

Better Health, Better Lives:

Children and Young People with Intellectual Disabilities and their Families

December 2010, Issue: 03

Produced by Lumos in partnership with WHO Europe

The [European Declaration on the Health of Children and Young people with Intellectual Disabilities and their Families](#) was officially endorsed and signed

on behalf of the 53 Member States in the WHO Europe Region at a high level conference in Bucharest, Romania 26 – 27 November 2010.

The conference itself was a great success and offered a rare opportunity for constructive in person dialogue between WHO and UNICEF, Member State representatives, self-advocates and international and national NGOs. Consensus, solidarity and a commitment to action on the Declaration's 10 priorities was expressed by all who were present.

The conference was attended by representative from 58 Member State delegates (representing 38 States) and 41 representatives international and national NGOs.

What people are saying:

"One thing that I have learned from this conference is that people from all over the world and Europe can learn from each other. I feel very proud for being here. This is the best conference I have been to in a long time because I was included and understand what is going on"

-A self-advocate at the conference

"After a long journey of consultation and drafting, the Declaration and Action Plan have been officially endorsed by Member States, in a way which was beyond my expectations. The most memorable moment of the conference for me, apart from the signature of the Declaration, was the session of self-advocates on Saturday morning, planned and facilitated by Lumos. When self advocates say it is the best conference they have ever attended, something must have been right, and when they told us they want change and want it now, it was a message all present heard very clearly."

-Matt Muijen, Regional Director for Mental Health, WHO Europe

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"We are serious about what we do. We want to change the world, and we want to do it now"

-Shaun Webster, Self-Advocate*

*for more information about Shaun, please see his interview in the self-advocates corner below.

Show your support: Endorse the Declaration

The final draft of the Declaration was endorsed and signed in Bucharest on 26 – 27 November 2010.

Official signatories include the Minister of Health, Romania (on behalf of all 53 states in WHO's European region), the WHO Regional Director for Europe and the UNICEF Regional Director for Central and Eastern Europe and the Commonwealth of Independent States.

Representatives of NGOs, DPOs, academic institutions and service providers are invited to endorse the Declaration in order to show their support and commitment to future action on the 10 priorities. Click here to [read the endorsement statement and view the signatures](#) collected to date.

To show your **support by endorsing the Declaration**, please send an email with your name, organisation's name and e-signature or logo to BetterHealthBetterLives@lumos.org.uk.

Self-Advocates' Corner

Shaun Webster co-facilitated (with Jane Anthony from Lumos) the participation of self-advocates at the conference in Bucharest. Shaun says, "I am a parent with learning disabilities, I have worked for [CHANGE](#), a human rights organization, employing people with learning disabilities to work for their human rights as a human rights and self advocacy Trainer, Speaker and Campaigner for 7 years.

In this interview, Shaun talks about his life in the UK, the rights of all children and his experience as a facilitator at the Bucharest conference.

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Jane Anthony & Shaun Webster facilitate a parallel session for self-advocates in Bucharest

"Ending Institutionalized Childhood"

In the following excerpt, Oliver Lewis, Director of Mental Disability Advocacy Centre talks out about the Declaration:

"In November, representatives of member states of the World Health Organization's Europe region met in Bucharest, where they signed

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Better Health Better Lives in Bucharest, Continued from page 1

"What struck me about the conference was the honesty with which people - doctors, officials, parents, from different countries - some more developed than others - spoke about their difficulties in including people with intellectual disabilities in everyday life. They all appeared genuinely dedicated to their inclusion and committed to improving their situation. I was also struck with the endless power of human spirit and with what the self-advocates had achieved, some with almost no support from the society. I realised how privileged we all were to have the opportunity to communicate with these young people and how much we could learn from them about tolerance, understanding and compassion. And I keep asking myself 'Who are we to judge what a person with intellectual disabilities can achieve? They can 'change the world'. And they did, mine."

-Rossi Petrova, Lumos Bulgaria

While the signing of this landmark declaration should be celebrated, all involved with its preparation recognise that the hard work is only just beginning. Continued efforts to realise the Declaration's 10 priorities is essential and the joint efforts across Member States, the WHO, UNICEF, self-advocates and NGOs demonstrated to date is critical to success.

"I have no doubt that the strong partnership that has developed between WHO Europe and our partners, including UNICEF and the EC, Member States, NGOs and self-advocates has been crucial to reach the point we are at, but it should of course also be recognised that a Declaration is only a starting point. At the conference we showed a consensus and commitment that made a powerful impression on all present and as a consequence, we are now well set up for further actions. My Regional Director has committed herself to take the Declaration to the Regional Committee for endorsement in a resolution, as she stated during the conference. We intend to develop action plans and programmes with countries, and we hope we can join with experts, NGOs, self-advocates and other agencies to be as effective as possible."

-Matt Muijen, Regional Director for Mental Health, WHO Europe

To show your support by endorsing the Declaration, send an email with your name, organisation's name and e-signature or logo to BetterHealthBetterLives@lumos.org.uk. The endorsement statement can be read here (http://lumos.org.uk/files/Final_Endorsement_Statement_With_E-Signatures.pdf).

Please see the resource bank on page 4 of this newsletter and check back regularly for additional information. If you would like to get involved, or tell us about work you are already engaged in, please email betterhealthbetterlives@lumos.org.uk.

Self-Advocates' Corner, continued from page 1

I am Shaun Webster, 38, parent to 3 children. I have a learning disability and work for CHANGE. I live in Rotherham in South Yorkshire. I live in KeyRing housing organisation for those with learning disabilities to live independently – part-time there. Because my reading and writing is not very good when I get letters from doctors or anyone else I need help with these things. I have been living on my own not with KeyRing for ten years and with KeyRing for ten years now, from 1991 on my own.

What challenges did you face when growing up?

I went to a special school from 1980 and because I couldn't read or write and because I used to be deaf for 5 or 6 years my speech problems were really bad. That was a big challenge for me because people didn't understand what I was talking about and I used to be picked on a lot. And because I'm dyslexic reading and writing was a problem for me as a teenager. I then went to special school from 1980 – 1988 but didn't like that school. My mother wanted me to go to a special school because she thought it would help me so she wanted me to drop out of normal classes. But we didn't learn much, we didn't learn anything about sex education.

What would things be like if you had been educated in a mainstream school?

At the time if I was at the normal school it would have been fairly hard for me because I'm dyslexic and was deaf and [have a] speech impairment, it would have been fairly difficult for me. I wouldn't have been able to cope with the workload and bullying and I would have been told to leave.



The signing of the Declaration

“Ending Institutionalized Childhood”, continued from page 1

the "European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families." The declaration commits governments to improving the health care of children with intellectual disabilities to enhance lifelong development, as well as inclusion and full participation in society, and sets out ten priorities for action, which include empowering children, protecting them against harm and abuse, and transferring care from institutions to the community. This is the first intergovernmental agreement to incorporate the 2006 UN Convention on the Rights of Persons with Disabilities (CRPD), a legally-binding human-rights treaty. The declaration applies the CRPD in a specific geographic region (Europe), for a specific target group (children with intellectual disabilities), and for a cluster of specific rights (the rights to health and to live in the community with appropriate support)."

To read the full article, published by Project Syndicate, please [click here](#).

Self-Advocates' Corner, continued from page 2

What can we learn from your experiences?

In 1980, people with learning disabilities were not respected then, they think you won't learn anything and they used to push us from everybody. And that is wrong. I have learning disabilities myself but I came to CHANGE and they've been able to help me a lot and I am a good speaker and a good listener. But at the time in the 80's the attitude was bad. Attitudes have got a lot better [in the United Kingdom] but we still have a lot to work on. People still think that people with learning disabilities can't do anything so we need to educate people.

Can you describe the achievements you have had?

I was working at [an electronic shop] in a warehouse and was working there for about 6 years and the first year was fine, the first year was okay, but the next year I was starting to get a bit bored so they got me doing stock control. I was slow at it but I found it interesting and I thought I could do more of that. So I asked the boss and they said they didn't have time to support me on that. And I feel that they got me doing the job that no one wanted to do. I used to get called names and people would lob shoes at me. I couldn't leave the job because of benefits, I had to stick it out. The firm

who got me the job were called Pathway, part of Mencap, they help to get you a job. They get you a job, and think that will make you happy, but you feel forgotten. I wanted to challenge myself but because you have a learning disability they think you can't do anything and the bosses don't want to train you so you end up with a boring, tedious job. And I would have put my notice in but somebody told me about this job at CHANGE. And I have experience going to meetings for KeyRing. I have been working at CHANGE for 7 years, I have an excellent boss, excellent co-worker. They look at things you can do, not things you can't do. We work in a co-worker model, where a person without learning disabilities and person with learning disabilities will work together with no bosses. [Neither one is the boss of the other], we

work together in a partnership.

What are your hopes for the future?

The conference really opened my eyes. I want to be a speaker and talk about my experiences. You can have a job, you can have a family and you can have a future.

How did you become involved in the meeting in Romania?

Philipa [Director at CHANGE] told me about Lumos and she asked me 'would you be interested to come?'. She told me about what [Lumos] stands for and I found it interesting because, it [a documentary] was on TV about Bulgaria and about institutions and it really got me interested and it got me wondering if I lived in that country would I live in an institution? And in that way I am happy that I have a lot to say. I loved running the workshop.

What was discussed during the meeting in Romania?

We talked about families and about health. Everybody had a turn to speak and that was good because they wanted everybody to have a voice. I told people from around Europe my story, this got the ball rolling and gave people the confidence to talk about their lives. It was good to see other people with learning disabilities empowered. We are serious about what we do. We want to change the world, and we want to do it now. We crossed borders, talking about doctors and about families. We found out people had a lot in common.



Shaun Webster and Philippa Bragman from CHANGE examine the Easy Read Version of the Better Health Better Lives Declaration

Self-Advocates' Corner, continued from page 3

How do you think the Better Health, Better Lives Declaration will help you and other people?

It is about having rights. It will help people with learning disabilities. A lot of the time we don't know we've got rights. And that declaration agreed by the governments, if we can show people that we know about our rights, we are not vulnerable. If we know about this kind of law people have to listen to us because we have got rights to live independently, to have relationships to have families to have jobs and not to put us down. We should get the book printed to show to people that they can't put us down. When I was talking with the girl from Croatia, when I told her about my children and family she was crying because I gave her hope.

Do you think your experience at the meeting in Romania has offered you more involvement?

Yes – I want to go back and do more. I can't stop buzzing about it. I told my kids about it. And it's funny – I think I'm starting to get on my kids nerves about it – I just want to go out there and tell people about my experience. It's got me buzzing.

I told people from around Europe my story, this got the ball rolling and gave people the confidence to talk about their lives. It was good to see other people with learning disabilities empowered. We are serious about what we do. We want to change the world, and we want to do it now.

I'm also doing some work with an advocacy organisation about SureStart once per month. I've been working for CHANGE for 7 years and it's not boring. That's what I love – you do different things – workshops, speaking, campaigns, and that's what I love about this job.

-An interview with Shaun Webster, CHANGE

*please note this interview is reported as recorded, in Shaun's own words. Information in square brackets has been minimally added for clarification purposes or to anonymise information.

Better Health Better Lives Resource Bank

The Declaration and Action Plan

Read the final signed declaration and its accompanying Action Plan, available in English and Russian, here [European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families](#)

Lumos has coordinated the production of an **Easy Read Version** of the Declaration, available in English and Russian.

[Better Health Better Lives Easy Read Declaration \(English\)](#)
[Better Health Better Lives Easy Read Declaration \(Russian\)](#)

Lumos has also produced an accessible A1 **poster** summarising the key messages of the Declaration, designed by self-advocates at CHANGE. The poster is available in English, Russian and Romanian.

[Better Health Better Lives Poster \(English\)](#)
[Better Health Better Lives Poster \(Romanian\)](#)
[Better Health Better Lives Poster \(Russian\)](#)

The WHO Europe [Background Paper](#) provides additional information on the rights and commitments underpinning the Declaration's priorities as well as identifies key issues and challenges, good practice examples and ways forward.

WHO Europe has commissioned a set of pragmatic **Priority Papers** ([complete set available in English and Russian available here](#)) to assist countries to develop and implement country action plans. These papers focus on each of the 10 priorities and provide additional explanation, examples of successful practice and resources for implementation.

- Priority 1: [Protect children and young people with intellectual disabilities from harm and abuse.](#)
- Priority 2: [Enable children and young people to grow up in a family environment.](#)
- Priority 3: [Transfer care from institutions to the community.](#)
- Priority 4: [Identify the needs of each child and young person.](#)
- Priority 5: [Ensure that good quality mental and physical health care is coordinated and sustained.](#)
- Priority 6: [Safeguard the health and well-being of family carers.](#)
- Priority 7: [Empower children and young people with intellectual disabilities to contribute to decision-making about their lives.](#)
- Priority 8: [Build workforce capacity and commitment.](#)
- Priority 9: [Collect essential information about needs and services and assure service quality.](#)
- Priority 10: Invest to provide equal opportunities and achieve the best outcomes. (link to follow)

For more information and resources on the Better Health, Better Lives initiative please see the following websites:

WHO Europe: http://www.euro.who.int/intellectual_disabilities
Lumos: <http://www.lumos.org.uk/what-we-do/better-health-better-lives.html>

Highlighting Best Practice: NHS Scotland

This issue highlights the NHS Scotland and the support it provides parents with learning difficulties.

NHS Health Scotland is Scotland's national health improvement agency. Our aims are to improve the health of the population of Scotland and to tackle inequalities in health. The Early Years Children and Families Team within NHS Health Scotland have been working to improve our services through working in partnership with parents with learning disabilities.

NHS Health Scotland is committed to distribute accessible resources as an alternative to our universal resources to support parents. These are entitled Ready Steady Baby! and Ready Steady Toddler! These resources were produced after we carried out an assessment to determine the impact of our resources on people with additional needs and a gap was identified in meeting the needs of parents with learning disabilities. As a result of this assessment, and discussions with advocacy organisations working with parents with learning disabilities, NHS Health Scotland is now working together with CHANGE, a leading national equal rights organisation led by Disabled People, to provide accessible resources for parents with learning disabilities. These resources are provided free of charge to Scottish NHS Boards on request. The books entitled My Pregnancy My Choice, You and Your Baby and You and Your Little Child have been written in partnership with people with learning disabilities and provide information to support parents from pregnancy until the child is 5 years old.

An evaluation of these resources is being undertaken in partnership with parents with learning disabilities. This will look at the use and uptake of the resources. This aims to gather the views of parents with learning disabilities and will inform how the resources will be used and distributed locally to ensure they are accessible when parents need them. The evaluation report will be available in 2011.

In addition we have been working together with parents with learning disabilities to raise awareness of the issues they face using universal services. Through the last three National Early Years Conference's, parents with learning disabilities have had an opportunity to speak directly to Early Years Professionals across the health service, local authority and community and voluntary sectors to share their personal experiences and help inform discussions on how to improve services to best meet their needs.

By: Laura Martin
NHS Scotland

*** 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 four will aim to highlight current examples of good practice in countries. Please send any submissions you would like considered for inclusion in the next newsletter to BetterHealthBetterLives@lumos.org.uk by February 1st.

To subscribe to the Better Health, Better Lives newsletter, please email BetterHealthBetterLives@lumos.org.uk

For more information on the Better Health, Better Lives initiative please see the following websites:

WHO Europe:

[http://www.euro.who.int/
intellectual_disabilities](http://www.euro.who.int/intellectual_disabilities)

Lumos:

[http://www.lumos.org.uk/what-we-
do/better-health-better-lives.html](http://www.lumos.org.uk/what-we-do/better-health-better-lives.html)

You can also contact:

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