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 NGOs and DPOs 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.

"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 Lives 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 have 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.

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 30th September, and will be considered and responded to by e-mail from the WHO by 14 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.
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 deinstitutionalisation 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 UNCRC, the concept of ‘best interests of the child’ is open to interpretation.
Better Health, Better Lives: Children and Young People with Intellectual Disabilities and their Families

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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 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 Right

Art. 8 stipulates the right for protection or 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 have 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
Update on the Convention on the Rights of Persons with Disabilities:


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

The MDG summit kicks off today and runs from the 20-22th September with the primary objective to accelerate progress towards all the Millennium Development Goals (MDGs) by 2015. The summit is expected to undertake a comprehensive review of successes, best practices and lessons learned, obstacles and gaps, challenges and opportunities, "leading to concrete strategies for action". For more information see http://www.un-ngls.org/spip.php?page=amdg10&id_article=2986.

*** 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 three 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.