Turning Words into Action

Transnational Planning Workshop
Sofia, 18-20 September 2012
Who is here?

- Children and Young People from the Child Participation Groups
- Parents and carers
- Policy makers
- Members of the National Working Groups
- Lumos staff
- CHANGE
Our Objectives

• To learn more about the project and what’s happening in the Czech Republic, Bulgaria and Serbia. (Sharing and learning from each other)
• To understand better how we can use the Better Health Better Lives Declaration to improve things for children and young people with intellectual disabilities. (Policy and practice.)
• Child participation in practice (A new way of working together.)
• Get inspired by the work of others and develop our own national action plans. (Working in country groups. “How can we make change happen in our country?”)
About the Agenda Today

**This Room**
- EVERYBODY TOGETHER FOR THE WELCOME
- 3 country presentations
- BHBL Implementation
- EVERYBODY TOGETHER FOR CHANGE PRESENTATION & THE SELF ADVOCATES’ FINAL PRESENTATION.
- Focus on transferring care from institutions to the community
- 3 country groups

**The other Room**
- Developing our message to the national working groups
- Feedback from the big room.
- Goodbye to self advocates
About the Agenda Tomorrow

• Evaluator’s Report
• Experiences of Child Participation (Observations from the Local Co-ordinators)
• Examples of Good Practice in Community Based Health, Education and Social Services
• Work in 3 Country Groups
• Conclusion and next steps
And...

- Parallel sessions - time keeping
- Avoid jargon – remember the interpreters
- Facilitators – Nolan and David
- Filming
- Evaluation forms

With thanks to the European Union Social Innovation Fund
Turning Words into Action

Strengthening our Understanding of the Better Health Better Lives Declaration

LUMOS
Better Health Better Lives
Better Health Better Lives (BHBL)

- About BHBL
- How can we use it to “turn words into action”
- The priorities identified so far by the national working groups and child participation groups.
  - Priority 7: Self Advocacy
  - Priority 6: Family Support
  - Priority 8: Human Resources and Personnel
BHBL Priority 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.

EXAMPLES...
BHBL Priority 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.

EXAMPLES...
BHBL Priority 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.

EXAMPLES....
“Turning Words into Action”

Enabling the Rights and Inclusion of Children with Intellectual Disabilities in Europe

This project is supported by the European Union's Programme for Employment and Social Solidarity - PROGRESS (2007-2013).
This programme is managed by the Directorate-General for Employment, social affairs and equal opportunities of the European Commission.

The information contained in this presentation does not necessarily reflect the position or opinion of the European Commission.
STEERING COMMITTEE MEMBERS

- 2 self advocates (parallel session 20/12/11)
- Parent of a child with a learning disability
- WHO
- International experts involved in the BHBL initiative
- Implementing partners: Karin Dom Foundation (Bulgaria), Pardubice County (Czech Republic)
- Lumos staff
ROLE OF STEERING COMMITTEE

- Governance body
- Support, help, listen & offer feedback to those implementing the project
- Monitor progress and contribute to internal evaluation
- Check uses of finances
MAKING THE MOST OF
THE STEERING COMMITTEE and its MEMBERS

- Expert Mentors of National Working Groups
- Facilitators for Transnational Workshops
- Contributing to project documents
- Providing ad-hoc support
- Engaging 'upwards and outwards' to promote and inform wider action on the Declaration
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Enabling the Rights and Inclusion of Children with Intellectual Disabilities in Europe

First Steering Committee Meeting, 2011 11 24, London.

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Children with Intellectual disabilities are severely marginalized.

Reliance on institutions

Barriers to services and full enjoyment of human rights because of disability

Right to be heard to be consulted on issues that affect child's life
UNCRC Falls short to protect the right of children with ID for family life and inclusion.

UNCRPD lacks to cover specific needs of children.

ECHR fails to provide specific reference to children and their right for family life.
WHO initiative ‘Better Health, Better Lives’

- Persons with Intellectual Disabilities and their families
- Experts in the related area
- European Declaration on the Health of Children and Young People with Intellectual Disabilities
- NGOs
- Service Providers
What is this project about?

- Improving the quality of life of children with intellectual disabilities and their families
- Incorporating International Conventions into National Legislation and practice
- Supporting the national governments to develop their action plan about children with intellectual disabilities addressing one or more priorities of the Declaration.
- Empowering and providing opportunities for children with ID to express their views and feed them into the development of NAP
How is it going to happen?

Better Health, Better Lives Declaration

Steering Committee

LUMOS

Working to transform the lives of disadvantaged children

www.lumos.org.uk

Serbia

Pardubice Region

Karin Dom

EU Flag
Main Outcomes:

• New, updated or improved National Action Plans ensuring that needs and rights of children with intellectual disabilities are fully met.
• Improved awareness and attitudes towards children with intellectual disabilities and their families.
• Models of good practice that could be disseminated for further implementation of the BHBL Declaration across the whole region.
• Improved quality of life for children with intellectual disabilities.
Project Management Team.
TWIA Self Evaluation Tool

TWIA Steering Committee Meeting
London
6 June 2013
What is the tool for?

- Assess the impact of the project on BHBL implementation
- Opportunity to look back
- Comparison with control countries
- Assess a country’s level of implementation of the BHBL Declaration and Provide the user with an easy to digest assessment.
- Sustainable and useful resource on the BHBL which can be adapted with new examples of good practice

LUMOS
Protecting Children. Providing Solutions.
Purpose of the Tool

“This unique interactive tool assists governments, professionals and civil society to assess how close their country is to full implementation of the BHBL Declaration and to identify the steps they need to take to be in full compliance. It was developed as part of the Lumos ‘Turning Words into Action’ project.”
The Better Health Better Lives Declaration is a World Health Organization Europe Resolution which all of the countries of Europe have committed to implementing. It outlines in detail the practical steps governments should take to meet the needs and uphold the rights of children and young people with intellectual disabilities.

This unique interactive tool assists governments, professional and civil society to assess how close their country is to full implementation of this Resolution and to identify the steps they need to take to be in full compliance. It was developed as part of the Lumos "Turning Words into Action" project.

1. 30 Second Orientation

2. Start Evaluation
The Better Health Lives Declaration identified 10 priority areas for action. Each one is an essential ingredient to achieve full enjoyment of rights for children with intellectual disabilities. Under each priority, individual standards give more detail of necessary changes in policy and practice. Examples of good practice from across Europe are also included.
Care in 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 placement of children in families 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 demonstration education will create the phasing out of long-stay residential institutions for children with disabilities.

Continuing Care

Service providers take measures to improve the competence of caregivers delivering residential care. Continuing education, guidance and support are provided as children and young people are prepared to transfer to family-based in the community.

MORE EXPLANATION
Please answer the following questions:

What are we doing best?

What are our priorities to improve?
Results page...
What’s next...?

- Final development of online content, adding further examples and testing of the technology.
- Translation into Serbian, Czech, Bulgarian and French
- National Working Groups to complete the tool
- Control countries to complete the tool
- Assessment of results for the report to EC
- Tool to be made available offline and online
- Tool presented in Brussels – autumn 2013
TWIA Self Evaluation Tool

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A walk through...
TWIA Self Evaluation Toolkit

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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 the institutionalisation will enable the phasing out of long-stay residential institutions for children with disabilities.

Continuing Care

Service providers are measured to improve the competence of professionals delivering institutional care. Continuing education, adequate information and supervision are provided to children and young people so that they are prepared to transfer to family care in the community.
Continuing Care

Service providers take measures to improve the competence of children in living in foster care. Continuing education, support, and supervision are provided to children and young people and for transfer to family care in the community.

MORE EXPLANATION

When choosing an institution, all placements should be made in the best interests of each child. Hospitals should be moved to an unsuitable placement that causes the child or the child of the age of neglect, neglect, or abandonment is causing the child to be suitable for the institution. The training of the institution is important to ensure the availability of the care services and the appropriate care for the child and young people. Training of education and social support.

EXAMPLE: In a center, all hospital personnel were trained in assessments and interventions, placed in the institution, and ongoing assessment of the child's health and physical development. None of the trained personnel were involved in the development of individual placement and care plans for each child. As a result of this process, the institution's placement strategy was developed to meet the needs of the children and care for the children, and the children's needs and recognition of staff's role in meeting these needs. Personnel were then involved in preparing children for their new placements. Where staff could be moving with the children, for example to another group home, this helped to strengthen the bonds between the personnel and individual children, resulting in better outcomes for the children. Finally, when the children moved to their new placements, the fact that they received personal care within the institution eased the transition process and helped to reduce stress levels in the children and family.

Involving parents in planning and care plans also helped to make sure that all needed measures and involve the personal care plan would be made when moving to the new role. In the last stages of foster care, education, and care, the child or family would be more engaged and involved. This would help to ensure that children are placed in foster care and family.
Please answer the following questions:

What are we doing best?

What are our priorities to improve?
What are our priorities to improve?


How do we involve children, young people, and their parents in ensuring this priority is met?


Submit Questionnaire


LUMOS

Protecting Children, Providing Solutions.
TWIA Self Evaluation Results

This text describes the results and how you can save and export them into a PDF to share. Lorem ipsum dolor sit a

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