfer care from institutions to the community

Residential institutions that have a negative impact on the health and development of children and young people should be replaced by high quality community support. New admissions to such

* "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity", Constitution of the World Health Organization.

institutions should be stopped through the development of community services.

4. Identify the needs of each child and young person.

Early identification and early intervention improve long-term outcomes. Children and young people require repeated assessment of their needs and planned support to make seamless transitions at each life stage.

5. Ensure that good quality mental and physical health care is coordinated and sustained.

Children and young people with intellectual disabilities need the same access to health care as other children but may also need access to specialist treatment and care.

6. Safeguard the health and well-being of family carers.

In order for a child with intellectual disabilities to grow up and develop within a family, the health and well-being of the family as a whole should be supported. Enabling families to care for their child from the time of identification of intellectual disability through to adulthood can prevent harmful family strain or rejection of the disabled child.

7. Empower children and young people with intellectual disabilities to contribute to decision-making about their lives.

Children and young people with intellectual disabilities can and will make their needs and wishes known and contribute to their community, given appropriate support and a receptive environment. Family members and advocates also need encouragement and support to make themselves heard.

8. Build workforce capacity and commitment.

The well-being of children and young people with intellectual disabilities is strongly reliant on the knowledge, skills, attitudes and commitment of staff in all settings and sectors.

9. Collect essential information about needs and services and assure service quality.

Quality standards and adequate information systems are needed to monitor quality of care, with transparent responsibilities for all stakeholders.

10. Invest to provide equal opportunities and achieve the best outcomes.

Ensure fair and, if necessary, preferential spending on services from which intellectually disabled children and young people and their families benefit.

Responsibilities

11. We, the representatives of Member States in the WHO European Region, recognize the urgency of ensuring that the human rights of children and young people with intellectual disabilities are respected and promoted and accept the responsibility to plan, adopt and implement policies that progressively realize these 10 priority objectives in an integrated, comprehensive and effective way. We welcome the actions as described in the Action Plan. We undertake to:

- identify areas for intervention in our own countries in order to meet the requirements of this Declaration and adopt and/or revise existing national action plans, with defined responsibilities and a time frame for their implementation;
- ensure that legislation and policies uphold the rights of children with intellectual disabilities and their families, as expressed in the international treaties on human rights, and set appropriate standards for services and monitor delivery;
- take active steps to establish intersectoral collaboration at the national level with education, social care, justice and other relevant departments, in order to ensure a cohesive policy approach;
- produce national action plans in plain language and other accessible formats;
- empower local leadership to ensure effective implementation, evaluation and accountability;
- collect information through which progress will be monitored
- regularly review progress in meeting the priority commitments set out in this Declaration.

12. We invite nongovernmental organizations, while fulfilling their own roles in inspiring change, acting as advocates, providing services and

conducting research, to become fully involved as active partners and to support governments in implementing this Declaration, for example by:

- involving and empowering children and young people and their families;
- raising awareness and changing societal attitudes;
- providing high-quality and sustainable services, and
- monitoring progress in implementing the 10 priority actions and the quality of services provided.

13. We invite the WHO Regional Director for Europe to take action in the following areas, according to WHO's mandate and work programme:

- offer a vision and exercise leadership concerning the role and functioning of health systems in accordance with all relevant European and international standards and policies, and as set out in the Action Plan;
- engage in partnership with UNICEF, the European Commission and the Council of Europe and other intergovernmental and nongovernmental organizations where joint action can facilitate implementation of the priority actions identified in this Declaration;
- provide technical support to Member States in order to promote quality in service provision and to establish sustainable capacity;
- support research initiatives that will result in ethical and evidence-based policy and practice;
- monitor the health status of children and young people with intellectual disabilities and their families and assess progress towards the implementation of this Declaration and the Action Plan.

14. We call upon UNICEF, the European Commission and the Council of Europe to support this Declaration within the scope of their mandates and competences.

15. We commit ourselves to report on the progress in implementing commitments from this Declaration to the WHO Regional Committee for Europe in 2015.

Action Plan

Actions to give effect to the European Declaration on Children and Young People with Intellectual Disabilities and their Families: Better Health, Better Lives

Implementation of the Declaration will require both concerted national leadership in meeting the responsibilities identified, and empowered local leadership to ensure that national action plans are carried out. This Action Plan offers a set of actions that are recommended to meet the ten priority commitments set out in the Declaration.

1. Protect children and young people with intellectual disabilities from harm and abuse

Children need safe and stable environments in which they can grow, develop, play and learn. Children with intellectual disabilities are disproportionately at risk of exclusion, neglect and abuse. They face additional risks, and require additional protection, in times of social or economic instability and conflict.

All children and young people with intellectual disabilities, wherever they live, must be guaranteed lives free from harm or abuse and should not live in fear or neglect as a consequence of discrimination, poverty, or a failure of the responsible agencies to provide appropriate protection and support.

Actions

- 1.1. Review existing policy and legislation to ensure that they are in line with the relevant international human rights standards and provide adequate guarantees of the right to health and freedom from abuse and harm.
- 1.2. Scrutinize child protection policies and procedures to ensure that they guarantee both equality of opportunity and specific provision for children with intellectual disabilities.
- 1.3. Enable effective communication and collaboration between social care, education and health agencies, and justice systems, in the identification of children at risk and of potential perpetrators of abuse; ensure that those found guilty of inflicting abuse are prosecuted.

- 1.4. Make training in child protection mandatory for all staff working with children and young people with intellectual disabilities and monitor compliance.
- 1.5. Implement child protection and reporting procedures in all services dealing with this population group, including care homes, schools, boarding homes, day-care facilities and group homes.
- 1.6. Introduce inspection and standards to prevent the use of restrictive practices that limit the freedom of movement and participation of children with intellectual disabilities during their hospitalization or placement in residential facilities.
- 1.7. Introduce widespread anti-stigma programmes to change society's attitudes towards people with intellectual disabilities and their families and to reduce negative attitudes, stereotypes, low expectations and consequent discrimination, including among health staff.
- 1.8. Address bullying, victimization and discrimination in schools and communities.

2. Enable children and young people to grow up in a family environment

Secure family attachments throughout childhood contribute to healthy personal development and stable relationships in adult life; this is equally important for children with intellectual disabilities. A strong focus on preventing family separation and promoting early child development reduces the impact and extent of intellectual, psychosocial and developmental impairments.

Children living away from their families of origin need foster or adoptive families or carers who can provide the essential family qualities of acceptance and warmth and opportunities to interact with other children and who are sensitive to the culture and needs of the individual child.

Actions

- 2.1. Prevent baby abandonment due to intellectual disability, in particular by improving access to support through the establishment of early contact with social services in health facilities.
- 2.2. Promote the development of community-based services and family support through policy and legislation.

- 2.3. Provide specific resources to ensure that children with intellectual disabilities can grow up in loving and safe family care. This includes supporting biological families to care for their own children and the development of specialized foster care and adoption services.

3. Transfer care from institutions to the community

Residential institutions that have a negative impact on the health and development of children and young people should be replaced by high quality community support. New admissions to such institutions should be stopped through the development of community services. Adequate replacement services include kinship care, foster care and adoptions, regulated in ways that encourage the recruitment of persons who are motivated to care for such children, sensitive to the specific needs of children with intellectual disabilities and likely to benefit them.

Providing and securing access to inclusive, comprehensive and effective health, social and educational services in local communities and combining them with clear targets related to deinstitutionalization will enable the phasing out of long-stay residential institutions for children with disabilities.

Actions

- 3.1. The first priority must be to stop all new admissions by providing adequate support to families who are struggling to care. Children with intellectual disabilities already living in institutional care should be given high priority in the allocation of access to community-based alternative services.
- 3.2. In existing institutional care, the care provider must take all necessary measures to achieve stability and competence in caregivers and to ensure that continuing education, specialist support and supervision are provided as children and young people are prepared for transfer to family care in the community.
- 3.3. In the process of transferring children from institutional care to community living, ensure that children with intellectual disabilities and their families receive adequate support, based on each child's individual needs.
- 3.4. Ensure that all children currently living in institutions have individualized assessments and care plans for moving into the community; waiting until

they are older and transferring them to an institution for adults should be made clearly unacceptable.

- 3.5. Ensure that children with intellectual disabilities and their families are involved in the planning, development and monitoring of community-based services and support.
- 3.6. Ensure the delivery of high-quality education to all intellectually disabled children.
- 3.7. Support full access of children and young people with intellectual disabilities to community sport, culture and leisure facilities.

4. Identify the needs of each child and young person

Early intervention in health, education and social welfare will lead to better long-term outcomes for children and young people with intellectual disabilities.

Children with, or at risk of developing, intellectual disabilities should be identified at the earliest possible stage through maternal welfare and screening programmes and channelled towards services providing early intervention, preschool education, day care and community health initiatives. Needs change during development, and assessments should therefore be reviewed regularly. Classification of individuals and their consequent care based on outdated and discriminatory models should be replaced with person- and family-centred systems of assessment, planning and service delivery.

Children and young people require planned support in order to make seamless transitions at each life stage. The interventions to facilitate the transition to adulthood and independence must be based on the young person's particular needs and preferences.

Actions

- 4.1. Establish health screening, aetiological investigation and early intervention programmes for children with intellectual disabilities and their families at key stages throughout development, commencing in the perinatal period.
- 4.2. Ensure that all children with identified or suspected intellectual disabilities receive a specialist multidisciplinary assessment as early as possible following diagnosis, leading to an individualized and integrated health,

social care and educational plan that is reviewed and developed regularly throughout childhood, transition to adulthood and in subsequent years.

- 4.3. Establish a coherent system of guidance and support in transition from school to adult life.
- 4.4. Assessments should be based on person-centred processes and assessment tools that provide a holistic focus on the individual child, rather than just focusing on their impairments.

5. Ensure that good quality mental and physical health care is coordinated and sustained

Children with intellectual disabilities are exposed to the same risks and can have the same illnesses as all children, thus their health care has to be delivered in regular health establishments.

They can also have complex physical and/or mental health problems associated with intellectual disabilities, which need recognition, and adequate specialist treatment and care should be available.

Public health agencies should ensure that children and young people have access to all childhood and youth health promotion initiatives and that these are suitably adapted to their needs. Health practitioners within primary and secondary care must become more knowledgeable and skilled about intellectual disability, autistic spectrum disorders and the accompanying physical and psychological conditions. General health services should be responsive to the specific and varying needs and conditions of children and their families, offering timely and evidence-based therapeutic interventions.

Specialist support needs to be available and coordinated across sectors. Intersectoral arrangements should be made for adequate participation of health care services in education and social programmes, enabling the education and social inclusion of children and young people with intellectual disabilities.

Actions

- 5.1. Strengthen child public health programmes to ensure that both the general and the specialist health needs of children with intellectual disabilities are specifically targeted.

- 5.2. Develop national strategies and appropriate support for routine and regular health checks for children with intellectual disabilities.
- 5.3. Provide specialist physical and mental health expertise for children with intellectual disabilities that is integrated within mainstream child health services.
- 5.4. Include children with intellectual disabilities in general health promotion materials and programmes to disseminate the message of “good health for all”.
- 5.5. Develop easy-to-understand health information resources for parents/carers and for children and young people with intellectual disabilities to help them better understand their body functions, take care of their health and cope with illness and dying.
- 5.6. Develop a coherent and coordinated programme of legislation, policy and practice, to address discrimination against children with intellectual disabilities in access to health care and social support services.

6. Safeguard the health and well-being of family carers

In order for a child with intellectual disabilities to grow up and develop within a family, the health and well-being of the family as a whole should be supported.

Enabling families by offering the knowledge, skills and resources to care for their child from the time of identification of intellectual disability through to adulthood can prevent harmful family strain or rejection of the disabled child.

Actions

- 6.1. Ensure that professional and parent organizations are involved in the development of education and training programmes for service providers on how to communicate with families and carers about a child’s disability and on the requirement to provide comprehensive information, guidance and support.
- 6.2. Establish programmes of support, training and counselling (including providing appropriate educational materials) for family members and carers, to promote the development and well-being of children with intellectual disabilities, their autonomy and self-determination.

- 6.3. Ensure that the family carers of children with intellectual disabilities have an automatic entitlement to a multi-agency needs assessment.
- 6.4. Develop national, regional and local health and social care strategies that address the health and well-being of carers.
- 6.5. Ensure that the education and training of health and other professionals emphasizes the importance of the health and well-being of family carers, including their mental health.

7. Empower children and young people with intellectual disabilities to contribute to decision-making about their lives

Empowering children and young people and creating opportunities for their voices to be heard and for them to make a contribution to community life, benefits not only the children and young people themselves but also families, staff, professionals and communities.

Children and young people with intellectual disabilities can and will contribute to decision-making about their lives, if the will to listen is present and if time, skills, resources and adaptations to procedures and policies are dedicated to ensuring their involvement.

Family members and other advocates for children and young people with disabilities also need to be encouraged and empowered, since their insights and experiences are essential.

Actions

- 7.1. Ensure that people with intellectual disabilities, families and organizations representing children and young people with intellectual disabilities are always directly involved in the development of national and local policies and strategies, and in the planning, development and monitoring of community-based services.
- 7.2. Encourage and support the development of organizations that promote the rights of children and young people with intellectual disabilities and enable them to voice their opinions with appropriate support and to make a contribution to society.
- 7.3. Involve children and young people with intellectual disabilities and their families in the preparation of individual plans for care, education and employment.

- 7.4. Involve children and young people with intellectual disabilities and their families in the development of accessible information to support their health and well-being.
- 7.5. Produce relevant policies and strategies in easy-to-understand formats, so that children and young people with intellectual disabilities and their families know their rights and entitlements.

8. Build workforce capacity and commitment

The well-being of children and young people with intellectual disabilities is strongly reliant on the skills and commitment of staff in all settings and sectors. A workforce is required that can provide practical, educational and emotional support to families.

Positive, non-discriminatory professional attitudes will result in high-quality care, therapeutic optimism and the child's well-being. Appropriate training, retraining and continuing professional development for all staff providing services and equitable salaries are essential.

Actions

- 8.1. Ensure that there is a syllabus to improve knowledge, skills and attitudes about intellectual disability in the undergraduate and general training of all health professionals (e.g. primary care doctors, school health practitioners, community-based nurses, secondary care medical and nursing staff) and as part of the specialist training of child and adolescent psychiatrists and paediatricians.
- 8.2. Improve the knowledge and skills of those working in primary care, child and family health – emphasizing the importance of early intervention.
- 8.3. Develop a workforce that can provide practical, educational and emotional support to families.
- 8.4. Develop a workforce that can provide support in educational and vocational transition to adulthood.
- 8.5. Engage health services in the provision of training and support to educational and social child care facilities to enable them to include, and meet the needs of, children with intellectual disabilities.
- 8.6. Ensure that staff moving from institutions to the community have the skills required for their new roles.
- 8.7. Ensure that the development and delivery of training for health, social care and education professionals includes the rights of children with

disabilities and involves children with intellectual disabilities and their families.

- 8.8. Regularly review workforce statistics to ensure the provision of an appropriate range and level of support and the development of specialist professional roles.

9. Collect essential information about needs and services and assure service quality

The lack of reliable health monitoring data, fragmentation of health care services and the need for partnership across many agencies at every level of the public and private sectors pose major challenges for quality assurance.

To ensure that the priorities in this declaration are met, adequate information systems are needed that enable transfer of knowledge and monitoring of quality of care, together with transparent responsibilities and roles for all stakeholders coupled with systems of accountability.

Actions

- 9.1. Ensure that all children with intellectual disabilities are identified through the health system in their early years and use information about their needs to anticipate, plan and provide family support, education and transition to adult life, thus avoiding crisis-driven care.
- 9.2. Ensure that information regarding the needs, welfare and protection of children and young people with intellectual disabilities is shared between relevant health, social care, education and vocational agencies.
- 9.3. Develop quality standards to support the provision of family-like care for children with intellectual disabilities who are not living with their own families.
- 9.4. Promote quality standards and quality assurance systems across agencies, to ensure that children and young people with intellectual disabilities are not subject to discrimination.
- 9.5. Establish performance targets for health services aimed at identifying and eliminating differences in access to services and in achieving optimal health outcomes.
- 9.6. Establish health targets for children and young people with intellectual disabilities with regard to routine health interventions and general and specific health (e.g. dental and ophthalmic) checks.

- 9.7. Establish national schemes that enable examples of good practice in health care and integrated and coordinated intersectoral care to be publicized, promoted and actively supported and rewarded.
- 9.8. Include a specific section on the right to health of children and young people with intellectual disabilities in country monitoring reports related to the Convention on the Rights of Persons with Disabilities.
- 9.9. Ensure that children with intellectual disabilities are identified in population-level child health surveillance systems (e.g. UNICEF-supported multiple indicators cluster surveys).
- 9.10. Facilitate international benchmarking and knowledge transfer across Member States.

10. Invest equitably to provide equal opportunities and achieve the best outcomes

All children and young people deserve fair investment in high-quality support and health care. Reflecting their relatively greater needs, children with intellectual disabilities often require higher investment to derive similar benefits to other children. Offering every child with intellectual disabilities an equal chance to meet his or her potential is integral to meeting their fundamental human rights.

Actions

- 10.1. Ensure fair and, if necessary, preferential spending on services from which intellectually disabled children and their families benefit.
- 10.2. Review welfare and benefits programmes to ensure that they adequately support the health and well-being of children with intellectual disabilities living in the community and their families.
- 10.3. Conduct local/regional needs assessments and adopt integrated multi-agency strategic plans for the provision of family-based care.
- 10.4. Establish clear transition plans that support the coordinated shifting of resources from institutions to appropriate community-based support and services.