

Better Health, Better Lives:

Children and Young People with Intellectual Disabilities and their Families

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Produced by Lumos in partnership with WHO Europe

INTERGOVERNMENTAL CONFERENCE TO ENDORSE AND LAUNCH THE BETTER HEALTH, BETTER LIVES DECLARATION

The Declaration *Better Health, Better Lives: Children and Young People with Intellectual Disabilities and their Families* will be launched at a high level conference in Bucharest, Romania 26 – 27 November 2010. This event is hosted by WHO Europe in partnership with UNICEF. This conference will offer unique opportunities for constructive dialogue between international and national non-governmental organisations (NGOs) and Disabled Persons Organisations (DPOs), academics and service providers with Member State Representatives as well as the WHO and UNICEF.

CALL FOR EXPRESSIONS OF INTEREST FOR ATTENDANCE AT THE CONFERENCE

WHO Europe is currently seeking expressions of interest for attending this conference. It is hoped that NGO representation will match that of Member State Representatives. Interested individuals from relevant national or international NGOs, DPOs, self-advocates, funding organisations, service providers or researchers/ academics are encouraged to apply.

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“to ensure that all children and young people with intellectual disabilities are fully participating members of society, living with their families, integrated in the community and receiving health care and support proportional to their needs”

AIM, WHO EUROPE Better Health, Better Live Initiative

UPDATE ON THE INITIATIVE

In 2008, WHO Europe launched the initiative ‘Better Health, Better Lives’ in response to increasing evidence of disproportionately poor health care for many children and young people with intellectual disabilities across the European Region. WHO has produced, in consultation with various stakeholders including self-advocates, the Declaration *Better Health, Better Lives: Children and Young People with Intellectual Disabilities and their Families*.

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APPLYING FOR PARTICIPATION IN THE BETTER HEALTH BETTER LIVES CONFERENCE

Participation at the conference is by invitation from WHO Europe. If you would like to be considered for participation, please submit the following details in an e-mail to ngb@euro.who.int.

- Name
- Function/title
- Organisation
- Address
- E-mail address or, if needed, details of the best mode of communication and contact information
- Details of any disability and support/assistance needs

A small number of funded places are available at the discretion of WHO. If you would like to be considered for this, please include justification in the e-mail requesting an invitation.

All requests for participation should be **received by 14th October**, and will be considered and responded to by e-mail from the WHO by 21st October.

WHY LUMOS SUPPORTS THIS INITIATIVE

Across the European region, governments, NGOs, communities and individuals strive to improve the situation of vulnerable and marginalised children. It is a long-term struggle and, over the decades, certain events and achievements act as milestones: demonstrating how far we have come, whilst simultaneously setting out the pathway to future achievement. At Lumos, we believe that the ‘Better Health, Better Lives: Children and Young People with Intellectual Disabilities and their Families’ represents one such milestone.

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Better Health, Better Lives Conference

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The WHO Conference, in partnership with the United Nations Children's Fund (UNICEF), will demonstrate Member States' solidarity and alongside NGO's, the shared concern over these issues, the progress already achieved and a commitment to change. It is planned that the Conference will result in the endorsement of the European Better Health, Better Lives Declaration .

Engagement across stakeholders

One of the strengths of the Better Health, Better Lives initiative is the commitment expressed by NGOs and the WHO to working in partnership to achieve the priorities of the Declaration. The conference programme will allow for opportunities for real engagement across stakeholders with the aim of forming useful partnerships towards action for implementation of the Declaration within various countries. WHO is also considering offering a marketplace and more informal workshops on the afternoon of the 27th November. If you are interested in holding a workshop or participating in a marketplace, please let us know (see page 4 for contact information).

Self-Advocate and DPO Participation

Recognising the importance of Priority 7, which highlights the need to empower people with intellectual disabilities to fully participate and meaningfully contribute to decision-making about their lives, self-advocates have been involved in the Better Health Better Lives Initiative and drafting of the Declaration. Their attendance at the conference is a high priority and self-advocates and DPO representatives are highly encouraged to apply.

Exhibition

There will be opportunities for organisations to show material in an exhibition space. If you are interested in exhibiting please contact WHO Europe (see page 4).

Examples of good practice

The Conference will also showcase examples of good practice from across the European region, particularly in the areas of de-institutionalisation, development of family support services, delivery of health promotion programmes and specialist support services. The roles of governance, workforce development and quality assurance will be addressed.

Achieving long-term objectives

To achieve the long-term objectives of this initiative, the Conference will provide a forum for planning follow-up activities and establishing partnerships to work together towards implementing the declaration at Regional, national and local levels.

More information about the conference, programme, background and venue can be found at http://www.euro.who.int/intellectual_disabilities.

Why Lumos supports the Better Health, Better Lives Initiative

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The strength of the Declaration is that it begins to address a gap in the international legislation related to the rights of children with intellectual disabilities, or rather to be more explicit about their rights and present them in a holistic way. The Declaration is founded specifically on the needs and rights of children with intellectual disabilities to live with, and be cared for, by their families, and the rights of those families to specific support in order to enable children to stay with them. There is a clear, specific priority on de-institutionalisation and the transformation of care systems that rely heavily on institutional care, by replacing these institutions with community-based services that support children to remain with their families.

But why is a Declaration necessary, since there are three major international Conventions that govern the rights of children with intellectual disabilities? The problem is that in terms of meeting all the needs of children with intellectual disabilities, each of these Conventions has its limitations:

The UN Convention on the Rights of the Child (UNCRC)

Disability is only mentioned in two articles throughout the whole Convention (Art. 2 and 23). The specific article on disability (Art. 23) does not mention the child's right to family life.

Instead, it focuses on children's development of independence and their access to health, education and other services. This, coupled with Art. 20, which allows placement in "suitable institutions" has been interpreted in some countries as a justification for institutionalisation. Since there are inadequate community based specialised health and education services, institutionalisation in residential special schools or special hospitals is seen as a way of ensuring children's rights to access those services. But this is at the expense of the right to family life

The UN Convention on the Rights of Persons with Disabilities (UNCRPD)

The majority of the Convention sets up a framework to ensure the fullest possible independence and integration in the community of persons with a disability. However the specific article on children (Article 7) does not emphasise their right (and need) to be raised in a family environment. As with the UNCRPD, the concept of 'best interests of the child' is open to interpretation.



Update on the Initiative

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The Draft Declaration and Action Plan sets out 10 Priorities for Member States in redressing this imbalance, the latest version is available by clicking [here](#). The Declaration covers 4 key objectives:

- ⇒ 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 allows 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 transition through life.

Major outputs

1. A **Declaration on Children and Young People with Intellectual Disabilities and their Families - Better health, better lives**, stating explicitly the common principles and goals, in line with the provisions of the relevant UN conventions, other human rights instruments, and commitments. NGO representatives contributed attended a consultation session on the draft text in December 2009. Representatives of Ministries from Member States of WHO Europe discussed and agreed the draft Declaration in March 2010. The launch of the Declaration will occur at the Bucharest conference. The draft is available by clicking [here](#).
2. The Declaration is accompanied by an **Action Plan** which outlines the initial steps needed to realise the priorities outlined in the Declaration. To be launched at the Bucharest Conference.
3. A set of **Expert papers** to form part of a resource bank. Expert papers, which are intended to be pragmatic guides to assist countries to develop and implement country action plans, will be launched alongside the Declaration and Action plan in Bucharest in November.
4. Lumos is coordinating the production on an **Easy Read Version** of the Declaration which will also be launched at the Bucharest Conference.

Why Lumos Supports this Initiative

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Art. 23, Respect for home and the family, refers to a child's right to family life and the need to support parents in order to 'prevent concealment, abandonment, neglect and segregation'. However, it is not explicit in terms of preventing arbitrary separation used ostensibly to provide children health and education services (the primary reason for institutionalisation of these children in Central and Eastern Europe).

The European Convention on Human Rights

Art. 8 stipulates the right for protection of private and family life and that no public authority should intervene in that unless strictly necessary. But this Convention has no specific references to children, for whom interference in private and family life has a different perspective from that of adults.

In addition, when ensuring the participation of children or disabled people in consultation on issues that affect them, there is a tendency to exclude children with intellectual disabilities, due to the challenges related to their specific communication needs. Children and young people with intellectual impairments then become one of the most marginalised groups amongst the already marginalised and, significantly, fall between both UN Conventions.

The Declaration goes some way to filling this gap on the rights of children and in particular, those with intellectual disabilities, by making explicit the implied inter-connected rights of children to live with their families *and* access appropriate health and education services *and* participate fully in the community, live with dignity and achieve independence. Moreover, it provides a framework for ensuring these rights are realised.

Georgette Mulheir
Director of Operations,
Lumos



In Other News

Update on the Convention on the Rights of Persons with Disabilities:

The Office of the High Commissioner for Human Rights has recently published on its website on disability a document titled "Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors". To read the document in English, go to http://www.ohchr.org/Documents/Publications/Disabilities_training_17EN.pdf

United Nations High-level Plenary Meeting on the Millennium Development Goals (MDG Summit)

The MDG summit, 20-22th September, had the primary objective to accelerate progress towards all the Millennium Development Goals (MDGs) by 2015. The summit undertook a comprehensive review of successes, best practices and lessons learned, obstacles and gaps, challenges and opportunities. The outcome document of the three-day Summit – [Keeping the Promise: United to Achieve the Millennium Development Goals](#) – reaffirms world leaders' commitment to the MDGs and sets out a concrete action agenda for achieving the Goals by 2015. This information is taken from the millennium campaign website; for more information please see http://www.endpoverty2015.org/en/2010_mdg_review_summit.

*** Invitation to Contribute ***

Subsequent issues of this newsletter will focus on disseminating information about initiatives and action at an international and national level towards implementation of the [Better Health, Better Lives Declaration](#). Issue 3 will aim to highlight current examples of good practice in countries in advance of the Better Health, Better Lives Conference. Please send any submissions you would like considered for inclusion in the next newsletter to [Jane Anthony](#) at Lumos by November 1st.

For more information on the Better Health, Better Lives initiative please contact:

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