

Turning Words into Action (TWIA): Enabling the Rights and Inclusion of Children with Intellectual Disabilities in Europe.

This Interim report covers implementation period between September 2011 and 30 June 2012.

Results.

1. List each objective of the project and explain how they were met during the implementation period. Please focus on the results/outcomes of your action. What were the benefits? Include detail on what change your action has brought about. Explain the added value of the action, i.e. the lasting impact.

Objectives of the TWIA.

Project Objective a: To provide opportunities for the genuine inclusion of the voices of children and young people with intellectual impairments and their families and carers. To demonstrate implementation of inclusive policies by providing a model of good practice in consultative participation and what is both possible and apposite for children with intellectual impairments.

Activities undertaken to meet the objective and their benefits.

- Three groups of children and young people comprising a total of 49 young participants have been established in three project countries, in Bulgaria, Serbia and Czech Republic. These groups consist of children and young people with intellectual disabilities living in institutions, including Roma children, children with intellectual disabilities living with their families and their siblings.

By participating in on-going activities provided by 3 Local Coordinators, children have been learning new skills and knowledge through fun based games and exercises.

They have been practising social skills such as listening, negotiating, showing respect and communicating in different ways, and life skills such as solving problems, making decisions and analysing information. Carers and parents have been observing and reporting that self-esteem and confidence of their children have been enhanced from knowledge, new skills, stimulation and support that were provided for them.

- Through these groups, children have increased their knowledge about their rights, about the World Health Organisation (WHO) Better Health, Better Lives Declaration and its 10 priorities promising a better quality of life for them and their families. Six of these young people were prepared and supported to take part in 1 international and 4 national events with policy makers and service providers to influence decision making processes by expressing their views and opinions on matters that affect their lives. By participating at these high level meetings, young people are becoming aware of different perspectives and democratic processes, including improving services through participation, consultation and making compromises. They are learning that they play an important part in their own lives and in the life of their community. Through practical experiences and opportunities, these young people are learning how to advocate for their own rights and the rights of other young people with intellectual disabilities, particularly those living in institutions.

During the period covered by this report, the 3 Local Coordinators employed for this project organised approximately 15 meetings and training sessions for family members, personnel working in residential institutions, members of the National Working Groups and NGOs to raise their awareness on the rights of children with intellectual disabilities and the basic principles of Child Participation. At these meetings parents and carers discussed children's abilities and their capacity to contribute to decisions about their own lives and the need to overcome the many negative stereotypes of disability with which they are often confronted.

- A Knowledge, Attitudes and Practice (KAP) survey was developed and undertaken in all project countries by project participants, including young children from Child Participation groups. This study will not only provide an insight into what people know and believe about the topic, but will also allow for an assessment of the changes that the project will bring about among target groups. The same survey is therefore planned to be undertaken at the end of the project.

The added value of these activities are:

- Targeted and improved services can be developed as a result of increased awareness of the needs of children. This more cost effective, sustainable and relevant to children and families.
- Increased awareness of the needs of children with intellectual disabilities should lead to better quality and more inclusive policy and decision-making.
- A better understanding of the needs of children and young people with intellectual disabilities in the community which will improve the social inclusion and protection of these children.
- Enhanced credibility and reputation of children and young people with intellectual disabilities.

- Genuine empowerment and inclusion of children and young people with intellectual disabilities which will improve their health, educational outcomes and life chances. As a result, it is hoped that many more of these children will be able, as adults, to take up meaningful employment and to contribute to their communities' development.
- Better relationships between people with and without disabilities in the community.

'Since I have been part of this project I feel grown up, like a TV presenter. I learned about the dreams of young people and those of my friends, about their desire to work and their desire for a small, almost non-existing opportunity to achieve that.'

Young person with an intellectual disability from a Child Participation Group.

'This project definitely changed my daughter – first of all, she is pleased with all the new contacts and friendships, the new experiences she got from meeting people. Because of this chance, she looks more confident now, with great self-esteem. She is surprising me with her new knowledge, even with the new language that she has started to use. She is raising her and our expectations for her future. She shared with me recently, "Mum, I want to continue my education!"'

Parent of a young person with intellectual disability.

Project Objective B: Using the Better Health, Better Lives Declaration as a framework, assist countries to develop, and understand how to implement, national plans for deinstitutionalisation through the development of community based health, education and social service alternatives. To ensure countries consider and are able to accommodate the specific challenges of meaningfully including children with intellectual disabilities.

Activities undertaken to meet the objective and their benefits.

- 53 individual and group meetings were held in project countries introducing the project, its aim and objectives on translating the Better Health, Better Lives Declaration into the national agenda. Followed by these meetings, three National Working Groups were established, one in each country, comprising policy makers at various levels of governments, service providers, NGOs, international organisations like WHO and UNICEF, families of children with intellectual disabilities and young people with intellectual disabilities themselves. These groups have started analysing the current situation in their

country regarding children with intellectual disabilities and are planning either to improve existing National Plans regarding children with intellectual disabilities or to develop new Action Plans integrating priorities of the Declaration.

- To ensure meaningful inclusion of young people with intellectual disabilities in project meetings, training and sensitisation meetings were held for members of the National Working Groups. The participation of young people facilitated by the Local Coordinators with the support of Expert Mentors has enhanced the understanding among policy and decision makers of disability and the unique needs of children with intellectual disabilities and their families. This knowledge will feed into National Action Plans and in the end will result in better policy solutions for young people with intellectual disabilities. The 3 National Working Groups are also themselves learning and modelling good practice in how they are addressing the participation of children with intellectual disabilities in planning services and policy making. This will serve to increase their capacity and commitment to further include the views of excluded children in all aspects of their future work.
- 10 meetings on the priorities of the Declaration have taken place for personnel at residential institutions and for families of children with intellectual disabilities.
- Young people from the Child Participation Groups have been discussing and understanding each priority individually and in groups.

The added value of these activities are:

- Multi-stakeholder working groups have been learning and demonstrating a model of good governance, transparency and genuine participation of children with intellectual disabilities in the development of national policy and practice. Self-evaluation and monitoring tools will be used over time to reassess their progress in terms of meeting the needs of children with intellectual disabilities.
- By working together in a multi-disciplinary way, the stakeholders are establishing patterns of working together with clear demonstrable benefits in terms of quality outcomes and efficiency. A precedent has therefore been established which could lead to this model being adopted as a sustainable approach to policy and practice design.

'My friends can't read or write because they have no parents. The institution couldn't make up for the lack of a family so they should have the opportunity to learn to read, write and do maths.'

Young person from Child Participation group.

Project Objective C: To increase mutually beneficial partnerships and learning including transnational cooperation and in-country collaboration of stakeholders.

Activities undertaken to meet the objective:

- Three Child Participation groups were formed comprising of 49 children with intellectual disabilities from residential institutions, including Roma children and children with intellectual disabilities living with their families.
- Children from the participation groups are learning about the different needs and abilities of each other and the benefits that they all bring to the community. They are learning social and communication skills, constructive and democratic ways of solving their problems.
- An agreement was formed with a leading human rights organisation, CHANGE, to provide opportunities for children involved in the project to meet and learn from adults with learning disabilities. As part of the steering committee meetings, designated CHANGE staff, themselves with learning disabilities worked directly with the young self-advocates to develop models of genuine participation so that they could easily share their views with policy makers. The adult self-advocates therefore act as role models and increase the children's and young people's confidence to advocate for themselves and for others in their own way.
- Three National Working Groups have been formed comprising policy and decision makers from different ministries, service providers, NGOs, United Nations Agencies such as WHO and UNICEF, families of children with intellectual disabilities and young people with intellectual disabilities. These groups are supported by Expert Mentors, who as detailed in the project design are already providing their technical expertise and advice to the groups.
- Members of the National Working Groups are engaged in unique, never experienced before practice, where they are envisioning and designing services together with children with intellectual disabilities and learning from them. They are also learning from the Expert Mentors, who are providing insights including knowledge from other countries who have previously undergone reforms.

- A multi-sector Steering Committee was established to oversee the implementation of the project. Members of the Steering Committee comprise experts in the area of intellectual disability many of whom contributed to the development of the BHBL Declaration and to the design of this project. They have met twice to discuss the progress of the project and to provide technical support towards successful achievement of its objectives.

The added value of these activities are:

- Experience and lessons learnt from these events are being documented and will be disseminated widely in the project countries. Project output and outcomes will be widely accessible to all stakeholders through all 3 partners and their websites.
- Experts at both the national and international level are advising the project team and a mechanism is in place to ensure that project learning is shared at the transnational level and with the 3 national working groups. Their in-depth understanding of the BHBL Declaration ensures that all project activities are relevant to its full and meaningful implementation.

"My dreams are to stop trafficking of children and women, abuse in families; I would like to build homes for the homeless and day care centres for children with and without disabilities together and to take children out of institutions. I would like that jobless people have jobs and to stop poverty. I would like to make everyone around me happy. I would like to have the opportunity to travel and to represent my country."

Young Person with Intellectual Disability at the second Steering Committee Meeting

Project Objective D: To strengthen the understanding, interpretation and implementation of international legislative and rights based frameworks in meeting the needs of children with intellectual disabilities and their families. For target countries to understand the harmful effects of institutionalisation and agree values and principles of inclusive living, including the right of all children to live with their families.

Activities undertaken to meet the objective:

- A National Working Group was established in each of the project countries comprising duty bearers from Governments, representatives from civil society, leading NGOs working on relevant issues and other stakeholders including children and families. For the first time in the project countries policy makers, service providers and young self-advocates are coming together to discuss

the issues they all deal with. These meetings are creating unique and innovative mutual learning opportunities to improve policies and practice on inclusion of children with intellectual disabilities.

- The three Child Participation groups are formed of children with intellectual disabilities living in institutions, including Roma children, those living with their families and children from vulnerable families. Through Child Participation activities children are learning a lot about each other, about each other's different needs, communication skills (including non-violent communication, tolerance, respect, and creative and democratic ways of solving problems.
- The 3 Local Coordinators have been exploring existing legislative and rights based frameworks with the children in a disability and age-appropriate way. They have been working with children and young people to help them understand how the rights contained in them are relevant to their lives. For example 'a right to health means seeing a doctor who is nice to you and examines you properly'. They then assist the young people to communicate their rights and look at ways to deliver this understanding to professionals and policy makers.
- A multi sector Steering Group comprising senior policy makers, child participation experts, academics, service providers, a WHO representative, young people with intellectual disabilities and their families, many of whom were involved with the original BHBL Declaration, was formed at the beginning of the project. Two meetings have been held in London so far, where the members discussed the progress of the project, provided technical expertise and advised on its implementation.

"Zlatka (Local Coordinator) was beautiful and kind. She wanted to hear our views. She offered us co-operation and other activities that could help to know better our human rights. It was beautiful and it had its heart and soul."

Young person with an intellectual disability from Child Participation Group.

"I come here because I like having fun and discussing serious things."

Child with intellectual disability from Child Participation Group.

2. Summary of progress of your action. Please summarise your action as well as any difficulties you have faced in implementing it. Please report separately on each group of activities, what was planned and what was implemented. Please explain if there was any variance from the original action plan.

Child Participation.

Child Participation is a relatively new phenomenon in the countries where the project is being implemented, i.e. Bulgaria, Czech Republic and Serbia. The expectation of children with intellectual disabilities is very low in the society. Consequently the project raised a lot of questions, concerns and doubts among stakeholders and families about the capacity of children with intellectual disabilities to participate in policy level discussions. Therefore in order to establish common understanding among the project team and to raise awareness and to gain support for the project among key stakeholders, training on Child Participation was organised for representatives from governments, NGOs, Institutions and families.

Each of the Local Co-ordinators recruited for this project brought different skills and experiences of child participation in general and methods of communication with children with intellectual disabilities in particular. To provide Local Coordinators with common tools and skills and to ensure high quality of child participation activities, three days of training was organised for them on methods and ways of communication with children with intellectual disabilities in London. They learnt how to create easy read materials and enriched their knowledge on how to communicate with children using pictures, symbols, objects of reference, games and exercises.

Three Child Participation groups were formed, one in each project country. These groups consist of children with intellectual disabilities living in institutions, children with intellectual disabilities living with their families, their siblings and peers without disabilities, including children from Roma communities and children living in poverty.

Taking into account the nature of the rigid system of institutions and lack of choices available for children there, children in institutions were provided with individual sessions at the beginning of the process. Local Coordinators spent time assessing each child's individual needs and preferred communication methods. They organised sessions that provided children with opportunities to learn to make choices, to learn to listen to their own feelings and thoughts rather than trying to guess what is 'the right answer' that the adult is looking for. Children were encouraged to feel confident to express positive and negative feelings, to accept and to be proud to be who they are, that is individuals with potential and abilities to be discovered. Some children for the first time in their lives were empowered to think and say what they would like to do with their spare time, what dreams and wishes they have and what is important for them. Sessions were focused to seek and support each individual's strengths and potential rather than their disability. Gradually when children were comfortable with these new experiences and different group activities, they had sessions to learn about their rights, about the Better Health, Better Lives Declaration and what it means for them in their everyday lives.

- *'We believe every child deserves to be happy with his/her own family.'*
- *'Not even one child deserves to be alone and to have an unhappy childhood.'*
- *'Every child needs a kiss goodnight.'*
- *'Father, mother and kid are together!'*

Children from a Child Participation group expressing their opinion on the second priority of the BHBL Declaration.

Later as the project progressed, children elected two members from their teams to represent their views at the National Working Groups. These representatives participated at the first National Working Group meetings in their country and contributed to discussions on the lives of children with intellectual disabilities by sharing their experiences, their hopes and difficulties that will feed into the design of the future action plans.

'I told others to accept people with disabilities because we are all equal. I'm pleased. I felt very calm and happy that I shared my impressions so far. I hope that from my stories and from the words of mothers we can achieve some positive results. For new horizons should open in front of us, the young people with special needs. I hope that in the future we can have more of these meetings because they are very useful for each one of us.'

Young person about her participation at National Working Group Meeting.

National Working Groups.

In total, 53 individual and group meetings were held for representatives of Governments, NGOs, International Organisations such as UNICEF and WHO to gain their commitment and support at the national level and their involvement in the National Working Groups. This was essential to ensure that the BHBL Declaration is incorporated into the national agendas and for each National Working Group either to improve existing national plans or to develop new national action plans (in line with the project description). This resulted in for example the Ministry of Health in Serbia committing to the implementation of the BHBL Declaration and making an statement to support the National Working Group and to continue the process even after the project is finished.

These individual meetings were followed by the establishment of National Working Groups in all project countries. Each group has been analysing their existing legislation, gaps and areas of good practice in order to identify each country's individual starting point. Young people with intellectual disabilities and their families

are providing their expertise and advising on issues that they think are important for the National Working Group to focus on.

Examples of children's contribution to National Working group meetings.

'I have graduated from 10th grade at secondary school. I would like to know and I ask how can I continue my education? Because when we grow up our parents will not be around and we have to continue our life on our own. My friends from small group home cannot read and write. If they are given a chance to study and work they would feel and be useful. I want to finish my education and work in the library or become a singer.'

Young person at National Working Group.

I want for all people not to avoid people with disabilities but to be able to communicate with them, to treat them normally and to accept them as healthy people, which they actually are.

Young person at National Working Group.

'The project has become like a school for us with a clear purpose, and I can see the real results even during a short time. Naturally I started comparing our new experiences abroad with local social services for my daughter at home. Now I can see how much and what concretely could be or should be changed for children and young people in our town, for other children and for my daughter. I feel more confident in supporting my child as a parent, and I even started volunteering for other children with intellectual disabilities in my country. More and more young parents with children with intellectual disabilities share with me their concerns, and I try to support them with all the knowledge and experience I have now.'

Parent of a child with intellectual disability.

Social Experimentation.

A Knowledge, Attitudes and Practice survey was developed and undertaken in all project countries by project participants, including young children from Child Participation groups. This study will not only provide an insight into what people know and behave around the topic, but will also allow for an assessment of the changes that happened during the project. The same survey is planned to be undertaken at the end of the project.

Self-monitoring and evaluation tools are at the stage of being finalised. The complexity of the many policy areas which fall under the BHBL means that such a Self Evaluation tool must be able to cover all of these areas and yet still be practical. For this reason we have dedicated more time than originally envisaged to prepare these tools. The project team is very keen for this document to be of a very high quality so it can be useful not only during this project period but also in future to reassess the situation regarding inclusion of children with intellectual disabilities in policy and practice.

In conclusion, in terms of overall implementation of the project, all planned deliverables were attained. Some deviations related to the timing of the actions did occur, but they did not affect the progress of the project and all actions are either underway or planned.

3. Transnational dimension. Did you contribute to any transnational dimension of the project? If yes, then how.

'To increase mutually beneficial partnerships and learning including transnational multi-sector cooperation and in-country collaboration of stakeholders' is the third objective of the project.

To meet this objective, a Steering Committee was officially established at the beginning of the project. A majority of members, representatives from different countries had worked together closely on the Better Health, Better Lives Declaration and in designing the project Turning Words into Action. Two meetings have taken place so far, since the beginning of the project, on 24th November 2011, and 26th April, 2012.

Steering Committee members have been providing technical expertise and advice to the project team on the implementation of the project. Two members of the Committee are providing their technical support to National Working Groups as Expert Mentors.

CHANGE has been providing good examples of the empowerment and involvement of people with intellectual disabilities in the implementation of the project. They have been using role models to facilitate and learn to be genuinely inclusive of children with intellectual disabilities for all project countries involved.

The first of two Transnational Workshops is planned to take place in Sofia, Bulgaria on the 18th, 19th and 20th of September 2012. Members of National Working Groups from three countries, Steering Committee members and members of the Child Participation group in Bulgaria will come together to update their knowledge on the issues around intellectual disability, to share the progress of the project in each country, challenges, good practice and to build mutually benefiting partnerships. This meeting was slightly delayed from its originally scheduled date in July to ensure that the steering committee and national working groups had enough time to advise on its agenda and content.

4. Partners or stakeholders. Please list here all partners or stakeholders and describe the contribution they made to the project. Has the role of any partner changed during implementation? If yes, please explain how and why.

Karin Dom is a Day centre for Rehabilitation and Social Integration of Children with Special Needs and their Families in Varna, Bulgaria. As a project partner, since the beginning of the project they have been providing invaluable support to the implementation of the project. They helped to establish a Child Participation group by identifying children with intellectual disabilities, disseminating information about child participation initiatives and providing working and meeting space for child participation activities. They designated two staff to be members of the Steering Committee and the National Working Group, who have been contributing by providing their expertise to the project implementation and National Working Group meetings.

Pardubice County, also a project partner, is a local authority in the Czech Republic, undergoing reform of their residential system of care for children with disabilities through the development of community based services. They have been providing support to the project and contributed by delegating a staff member to contribute to the work of the National Working Group, and by building partnerships with institutions and schools where children with intellectual disabilities come from. They have provided a working space for the Local Coordinator and have been supporting her in her everyday work. They also attended the second Steering Committee meeting. It should be noted that the project started slightly later in the Czech Republic due to a change in staff at Pardubice County since the original project proposal was drafted. It took time to re-establish contacts and forge agreements with new members of staff working for our partners in Pardubice County.

'Centar za Prava Deteta' (or Child Rights Centre in English) is an Association of Citizens founded as a Non-party and Non-profit Association in Serbia. Lumos does not have a branch office in Serbia. Therefore the Child Rights Centre and Lumos signed a contract to partner in the implementation of the *Turning Words into Action* project. With the support of the project team in London and a member of the Steering

Committee, the Child Rights Centre has been implementing all of the required steps in project implementation. They proved to be effective and efficient by gaining crucial political commitment at the National Level to the work of the National Working Group and by employing a skilled professional to work at the local level with children.

The project started three months later than envisaged in Serbia due to the fact that Lumos had to establish these new contacts and agreements to implement the project.

CHANGE is a leading international human rights organisation based in the UK and led by Disabled People. To promote involvement of self-advocates in Steering Committee meetings, National Working Groups and Transnational Workshops, it is vital that they are provided with information which is easy to read and accessible for people with intellectual disabilities. It is important that young people have extra time to prepare for meetings to be able to participate and contribute meaningfully. CHANGE is best-placed to facilitate this important piece of the project work and ensure that the participation of young self-advocates is sincere. For this reason they have been assisting by developing easy read materials and methods that ensure better communication among participants with different abilities and capacities. CHANGE have also assisted and advised how best to involve self-advocates in project activities.

5. Equality. How did you make sure that equality considerations were taken into account? These can relate to ensuring an appropriate mix of people in your team, ensuring that all activities were accessible to all, making sure that all dimensions, in particular the gender dimension, were taken into account in your work.

Worldwide children and young people with intellectual disabilities are one of the most marginalised and disadvantaged groups. Institutions increase this segregation from society. This project aims to include all children by making its activities accessible and actively seeking their views. At every stage, we have sought to provide equal opportunities for boys and girls, Roma children and children with varying communication and accessibility needs. We have paid particular attention to ensuring that children living in institutions have the preparation they need to be able to participate fully in the child participation activities.

The composition of the National Working Groups provides opportunities for representatives of various backgrounds to contribute to social policy and decisions. The Steering Committee also has a diverse composition with policy makers, academics, civil society experts, service providers and beneficiaries. Gender balance is ensured.

6.Continuity. Is this action to continue after EU's financial support has come to an end? Please explain the next steps.

Lumos has offices and ongoing programmes in Bulgaria and the Czech Republic and is keen to ensure that the learning from this project is maintained in our programmes

in these countries by providing longer term support for the development of child participation after the project Turning Words into Action is finished.

Lumos intends to include children with more complex needs and this will require a longer term strategy which we intend to implement and maintain.

The project team is of the opinion that the project has sown the seeds for better ways of seeking the input of children with intellectual disabilities in policy and service design and we hope that the new multidisciplinary way of working, as exemplified by the National Working Groups linked to child participation groups, will lead to sustainable change in each country. This is just the first stage and more work is needed to ensure that this work is sustainable. Lumos would therefore suggest that a no-cost extension of 3 months would ensure that these new working methods and structures can be embedded to the best of their potential. A request to this effect will be forthcoming soon after the posting of this report,

There are promising signs that a formal commitment from the Serbian government to sustain and build on the work of this project might be made.

In the final phase of the project Lumos will ensure that the issue of sustainability of the project's activities and outcomes is prioritised.

Lessons learned and dissemination of results.

1. Outcomes and lessons learned. What are the most important outcomes and lessons learned from the action? What are the implications for relevant stakeholders? (such as the European commission; national /regional/local policy-makers, social partners, opinion makers including mass media, journalists; non-governmental organisations, academia, research institutions, think tanks, others where relevant

The true and meaningful inclusion of children with intellectual disabilities in policy making is an innovative and effective way of ensuring their rights are upheld. It has become apparent that Child Participation is a relatively new phenomenon in the project countries and that the concept itself required some adjustment. *To bring children with intellectual disabilities, many from residential institutions, together with policy makers at the same table and to have meaningful dialogue was a challenge.* The difference in power and status between the children on the one hand and the policy makers on the other could not have been greater. Nevertheless, the project is demonstrating that when young people are provided with sufficient support, meetings are structured in an appropriate way and if all participants approach the exercise in an atmosphere based on mutual respect and understanding, is possible to have meaningful dialogue and consultation which is beneficial to all participants.

2. Evaluation of the action. Did you carry out any evaluation of the action performed? Please outline the key findings and conclusions of such evaluation.

Implementation of the project has been monitored and evaluated on three levels.

Internal Evaluation:

- Regular meetings were held between Project Manager, Project Coordinator and Finance and Administration Officer discussing the implementation of the project.
- The Project Coordinator has regular teleconferences and meetings with the Local Coordinators in the three countries monitoring that activities are going according to the project plan and also discussing any practical challenges.
- Planned and ad hoc meetings are undertaken between the Project Management Team and members of the Steering Committee.
- Two Steering Committee meetings have taken place so far to evaluate the implementation of the project.
- Expert Mentors are providing their ongoing technical support to the National Working Groups.

External Evaluation.

- An external evaluator has been overseeing the implementation of the project since its start. [] an expert in this field with a psychiatry background has been participating at meetings and providing his expertise and advice ensuring that the project activities are being undertaken according to the project objectives. He has developed an evaluation framework for the project that is ensuring that project is on right track.

Social Experimentation.

- A Knowledge, Attitudes and Practice survey was developed and undertaken in all project countries by project participants, including young children from Child Participation groups. This study will not only provide an insight into what people know and behave around the topic, but will also allow for an assessment of the changes that happened during the project. The same survey is planned to be undertaken at the end of the project.
- Self-monitoring and evaluation tools are at the stage of being finalised. This tool will help National working Groups to assess the current situation regarding children with intellectual disabilities, prior and after the project cycle.
- These tools are planned to be implemented in three control countries, which will allow an assessment of the degree to which participating countries were able to improve the social inclusion and protection of children with intellectual disabilities through this project.'

3. News/Success/Best Practices. Please tell us about any news, success or if you have developed practices that you think others may want to know about or could benefit from. Please attach any relevant supporting information or material.

At this stage of the project, the most important success has been that the child participation groups are functioning well, with children gaining in confidence to express their desires and demand their rights. The National Working Groups are also showing promise as a good model of how young self-advocates with intellectual disabilities can be involved in the process of policy design and influencing. It is anticipated that the first transnational workshop, to be held in Bulgaria in September 2012 will gather together successes from the 3 countries and identify common challenges, successes and specific examples which will be collated and shared at a later date. It is also anticipated that the project will produce a training manual in child participation good practice based on the learning from the project.

4. Dissemination of findings. Please explain and describe how you involved relevant stakeholders during the action and whether there was any feedback.

It is anticipated that after the first transnational workshop has collated the various achievements and findings of the first phase of this project, that dissemination will commence in earnest. In all dissemination, special attention will be paid to ensuring that no child is placed in harm by any external communication and Lumos will apply its policies in this area.

Project information will be disseminated in the following ways to ensure maximum exposure.

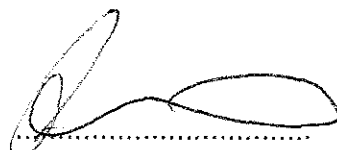
1. Web pages, which will contain free access PDF versions of each of the outputs and will also serve as a central point of information for the Better Health Better Lives Initiative. These web pages will be hosted as a subsection on Lumos" website, www.lumos.org.uk.
2. Production of the project outputs:
 - Newly developed or updated action plans for children with intellectual disabilities in each of the three countries. These will focus on one or more of the Better Health, Better Lives priorities as identified by working groups. An EasyRead version of each these plans will be produced.
 - A guide to national planning which will assist countries in translating the Better Health Better Lives Declaration's words into national action.
 - A guidance manual on the facilitation and active and meaningful participation of children and young people with intellectual disabilities in contributing to decisions which impact upon their lives. An Easy Read version of each these plans will be produced.
3. Further production of the self-assessment monitoring and evaluation too in other PROGRESS Country languages with wide distribution through supporting organisations such as WHO Europe and Inclusion Europe.

4. Production of 3000 data CDs containing all project outputs in all four project languages including the monitoring and evaluation self-assessment tool in other PROGRESS country languages.
5. Leaflets, posters and general advocacy materials will be produced in each country (total of 1,500) to support the messages of the child participation activities and advocate for the right and need of full inclusion for children with intellectual disabilities.
6. Publicity of the child-choice events (1 per country), which serves to make the inclusion of children and young people with intellectual disabilities in daily activities highly visible to the larger community.
7. Dissemination of project information and all outputs at a European level through supporting organisations such as, Inclusion Europe and WHO Europe. Project information and outputs will also be shared with the European Expert Group on the Transformation of Care from Institutional to Community Based Settings, of which Lumos is an active member. This will ensure wide dissemination across sectors and to organisations committed to the field of social protection.
8. It is also suggested, dependent on the outcomes of the project, that an OMC „peer review“ seminar be considered upon completion of the project to further disseminate information and increase collaborative mutual learning opportunities across Europe. Lumos would be prepared to contribute to this seminar even after the project has officially ended. It is likely that such a seminar would take place at the end of any no-cost extension which might be agreed with the European Commission.

All project events to date have featured clear European Union visibility. Similarly all publications will clearly mention that funding has been graciously received from the European Union using the phrase “with support from the European Union”. This will also be announced at all National and Transnational meetings and be printed on meeting handouts and used on power-point presentations. All communications, including the website, will clearly indicate that the sole responsibility lies with the beneficiary and that the Commission is not responsible for any use that may be made of the information contained herein.

9th of October, 2012.

Signed by Georgette Mulheir
for and on behalf of Lumos Foundation



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Chief Executive

11.10.2012.
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Date

