



Request for payment of the balance.

05.09.2013.

For the attention of
Olivier Rouland, Head of Unit

This request for payment of the balance is under the Grant Agreement between European Commission, DG Employment, Social Affairs and Inclusion and Lumos Foundation, UK for implementation of the project "Turning Words into Action: enabling the rights and inclusion of children with intellectual disabilities in Europe"

European Commission ref VS/2011/0161
Commitment no. SI2.598413
Call for proposals Ref.no. VP/2010/007
Application Ref.no. VP/2010/007/0035

Name and address of the Partner:
Ms. Georgette Mulheir, CEO
Lumos Foundation LBG
Berry Street 12-14
London EC1V 0AU
United Kingdom

Request for payment number: 3

Dear Sir,

I hereby request a remaining balance of the payment under the Partnership Agreement mentioned above. I certify that the information provided in this request for payment is full, reliable and true. The costs incurred are eligible in accordance with the agreement, and all receipts have been declared. The request for payment of the balance is substantiated by adequate supporting documents that can be checked.

The amount requested is [EUR 49 266.38] based on the budget below.

Please find attached the following supporting documents:

- *A final Report on the implementation of the action.*
- *A final financial statement of the eligible costs actually incurred.*
- *A full summary statement of the receipts and expenditure of the action.*
- *A certificate by an external auditor approving the action's financial statements and underlying accounts.*

12-14 Berry Street, London, EC1V 0AU, United Kingdom
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The payment should be made to the following bank account:

HSBC Bank PLC
22, Victoria Street, London, United Kingdom.
Lumos Foundation
IBAN_ ONLY

Yours faithfully,

Georgette Mulheir
for and on behalf of Lumos Foundation

Chief Executive

.....
Date



European
Commission

EUROPEAN COMMISSION
DG Employment, Social Affairs and Inclusion

Employment, social affairs and equal opportunities
Inclusion, socio-political aspects of migration, social integration policies

Call for proposals:	Call for proposals for Social Experimentations
Reference:	VP/2010/007
Budget Heading:	04.04 01 02

FINAL TECHNICAL IMPLEMENTATION REPORT

Application reference: **VP/2010/007/0035**

Agreement ref.: **VS/2011/0161**

SI2.598413

QUALITATIVE INFORMATION

Results

Original goals

List the original goals and objectives of the action as set out in the grant agreement, and explain how they were met during the implementation period. Please:

- focus on the results/outcomes of your action (i.e., benefits to the target group(s) addressed by your action);
- include detail on what change your action has brought about;
- explain the added value of the action, i.e., the lasting impact and/or multiplier effect.

Important: please note that all activities and deliverables must be presented not here but in the next box.

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

This final technical implementation report covers the whole project period between 19 September 2011 and 19 June 2013.

Throughout this report, findings from the Knowledge, Attitude and Practice (KAP) survey have been included to illustrate the impact of the project and highlight areas of concern. The KAP survey was completed by National Working Group Members and Children and Young People with intellectual disabilities. It is explained in more detail in section 2 of this report.

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

The following activities, as outlined in the project description for this objective, have taken place:

1. Child Participation Activities

Groups of children and young people with intellectual disabilities were formed in Bulgaria, Czech Republic and Serbia and the groups met regularly. Forty-nine children and young people with intellectual disabilities took part. The children and young people lived either in residential institutions or with their families and included Roma children. Over time the group co-ordinators explored new ways of working with children with intellectual disabilities so they could express their opinions and views more widely. This process is further described in Section 2 of this report and the experiences of the co-ordinators have been collated in the online publication, "Listening Together". The impact on the self-esteem and confidence of the children to express their own thoughts and ideas has been noted by the children themselves, parents, staff who work with the children, the external evaluator and policy makers and evidenced by the KAP Survey.

"Thanks to the project, I realised that we, all young people and adults, can fight for our voices to be heard." Testimony from a young participant in Serbia

"This project definitely changed my daughter. First of all, she is pleased with all her 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

KAP Survey Result: At the beginning of the project, only 20% of the Bulgarian and 50% of the Czech children and young people surveyed agreed with the statement, "Everybody is different; it's OK to have a disability." At the end of the project this figure had risen to 50% in Bulgaria and 80% in the Czech Republic. This can be taken as an indication of the rise in self-esteem and self-awareness of the children and young people who took part in the project.

The child participation activities also enabled the children involved to improve their skills, for example in communication and socialising with others.

"My daughter has positive expectations for each group activity. She can hardly wait and keeps asking me when the next one will be. For years, my husband

and I faced big barriers in supporting her communication and socialising with others. Thanks to this project, her communication has got a lot better." A mother speaking about child participation activities in Varna, Bulgaria

2. Children's Feedback on the Better Health, Better Lives (BHBL) Declaration

Better Health, Better Lives is a World Health Organization (WHO) Europe Declaration which is grounded in international human rights Conventions including the Convention on the Rights of the Child and the Convention on the Rights of People with Disabilities. Its ten priorities offer a common framework for all European countries to approach deinstitutionalisation, establish community-based services and promote respect for the rights of children and young people with intellectual disabilities. It also contains an action plan that gives a general framework for building the Declaration's priorities into national policy and practice.

Children and young people were supported to be able to understand and give their opinions about the WHO's Better Health Better Lives (BHBL) Declaration. These views have been collated in the **easy-read children's publication "Our Words. Our Actions"** which will be widely disseminated to raise awareness of this international agreement as an important tool to deliver equality and human rights for children and young people with intellectual disabilities.

KAP Survey Result: At the beginning of the project, 30% of the Bulgarian, 50% of the Czech and 67% of the Serbian children and young people agreed that, "The government in my country takes good care of children with disabilities." This figure had dropped to 0% in Bulgaria and Czech Republic and 43% in Serbia by the end of the project. This is a significant result which indicates that by learning more about their rights as contained in the BHBL Declaration, the young people could assess that their countries need to do more to ensure that their rights are respected. This can also be taken as an indication in the rise in confidence of the children and young people to speak out about their needs and demand more of their governments. This is a first step towards becoming active citizens.

3. Child Participation at National Working Group Meetings

Children and young people with intellectual disabilities actively participated and shared their views about the BHBL Declaration at National Working Group Meetings on an equal basis with policy-makers and other key stakeholders. These Working Groups dedicated themselves to developing national ideas and plans to implement the BHBL Declaration in each country. In Serbia this has led to a National Action Plan for BHBL Implementation which has been endorsed by the Ministry of Health, in the Czech Republic, changes in practices within institutions at the local level and in Bulgaria, specific commitments on inclusive education policies and youth participation. (These outcomes are further described under objective B of this report.)

The involvement of children with disabilities in such a forum represented a new way of working in each of the project countries which was widely praised by all participants. For example, a director of a special school in the Czech Republic, involved in the National Working Group meetings said: "For many years we've been learning all these different methods and ways of working with children, now I understand that we were missing the main piece: the children's opinions and participation."

KAP Survey Result: At the beginning of the project 86% of Serbian National Working Group respondents agreed with the statement, "People with disabilities cannot contribute to the economy". By the end of the project this had fallen to 36%. This could be explained by the positive contributions made by the children and young people at project meetings which demonstrated their capacities.

4. Child Participation at the Steering Committee Meetings and Transnational Workshops

Children and young people with intellectual disabilities also actively participated in the three Steering Committee Meetings and the two Transnational Workshops. These international forums gave the young people involved an opportunity to share their views with experts and their peers from other countries. They were able to express what they thought governments

should do to implement the EHRL Declaration because the Declaration and the role of the government in implementing it had already been widely discussed in the regular child participation meetings.

Through meeting other self-advocates from other countries, including experienced adult advocates with intellectual disabilities, they were inspired and supported to promote the rights of their peers. Special attention was paid to preparing the young people for each of these events so their involvement was not tokenistic. This is further detailed under objective C below.

In particular, the impact on politicians of this new way of working directly with a marginalised target group was noted. For example, at the Transnational Workshops, politicians spoke only after the children had formally opened the event, meeting agendas were only provided in easy-read formats and all speakers were asked to adapt their speeches to their audience.

The following quote from a Bulgarian politician speaking at the first transnational workshop illustrates how the new opportunities provided by the project changed attitudes among policy-makers and provided a forum where the abilities of children with intellectual disabilities could be demonstrated. It is hoped that this has laid the foundations for a new way of working in the future.

"I was wondering how to begin, but listening to your words reminded me how much better if we, politicians, spoke less and you, children and young people, spoke more. We will understand and fulfil the meaning and purpose of child participation better - and it is still not a well understood concept in many countries, not only in Europe but around the world. Listening to you, I have to admit I was very moved, because the issue of children and young people with intellectual disabilities is not well understood. I was reminded how much more meaningful and powerful it is when you, the people directly affected, speak about this issue to convince those who are not yet sufficiently prepared to understand your problems and accept you as part of society, as the worthy and diverse citizens that you are. We want to hear your opinions; for you, who have concrete ideas, to talk instead of us, so that we can execute your suggestions, your solutions and your wishes, because we have been elected to work for you." **Chairman of the Bulgarian Agency for Child Protection speaking at the TWIA Transnational Meeting in Sofia, September 2012**

5. Child Choice Events

Child-Choice events were organised in each of the three project countries. These events were planned and delivered by the children themselves giving new levels of visibility for children with disabilities in their communities and nationally. These events, which are further detailed in Section 2 of this report, included: a bus tour, "The Tour of Dreams", to share their views with youth groups and politicians in towns across Bulgaria, culminating with a meeting with the State Agency for Child Protection in Sofia; a high-profile awareness-raising event in a shopping centre in Serbia where children with and without disabilities painted messages of solidarity in a public art project and a community-focused event with a rock concert by a band made up of people with and without disabilities in the Czech Republic.

Each event, in a different way, brought children with intellectual disabilities greater visibility in their communities and raised awareness of the daily challenges that they and their parents face. Every event was covered by the media. The tour in Serbia featured statements of support from senior politicians. The Tour of Dreams in Bulgaria ended with statements of support from the State Agency for Child Protection. Speaking at the Child Choice Event in Belgrade in December 2012 Zoran Kovacevic, Deputy Minister of Health Serbia said, "This project, by showing how we can work together, create together and live together, not only explains what an inclusive society is, it also shows how working this way is the best way to break down barriers and prejudice." These events are currently being captured in an animation, voiced by one of the children from the project group in Bulgaria. This will be posted on the Lumos web site in Autumn 2013.

6. Publications

In line with the project description, various publications have been produced and will be made available online at www.wearelumos.org during Autumn 2013. These are outlined in full, together with a dissemination plan in Section 4 of this

report. These include: "Turning Words into Action", a guide to using the BHBL Declaration for National Planning involving children with intellectual disabilities which contains a summary of how the project influenced policy in each country; "Our Words, Our Actions", a children's publication in easy read format sharing the children's view of the Declaration, their experience of the project and their messages to policy-makers and "Listening Together", a web based resource containing practical advice and ideas for creating a suitable environment for child participation. Each of these publications, and other project outputs, are intended to demonstrate the benefit of the model of consultative participation which this project trialed.

The added value of these activities is:

This project trialed, in a relatively small scale over a short period of time, a new way of working with children with intellectual disabilities to best influence policy and practice. These experiences have been gathered together in three main publications and other outputs in order to ensure that the learning and experience can inform and guide others seeking to build new innovative models of consultative participation.

All of the activities of this project shared the same ultimate aim, to bring about improvements in the quality of life and the services received by children and young people with intellectual disabilities and their families. To raise awareness among policy-makers of the needs and concerns of their citizens in this area and to empower children and their families to express their views, actions were taken to establish a completely new model of consultative participation in each of the project countries. A guiding principle for this work was that an increased awareness of the needs of children with intellectual disabilities would lead to more cost effective, sustainable services which would be relevant to children and families.

• Child participation in National Working Group meetings led to an increased awareness of the needs of children with intellectual disabilities and this should lead to better quality and more inclusive policy and decision-making in the future. For example, the Serbian Ministry of Health has committed to implementing the National Action Plan for Implementation of the BHBL Declaration which was drafted by the project's National Working Group with active involvement of children and young people.

"People and especially children with intellectual disabilities are treated in Serbian society as a group which needs care and the State has done a lot to improve the help they receive. But the majority of these measures are planned for them not with them. We welcome the Turning Words into Action initiative precisely because it requires the full participation of the beneficiary group and we hope that this practice will become a model for the future." ~~Representative~~ **Representative** Social Inclusion and Poverty Reduction Unit of the Ministry of Health, Serbia (SIPRU) Representative speaking at the first NWG meeting.

• Regular child participation activities built the confidence of children and young people with intellectual disabilities and this, together with their involvement in National Working Groups, transnational activities and child choice events have exposed them to new possibilities and enabled them to demand better health, education and employment opportunities. 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. This is evidenced by the increase in confidence and changing aspirations of the young people involved, many of which are collated in the publication, "Our Words, Our Actions". One such quote is included below.

"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.**

• Better relationships between people with and without disabilities in the community were achieved, as evidenced by the three child choice events, each of which focused on raising awareness among the general public about the needs of children with intellectual disabilities and children living in institutions.

These events received positive media coverage. It is hoped that such changes in attitudes will contribute to increased visibility and improved social inclusion of children with intellectual disabilities.

KAP Survey Result: There is some evidence of a shift in the perception of the public attitude towards disability during the project period. At the beginning of the project only 50% of Czech National Working Group respondents agreed that people in their society were "welcoming to individuals with intellectual disabilities". This figure had increased to 64% at the end of the project. However, such a change was not noted in the other project countries.

KAP Survey Result: In the Czech Republic, 50% of the children and young people with intellectual disabilities questioned at the beginning of the project agreed that "people often ignore or avoid me"; this figure had dropped to 20% by the end of the project. In Serbia meanwhile, the figure dropped from 100% to 57%. This indicates a major shift in the children's perceptions of the attitudes of the wider community which could be a reflection of their positive experiences of engaging with the community through the child choice events and other activities. However, it is worth noting that similar results were not recorded in Bulgaria.

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

The following activities have taken place:

1. Formation of a multi-sector National Working Group in each country.

In order to establish the membership of the National Working Group in each country, 53 individual and group meetings were held in the project countries to introduce the project and its objective of getting the BHBL Declaration onto the national agenda. Once these meetings had taken place, the National Working Groups were formed. As detailed in Section 2 of this report, membership was different in each country to reflect the national policy context. In each case, however, they comprised a cross-section of policy makers in various levels of government and local authorities, service providers, NGOs, international organisations such as WHO and UNICEF, families of children with intellectual disabilities and young people with intellectual disabilities themselves.

Once established, each National Working Group set to work to identify and influence policies and practices for the benefit of children and young people with intellectual disabilities, in line with the BHBL Declaration.

2. National Action / National Working Group Meetings.

In each country, the National Working Group analysed the BHBL Declaration to identify where national implementation was lacking. An analysis of the political environment and opportunities for influence in each country enabled the National Working Groups to effectively target their proposed action.

This call for action took the form of: a new National Action Plan in Serbia focusing on the Declaration as a whole; suggested improvements to existing plans and policies in Bulgaria, notably related to education policy and specific improvements to local policies and practices in institutions and a list of recommendations for national action in the Czech Republic. Children's and young people's views on the Declaration and how its priorities are implemented in their lives have been reflected in these documents.

Each country's experience and key outcomes are detailed in turn below:

Serbia:

Key Recommendations for National Action from the Serbian National Working Group

-Full implementation of the National Action Plan developed by the National Working Group

-To incorporate text from the National Action Plan across a range of legislation and instruments

-Properly accessible community-based services for all

-To extend the application of child participation for all children with intellectual disabilities, both in policymaking and other areas of their lives

A formal National Working Group was set up under the auspices of the Ministry of Health and was responsible for the development of an official National Action Plan. The group included members of the relevant ministries (Health, Social Policy, Education, and Local Government), the Centre for Child Rights, a number of other non-governmental organisations, institutions working with children with intellectual disabilities, family organisations and young self-advocates. The Group met four times.

The group determined priorities and, given the limited time available, decided to focus on reforms within the healthcare system and on the coordination of services.

The draft National Action Plan produced by the group is currently being revised by the Ministry of Health. This National Action Plan details how to address all ten priorities of the Declaration which the Ministry of Health will adopt and oversee its implementation after revision. Some of its recommendations have already been taken forward. For example, the Ministry of Health has committed to building an education programme for medical practitioners on developmental issues relating to intellectual disability, such as early identification of disability and child/family friendly communication methods. A reference to the new National Action Plan has been made in the new draft National Strategy for Protection from Discrimination.

All involved in the process have made clear their determination to ensure it does not stop now. The National Working Group will continue to meet formally after the end of the TiwA project to ensure the recommendations in the Action Plan are incorporated into policy and followed through in practice at an institutional and community level.

The Action Plan was developed under the Ministry of Health but its recommendations for other ministries are not binding. The group, however, which includes representatives of those ministries, will continue to meet and advocate for their implementation.

KAP Survey Result: A significant change in attitude towards institutions among members of the National Working Group in Serbia was noted during the project. At the beginning of the project 58% disagreed with the statement, "Children with intellectual disabilities are better protected from verbal abuse and humiliation in institutions rather than in the community." This had dropped to 33% by the end of the project.

KAP Survey Result: At the beginning of the project, 40% of Serbian National Working Group respondents agreed with the statement, "Some children with intellectual disabilities are unelectable." This had dropped to 0% by the end of the project. More analysis of the reason for this major shift in attitude is required, but it could be explained by the inclusive child participation methodology of the project having demonstrated the capacities of young people with intellectual disabilities.

Bulgaria:

Key Recommendations for National Action from the Bulgarian National Working Group

- Raise public awareness about disability and support inclusive education for all
- Integrate child participation at all levels of society and provide training to parents, carers, practitioners and all other relevant stakeholders
- Encourage partnerships between stakeholders

- Create competition between NGOs in service provision to improve the quality of the services
- Improve conditions for health and social work practitioners
- Improve support to parents and carers
- Create a common register for all children and young people with intellectual disabilities
- Establish 'cradle to grave' structures of care focused on the needs of the individual
- Make transport and facilities accessible
- Open crisis centres
- Provide social services for those over the age of 18
- Create part-time work opportunities for parents and for young people with disabilities

The National Working Group in Bulgaria looked at existing policies and national action plans and ways to influence their implementation in line with the rights contained in the BHRL Declaration. As a National Action Plan for Vulnerable Children already existed, it was not appropriate to develop a new plan. However the group identified opportunities to ensure that the needs of children with intellectual disabilities could be better represented in the existing plan and in policies and practice. For example, the group developed a series of key recommendations for improving the existing National Action Plan to address the lack of practical measures they had identified related to children with intellectual disabilities. Following discussions with National Working Group members, the Ministry of Education agreed to include measures addressing the support needs of children with disabilities within the inclusive education section of the new Draft Education Act. This had been identified by the National Working Group as a key area of concern. Another outcome of the National Action activity of the Bulgarian National Working Group was a commitment from the government to develop vocational and independent living opportunities for young people with intellectual disabilities. A working group has been set up to develop these plans.

"Following our involvement in the TWIA project, where the State Agency for Child Protection and the Agency for Social Assistance were also involved, we've together set up a working group to develop a new Programme to help children and young people with disabilities build skills for an independent life."

Mrs ~~XXXXXXXXXX~~ Head of the Department of Child Protection - Ministry of Labour and Social policy/Agency for social Assistance and a member of the TWIA National Working Group (speaking in May 2013)

Note: At the time of writing, (July 2013), political instability in Bulgaria is causing some uncertainty regarding the legislative timetable for these policy developments. It is hoped that the multi-sector and consensual nature of the National Working Group will ensure that these commitments are upheld. Lumos founded and is actively participating in a new coalition of organisations "Children 2025" which is seeking to ensure that children's rights and deinstitutionalisation remain on the political agenda.

Czech Republic:

Key Recommendations for National Action from the Czech National Working Group

- Increase autonomy and self-determination of children with intellectual disabilities both in residential institutions and in family environments
- Change the attitudes of service providers
- Increase cooperation between education and social protection providers
- Facilitate the sharing of good practice between peers, especially through site visits to social care homes and services.
- Support self-help and self-advocacy groups for children and parents

- Establish a Children's Ombudsman
- Update the Framework Education Programme for special schools
- Ban any further placing of children in institutions on the basis of contracts with parents

In the Czech Republic, Lumos worked with project partner Pardubice County to implement the TWIA project. Some 100 kilometres from Prague, Pardubice County is a pilot county in a National Project working on the transformation of systems of care for vulnerable children. It is home to a large-scale residential institution which has been identified as a particular priority for deinstitutionalisation given that children live there together with adults, putting them at risk of harm. Children living there are currently being prepared for a new life in family-based settings and small group homes.

National Working Group members agreed on the need for action and for a working group to coordinate it, but also felt strongly that the process should be a Czech one in order to meet the specific needs of the country. Attitudes towards deinstitutionalisation in the Czech Republic are sometimes negative and the group felt that a clear basis for it in local practice and local advocacy needed to be developed which could then influence and inform national processes. After the project had already begun, the central government in the Czech Republic made a commitment to deinstitutionalisation under the 2012-2015 National Strategy to Protect Children's Rights. This opened up the way for more fruitful action at national level, building upon the work done in Pardubice County.

This optimism was confirmed by the commitment shown by high-level government representation at the second transnational workshop in Prague. Key-note presentations highlighting the importance of the rights of children with intellectual disabilities included: Head of the European Commission Representation in the Czech Republic, Jan Michal; Deputy Minister of Education, Jindřich Fryč; Government Ombudsperson for Human Rights, Monika Šimůnková; Deputy Minister of Labour and Social Affairs for social inclusion and equal opportunities, Jan Dobeš and Vice-President of the Senate and member of the project's National Working Group, Miloš Horská.

As a result of the project, Pardubice County have made commitments to share their experience, tools and methods learnt on Child Participation with other counties and children's institutions. In so-doing, it has laid the foundations for policy and practice improvements across the country. The National Working Group has developed draft recommendations which it is hoped can be used to improve existing National plans and policies regarding children with intellectual disabilities in the future. The project experience of the Czech Republic is notable for the direct impact that was noted on staff behaviour and procedures within institutions, as evidenced by the following quotes.

"We would like to keep up these activities, maybe with a bigger group, and even extend them into other residential care services. We are already thinking about the sustainability of these activities for children and young people more generally. [Given appropriate support] we would like to create a kind of network of workers with pedagogical training or experience in working with children. We could then easily spread this initiative to other institutions in Pardubice County, for example. Our manual could be very useful for them in providing some idea of where to start, what to focus on and what to achieve." **Head of Direct Care, Pardubice County.**

"Our experience of communicating with children with difficulties and identifying their views is growing. We are doing our best to make it a common part of our county experience. We see it as a priority to prepare young people for reintegration. We would like to use [the child participation approach] in other institutions and share it with relevant stakeholders in neighbouring counties." **Director of the Social Affairs Department in Pardubice County**

KAP Survey Result: An interesting change in attitude of children and young people to institutions was noted in the Czech Republic during the project. At the beginning 100% of the children and young people surveyed agreed that, "Children are treated well in institutions." This figure had fallen to 50% by the end of the survey. Given that some of the Czech children and young people surveyed lived in institutions, this could be a reflection of an institutionalised culture where there were previously few opportunities to express opinions.

Following the project activities and the change in approach of the institution staff to encourage meaningful participation as outlined above, their confidence to share their own opinions would appear to have increased; in addition this change in attitude could be explained by the project having increased their awareness of their own rights and alternatives to institutions (for example by having met children and adults with intellectual disabilities from other countries who grew up in family environments). It could also be that those children surveyed who do not live in institutions, changed their positive attitudes towards institutions after interacting with their peers from institutions.

3. Transnational Workshops

As envisaged in the project description, two Transnational Workshops were held during the project cycle. (Sofia, Bulgaria, in September 2012 and Prague, in the Czech Republic in January 2013). There were more than 65 participants at each event, including senior government officials and representatives of the European Commission (which hosted the meeting in Prague), as well as (in Prague) Baroness Sheila Hollins, Chair of both the Steering Committee for the BHBL initiative and of the TWIA Steering Committee.

These workshops were intended to support the aim of the social Open Method of Co-ordination (OMC) of the European Union "to improve coordination, cooperation and agreement of the necessary principles and actions between all stakeholders involved in the development, implementation and monitoring of social policies."

Specifically, they offered National Working Group members from all three project countries, including young self-advocates, an opportunity to share their experiences of implementing the project and influencing national policies and processes. Expert mentors and steering committee members also provided insights and knowledge from other countries which had already undergone reforms of their institutional systems of care.

The Transnational Workshops also provided a forum where senior government officials publicly demonstrated their support for the rights of children with intellectual disabilities. At the first workshop, the Chair of the Bulgarian State Agency for Child Protection delivered a supportive speech on behalf of the government. In Prague a verbal commitment to the equality and human rights of children with intellectual disabilities was provided by the Deputy Ministers of Education and of Labour and Social Affairs as well as a Government Ombudsperson for Human Rights.

A significant outcome of these meetings was that the young self-advocates involved were supported to produce their own common policy recommendations during these events. These recommendations have been summarised in the child publication, "Our Words, Our Actions". The process by which these meetings were organised is summarised in section 2 of this report.

4. Child Feedback on the Declaration

A children's publication in easy read format, "Our Words, Our Actions", has been produced to share the children's views of the BHBL Declaration, their experience of the project and their messages and key recommendations to policy-makers. It has been translated into various languages and is intended to inform future national policy processes in the project countries and elsewhere in the Region. Notably, related to this specific project objective, the children made strong statements stressing the importance of deinstitutionalisation, for example:

Promise 1: Keep all children safe

"Children should be protected at all costs"

"Children should be able to play, go for walks and feel safe everywhere!"

"Ensure that all parents treat their children well"

Promise 2: Support children to grow up with families

"I think helping families should be a priority - when a child is born with a problem, parents have to be helped by specialists."

· *"Everybody should have a family and live with their family."*

· *"When you're with your family you feel safe and there are people you can rely on."*

Promise 3: No child should live in an institution

· *"Every child needs a kiss goodnight."*

· *"We want to be supported to live independently in our communities - not segregated in large residential institutions."*

· *"Close all institutions, the children's place is in the family!"*

5. Self-Evaluation Tool

A web-based self-evaluation tool has been developed to help National Working Group members and others assess a country's level of implementation of the BHBL Declaration of policy and practice. Originally intended to be developed at the beginning of the project and also act as a project monitoring tool. The tool was developed over the course of the project incorporating the learning from the National Working Groups and the Transnational Workshops with a view to it having sustainable impact after the project.

It has been tested in Serbia, the Czech Republic and control country Moldova and will be tested in Bulgaria before being finalised in autumn 2013. Lumos is committed to developing this tool as an aid for those who wish to identify gaps in policy and practice related to the rights of children with intellectual disabilities. The tool has been translated into various languages and will be disseminated widely after being finalised.

The process and the logic for the change related to the project description are described further in Section 2.

The added value of these activities is:

· The project was designed to allow National Working Groups to respond appropriately to differing national contexts when deciding National Action. Each National Working Group, formed of people who knew their own national context well, was able to put in place the best strategy for having the most potential impact on influencing policy and practice. This is reflected in the three different approaches taken to National Action in each country which are further described in the publication "Turning Words into Action."

· The multi-stakeholder nature of the National Working Groups (membership included policy makers, civil society, academics, practitioners, children and parents) was new to each country. Participants learnt and demonstrated new ways of working together in a multi-disciplinary way

· The involvement of children, already prepared with their key messages about the Declaration and inspired about its potential, gave the meetings immediacy and ensured that they were focused on outcomes. (The clear messages provided by children on the BHBL Declaration have been summarised in the publication, "Our Words, Our Action").

· It is hoped therefore that the project has established a precedent which could lead to such a multi-stakeholder model being adopted as a sustainable approach and better policy design and implementation in the future. The following quote expresses the added value of the project's way of working in terms of better policy outcomes for children with intellectual disabilities:

"When the National plan for the healthcare of women, children and youth was adopted we knew that more was needed to address the healthcare needs of the most vulnerable groups. Turning Words into Action will enhance these efforts and guide us to develop other new measures. It will also help us stress the importance of developing better inter-departmental cooperation so that we can deliver a holistic approach to match the needs of each child and each family." Dr. ~~XXXXXXXXXX~~, Deputy Minister of Health, Serbia speaking at the start of the project

· The Self-Evaluation tool was designed to be a useful resource for all European countries (governments and civil society alike) seeking to evaluate the implementation of the BHBL Declaration and assist in planning national

action or advocacy campaigns on related themes even after the project is finished.

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

The following activities have taken place:

1. Formation of multi-sector collaborative Steering Committee, National Working Groups and Child Participation Groups

Three National Working Groups were 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 were supported by expert mentors, who as detailed in the project design, provided their technical expertise and advice to the groups.

Members of the National Working Groups engaged in a unique practice where they designed plans together with children with intellectual disabilities and learnt from them. For example, in the words of the Serbian National Working Group itself, in its report, "in this project there was a prevailing sense of partnership between stakeholders. Our conclusion is that it is important both to include as many stakeholders as possible and to have clear leadership by the responsible ministry or community decision-maker, as well as NGO facilitation."

A multi-sector Steering Committee was established to oversee the implementation of the project. It met three times in London to discuss the progress of the project and to provide technical support towards successful achievement of its objectives.

Members of the Steering Committee comprised experts in the area of intellectual disability, many of whom contributed to the development of the original BHBL Declaration and to the design of this project. All project partners were represented on the Steering Committee.

This group was chaired by a member of the UK House of Lords, [REDACTED] who also jointly wrote the foreword to the project publication "Turning Words into Action" together with a young self-advocate from Bulgaria. This, in itself is a strong demonstration of the spirit of co-operation between policy-makers and young people which the project engendered.

2. Transnational Workshops

Two Transnational Workshops were held during the project implementation period. They were attended by over 65 participants each. This included children and young people from the child participation groups representing each of the three project countries, families and carers of children with intellectual disabilities, service providers, academics, professionals, policy-makers from senior government and the project management team. These meetings provided an excellent opportunity for cross-country learning and sharing of experiences and created a space for a collaborative, fun and participatory approach to learning and policy planning.

The following quote from a mother of a child with an intellectual disability highlights the positive impact of transnational learning:

"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

3. Child Participation Activities

A specific collaboration, not part of the original project description, which has been invaluable to the project's child participation activities has been the involvement of CHANGE[1], a UK based human rights organisation led by disabled people.

CHANGE worked with the young people in advance of each steering committee and transnational workshop to help them prepare for those meetings and also helped design accessible and appropriate meeting formats, agendas and materials. They also developed the easy-read project publication, "Our Words, Our Actions" which encompasses the views and opinions of the children and young people about the project and the BHBL Declaration.

██████████ is a self-advocate from CHANGE. An adult with an intellectual disability, ██████████ is an experienced trainer and has spoken at many high-level events. Together with the CHANGE team, ██████████ worked directly with the young people, enabling them to use drawings, prepare speeches and engage in discussion in large, mixed groups of professionals, advocates and politicians.

For many of the children and young people involved, ██████████ was the first adult with an intellectual disability that they had met who was confident and able to speak about the rights of people with intellectual disabilities. As ██████████ outlines below, this has encouraged and supported the young people, many of whom now wish to continue to work to promote rights after the completion of TWIA.

"The children and young adults involved in the project are growing in confidence. They are developing skills in becoming powerful self-advocates. The Project has given them role models such as myself and they will go on to be role models in their own right. It's like passing the torch on!" ██████████

██████████ CHANGE, speaking at the Transnational Workshop, Sofia, September 2012.

The added value of these activities is:

- That the Steering Committee was chaired by and involved several experts who had also been involved in the drafting of the BHBL Declaration. It helped them offer advice to National Working Groups and the project team on project implementation. It is hoped that members of the committee will continue to offer advice related to BHBL implementation, for example by helping to adapt and disseminate the Self Evaluation Tool.
- Involvement of experts from other countries which have already undergone the process of deinstitutionalisation (e.g. CHANGE as a UK-based organisation, and members of the Steering Committee) ensured that these experiences could be shared.
- The good practice, as demonstrated by CHANGE, which is further outlined in the publication "Turning Words into Action" and section 2 of this report, inspired both the young self-advocates and other participants in the project countries to adopt similar inclusive practices and support the younger self-advocates. This approach helps to build sustainable child participation groups and also should assist these older young people involved to move on to other opportunities after the project.
- National Working Groups in each country were new structures which had not existed before. The Group in Serbia is being maintained by the Ministry of Health. In Bulgaria and the Czech Republic, Lumos plans to continue to support these groups, so that they can continue to influence policy and practice. Regular meetings of the Child Participation groups established by the project will be maintained by Lumos in Bulgaria and the Czech Republic and by the Child Rights Centre in Serbia and further international opportunities for the young people involved have already been planned. (See the Continuity section (6) of report for more detail).

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

The following activities, as outlined in the project description for this objective, have taken place:

1. National Working Group Meetings

A unique feature of the National Working Group meetings was that the children and young people who participated were already informed of their rights under the BHBL Declaration (through the child participation activities) so were ready to use the Declaration as a tool with which they could advocate for their rights. The three Local Coordinators explored existing legislative and rights based frameworks with the children in a disability and age-appropriate way.

They worked 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 assisted the young people to communicate their rights and look at ways to deliver this understanding to professionals and policy makers.

This 'translation' of the ten priorities into easy to understand and vocalised 'promises' enabled the children and young people involved to share their views on the Declaration at National working Group Meetings. Notably, the children made particularly strong statements related to the importance of growing up in a family and not in an institution. Policy-makers therefore witnessed, in person, how these international agreements can come to life if advocates are empowered to claim the rights that they contain.

The children and young people's views have been summarised in the project publications "Our Words, Our Actions" and "Turning Words into Action". These publications will be translated and widely disseminated to policy makers in other countries and at the European Union level to strengthen the awareness of the BHBL Declaration and also share experiences on how similar international human rights agreements could be brought to life and demystified through similar consultative and participatory processes.

2. Transnational Meetings

Participants of Transnational Workshops came together to share their experiences of interpreting the BHBL Declaration and to come to a common understanding of how best to involve children in its implementation.

Both workshops were opened and closed by children and young people with intellectual disabilities so that all workshop participants could get a clear idea of what self-advocates thought about the project and the Declaration and how they would like their lives to change.

At the first workshop, children prepared banners and presented them at the end of the event. In the second workshop, they delivered a play telling the story of the Turning Words into Action Project, which incorporated simple demands based on each of the BHBL's 10 priorities which were written on paper aeroplanes and sent in to the audience.

These meetings, therefore, demonstrated a model of Child Participation linked to the implementation of an international human rights agreement which could act as inspiration for others. They also demonstrated that different languages need not be a barrier and messages can be conveyed through pictures, actions or simple slogans.

3. Child Visibility through National Action and Child Choice Events

Priority 7 of the BHBL Declaration describes the importance of involving children and young people with intellectual disabilities and their families in its implementation. It is key therefore that the views of children and young people with intellectual disabilities are in the public domain so that policy-makers can be held to account.

The views expressed by the Children and Young people involved in the project have been collated in the publication "Our Words, Our Actions". Similarly, the Child Choice Events planned and implemented by the Young people themselves, showcased the views and demands of the children and young people to the general public and were covered by the media in each country. This will help to raise public awareness of the international human rights commitments made by governments and the rights and aspirations of children with intellectual disabilities, including the importance that they address to

deinstitutionalisation. The following quote illustrates their desire to change public attitudes:

"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 with intellectual disabilities, Serbia.**

The added value of these activities is:

- Media friendly activities, such as the three child choice events were designed to increase awareness among the public of the rights of children with intellectual disabilities, the realities of life for children in institutions and also of the international commitments that national governments have made to their human rights.

- The involvement of children both living with families and living in institutions ensured that the children and young people were able to explore their different experiences and clearly express the drawbacks of an institutional system of care. For example, the following quotes from young people at a child participation group meeting related to the lack of educational opportunities in institutions:

"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." *"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 the 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 people with intellectual disabilities, Bulgaria**

- The various project outputs (publications, animations, short films etc) will raise awareness of the EHBL Declaration and the rights it contains among policy makers and other key stakeholders across Europe. They will also raise awareness of the key issues of importance to children and young people with intellectual disabilities themselves including better healthcare, more job opportunities and an end to institutionalisation - all key principles of the EHBL Declaration. Finally, the publications, by showcasing the participative nature of the TWIA project, will serve as a reminder of the importance of meaningful participatory consultation in any national implementation of any such international agreement, the value of sharing experiences transnationally and offer some guidance for those seeking to implement similar projects.

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 and/or component of your action.

Activity

Planned

Please shortly present your project plan/activity plan as outlined in the approved action grant agreement.

Child Participation Activities

"Activities will aim to integrate children with intellectual disabilities and their families with their non-disabled peers, raising community awareness and demystifying disability through demonstration of meaningful participation. The guiding principle of these workshops will be to provide opportunities for children with intellectual disabilities and their families to have fun, participate in community activities not often afforded to them and to be seen and heard by members of their ordinary communities. Importantly, all workshops will also include time for consultation of children with intellectual disabilities on the action plan through meaningful opportunities to communicate their views, needs and wishes in a manner appropriate to their individual skills and communication styles." (TWIA Project Description).

Implemented

Please describe the activities and deliverables in the action

Child Participation

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

In each country, child participation activities were designed to be open and welcoming to their wider communities in order to promote positive views of disabled children and young people, and better integrate children with and without disabilities. For example, in Serbia children without disabilities from institutions and the community also took part in meetings, in Bulgaria siblings and friends also participated. In the Czech Republic and Bulgaria in particular, parents were also actively involved.

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 positively on identifying and supporting each individual's strengths and potential rather than on their disability. Over time, the three local coordinators organised activities through which the children practised 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 observed and reported that self-esteem and confidence of their children had been enhanced from knowledge, new skills, stimulation and support that were provided for them.

Gradually when children were comfortable with these new experiences and different group activities, they had sessions to learn about their rights, about the EHRL Declaration and its ten priorities and what it means for them in their everyday lives.

Two of these young people in each country were supported to take part in two Transnational Workshops and at least four National Working Group meetings with policy makers and service providers to influence policy and practice by expressing their views and opinions on matters that affect their lives. Two young people with intellectual disabilities participated and contributed to discussions at three Steering Group Meetings. They shared not only their views on the progress of the project but also views and voices of children and young people in Child Participation groups in Varna and Belgrade. To ensure that their participation was not tokenistic, special preparatory meetings were organised for the young people, supported by CHANGE. These are described further in the *changes* section of this chapter.

By participating at these high level meetings, the young people became aware of different perspectives, making compromises and of how to influence change. Through practical experiences and opportunities, they learnt how to advocate for their own rights and also the rights of other young people with intellectual disabilities, particularly those living in institutions or who were less ready to participate. The following quote from a young person in Bulgaria, illustrates the personal impact the child participation activities had.

"The project helped me to grow and to be useful to the others. I have become braver, more confident. I felt that people listen to what I told them. This helped me to be a more thinking, independent and analyzing person. The project opened to me the door to society, gave me the opportunity to realize my goals.

Through the project my new friends and I met politicians and influential people to whom we gave the task to think about us and to prevent us from becoming people without direction and future when we graduate from school." **Young person from the Child Participation Group in Bulgaria.**

In a parallel process, during the project period, the three 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.

"These child participation activities are changing our mind-set, too. At first I was shocked when I was asked what my son can do. It never occurred to me that I did not think about what he could do; I only thought about the things he couldn't do." **A mother speaking about child participation activities in Varna, Bulgaria.**

The Child Participation activities in all three countries culminated in three unique Child Choice Events. In line with the project description, children and young people were provided with support and resources to design, plan and carry out a fun event of their choosing. In each case this was highly visible to the general public and sought to demonstrate their inclusion in the community and to highlight the EHRL Declaration's priorities. In all three countries, a key focus of the child choice event was to reach out to the wider community, demystify disability and build bridges. These are detailed in the following section, which further illustrates how the project's approach to child participation was applied in each country.

In July 2013, after the end of the project, Lumos arranged for representatives from the Serbian and Bulgarian groups to participate at a major international workshop in Switzerland, "Children as Actors for Transforming Society" [1]organised by Initiatives of Change, in partnership with the Child to Child Trust. This event brought groups of children from around the world to explore new ways of working together to influence change. The TWIA representatives were the only group made up of children with disabilities and were able to share the experiences of this project and raise awareness of the rights of children with intellectual disabilities at this mainstream international event.

A selection of methods used and lessons learnt during the Child Participation activities in all three countries have been documented in the publication "Listening Together". It will be available for practitioners interested in Child Participation at Lumos' website www.wearelumos.org

Child Participation Experience in Bulgaria

Working alongside project partner the Karin Dom Foundation, which hosted some of the child participation workshops, the project team sought to include 15 children from a wide range of backgrounds: those with intellectual disabilities from both residential institutions and from families, their siblings, children from mainstream schools and young activists. The team then set about engaging parents, professionals, institutions and staff and enlisting their support for child participation principles and values. Once a programme of activities had been developed, the team created a stimulating environment in which the children could participate, have fun and accept this new experience as part of their routine.

Potential child participants were visited at locations at which it was felt they could comfortably be introduced to the concept of participation. They were then invited to join the group. A colourful, personalised invitation booklet was prepared for each child, presenting some basic idea of what the child might experience in the group. This approach was designed to

help build a sense in each participant that they owned the group and that their participation in it was valued. It was hoped that this approach would contribute to build the self-esteem and confidence of the participants.

The Child Choice Event that the children organised was a three-day trip from Varna around the country and on to Sofia, which the children called their "Tour of Dreams." At stops along the way they met and debated with groups of young people - members of youth councils and voluntary organisations, civil society groups and political representatives - advocating for recognition of their rights and for the changes they thought were needed to make the BHBL Declaration a reality in Bulgarian law and practice. The children prepared their own materials for their tour, including posters and a carpet into which they wove their interpretations of the Declaration's priorities.

Their messages reached local, national and thanks to the project's second transnational workshop, even international audiences. An animation of the experience, voiced by one of the children who took part has been developed and will be placed on the Lumos web site in autumn 2013 and will be widely disseminated.

Child Participation Experience in the Czech Republic

"For many years we've been learning all these different methods and ways of working with children, now I understand that we were missing the main piece: the children's opinions and participation." **Director of a special school in Pardubice, Czech Republic**

Most of the participants in the Czech Republic from the Child Participation Group were either:

- young people (aged 20-30 years) with varying degrees of intellectual disability who were living with families or in the institution;
- or children (aged 7-10 years) with more severe intellectual impairments and who were living in the institution.

There were three objectives in working with these young people:

1. to introduce the concept of child participation for children and young people with intellectual disabilities to staff and children, particularly in the context of deinstitutionalisation - a process which was underway in Pardubice County;
2. to introduce all participants to the BHBL Declaration and its priorities and prepare the children to be active self-advocates for its adoption and implementation, should they so wish and
3. to elect and prepare two members to represent the Child Participation Group as members of the Working Group and at the transnational meetings.

The coordinator worked with the older members of the group to develop their capacity to express and make decisions for themselves. Initial meetings took place at a special school and focused on getting to know each other and learning to respect each other's needs, differences and life experiences. After a few sessions the group gave itself a name and found a new place for meetings, developing its own rituals and identity.

The activities then shifted to learning about the rights of children and young people and organising a Child Choice event. The young people had their own 'easy read' version of the BHBL Declaration and cards and a chart were made of the priorities. They made signs marked 'agree', 'disagree' and 'do not know' and placed them around the room. Each statement was read aloud and individuals would move between the signs to express their response. In time, the children and young people came to focus on deinstitutionalisation as an expression of their hopes and beliefs.

With the younger group, a focus on the Declaration proved impractical; instead, this group were supported in developing their capacity for everyday participation. Regular meetings twice a week focused on games, the expression of wishes, being active and being together. The children's freedom to choose what they did led to an increasing number of

activities outside, including trips, walks and meeting with children from the community.

The work of the Child Participation Group culminated in a Child Choice event which the group decided on, designed and organised themselves. The young people did not feel ready to lobby policy makers and decided instead to hold a concert to which they could invite their friends and the community. The coordinator and school staff assisted in planning activities and producing a poster about the BHSL and similar materials about their rights and wishes, the children and young people being responsible for the activities themselves. The highlight was a performance by their favourite music band, Bedňáci, which included young people with disabilities. This event attracted the interest of the local media and a film of it was shown to participants at the second transnational workshop.

Child Participation Experience in Serbia

"There was no problem because of age difference between me and other members of the group. Everybody in the group welcomed me warmly and I think they like me. I feel like an older brother to them. I like listening to their stories and problems, because it reminds me of the situations I experienced myself in my life. They like to listen to my stories too, because I believe they can learn something from me and because they can expect similar things in their lives." A young self-advocate, member of the Steering group from Serbia describes his experiences with the Child Participation Group

Project partner, the Child Rights Centre led TWIA child participation activities in Serbia. In addition to its policy work, the Centre has considerable experience in working directly with children to promote their participation and safeguard their rights. The Centre could thus deploy its own staff and draw on its accumulated expertise, as well as that of cooperating institutions, organisations and individuals in designing and conducting its child participation activities.

A group was formed of 15 children and young people (aged 11-27 years), most with some form of intellectual disability and living in institutions. Membership and attendance were voluntary; some left and others joined during the process. Each workshop was attended by six or seven children on average.

The Centre began workshops in April 2012, focusing on getting to know each other and self-expression. As the methodology was tested, workshops were developed in phases:

1. strengthening individual capacities, establishing internal rules, and adapting the methodology (May-June 2012);
2. building individual self-awareness - "Me" (July 2012);
3. building group cohesion - "Me & The Other Members" (August 2012);
4. building group self-awareness - "We" (September 2012);
5. planning and organising the Child Choice event (October-December 2012).

Meetings were adapted over time to meet the group's needs, shifting from highly structured, two-hour sessions held twice a month to more loosely-structured, hour-long weekly meetings with lots of discussion, manual activities, games, energisers and optional sub-activities. Activities took place in a club, as well as through field trips such as to the cinema or historical monuments.

The children were given considerable room to express themselves and to talk in front of others, allowing them to identify with the Group as a cosy, safe place where they are accepted and respected. There was full confidentiality. The facilitators themselves were surprised at how hesitant the children were to talk about themselves. Nobody had ever asked them to do this before and it took time to learn to open up. By the end of the project period, they had begun to talk freely about their opinions, needs and feelings and even initiate discussions.

Some children also began to use the group as a forum to discuss their problems and ask for advice and support. Before the workshops, some would not have confidence to go to school alone. By the end, they travelled alone to the workshops alone and without reminder. Children who had been unwilling to express their own opinions were now ready to defend the rights of others.

Common rules were agreed by the group participants. The co-ordinators observed that these rules helped to set the boundaries for group communication and to build a sense of responsibility and ownership.

In Serbia, group membership was based on institutionalisation rather than disability and members identified as advocates of the Declaration, rather than self-advocates. The inclusion of non-disabled children in the group reduced stigmatisation and increased their solidarity with each other and with society.

The children found a sense of mission and usefulness in their task as advocates. By learning about the Declaration, they came to understand the basic mechanisms behind government actions and that they could and should have a role in decision-making as well as, to their considerable interest, their right to be consulted on the quality of services offered to them. One consequence of this is that they have begun actively seeking change in the institutions where they live, starting with the menus.

As in the other two countries, the children elected two members to attend the National Working Group and two Transnational Workshops. The two members chosen were given additional training to prepare them, while the whole group contributed to defining their message.

The Child Participation Group decided to hold its Child Choice event at a major shopping centre in Belgrade just before New Year 2013.

The children designed and painted two large cubes with pictures and mottos from their discussions on the SHBL Declaration, representing their understanding of the priorities. They installed the cubes at the heart of the shopping centre and handed out bags printed with their drawings, together with New Year greetings cards they had designed themselves and 'easy read' versions of the Declaration.

For both children and the organisers, this truly represented the culmination of their work in all the workshops over the course of the project. A busy shopping centre was chosen as the most visible way to reach out to the community and demystify disability.

Changes

Was there any variance from the original action plan?

☒ Yes
☐ No

Describe any variance from the original action plan. Describe how and why, provide justification of the change(s) made and impact on project implementation.

In Serbia, where Lumos does not have an office and project activities were delivered by project partner the Child Rights Centre, the role of Local Co-ordinator was provided by three individuals, each performing different functions. These were project management, National Working Group facilitation, reporting, communication; working with and preparing the children in the institution; co-ordination of the child participation workshops. This split reflected the different skill-sets required and ensured that all tasks were completed.

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. This training was not planned in the original project proposal.

<p>Activity</p> <p>Planned</p> <p>Please show, present your project plan/activity plan as outlined in the approved action grant agreement.</p>	<p>Similarly child participation of the type envisaged in this project is a relatively new phenomenon in the countries where the project was implemented. 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 a common understanding among the project team and to raise awareness and to gain support for the project among key stakeholders, meetings on Child Participation were organised for representatives from governments, NGOs, institutions and families. This was not explicitly described in the project description.</p> <p>The age criteria for participation was applied flexibly. For example children and young people, in some cases up to the age of 30, participated in the group activities. Young adults with intellectual disabilities, many of whom had grown up in institutions were included in these groups in response to their lack of opportunity, access to vocational training or education. The project represented an opportunity for them to learn more about their rights and to express their need for employment, lifelong training and education opportunities. They were also able to support and mentor their younger peers, following the example modelled by CHANGE.</p> <p>To promote the involvement of self-advocates in Steering Committee meetings, National Working Groups and Transnational Workshops, it was vital that they were provided with information which was easy to read and accessible for people with intellectual disabilities. It was also important that young people had enough time to prepare for meetings to be able to participate and contribute meaningfully.</p> <p>An important element of the child participation process was therefore engaging CHANGE, a UK-based human rights organisation, to increase the young people's confidence in advocating for themselves and others, in their own way and when they felt ready to do so. CHANGE developed easy read materials such as meeting agendas and the Our Words Our Actions publication.</p> <p>Designated CHANGE staff, both with and without intellectual disabilities, also worked directly with the young self-advocates in advance of each Transnational Workshop and Steering Committee. These fun, preparatory sessions, helped the young people to agree common messages they wanted to convey to policy makers at the meetings which followed.</p> <p>CHANGE staff also offered guidance and mentorship during these international meetings to ensure that they were as accessible and inclusive as possible. For example, on occasions they interrupted and asked speakers to avoid jargon words which would be difficult to understand. Witnessing the self-advocates at CHANGE speaking up in such a way greatly boosted the young people's confidence to do the same.</p> <p>This collaboration with CHANGE and the preparatory meetings were not envisaged in the original project proposal so some additional expenditure on travel and meeting costs were incurred.</p> <p>The guidance manual in child participation envisaged in the project description has been entitled "Listening Together". This publication shares some of the tools and experiences of the project and will be web-based. It is hoped that, by making this a web-based resource, that the ongoing experiences and learning in child participation methodology can be incorporated as Lumos builds on the work of this project.</p> <p>National Action</p> <p>National action will be supported and implemented by a 'National Working Groups' in each country. Working groups will focus on multi-level stakeholder cooperation in the development and initial implementation</p>
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of an action plan specific to children with intellectual disabilities. These action plans will seek to build on current national policy and priorities for the social protection and social inclusion of children, and extend the thinking to specifically consider how to ensure these same rights are secured for children with intellectual disabilities. Each working group will be empowered to identify their country's specific priorities, gaps and burgeoning good practices upon which to build, using the Better Health Better Lives Declaration priorities as a framework and ensuring consistency with national OMC priorities. In this way, each country's National Working Group may choose to focus their action plan on slightly different aspects of social inclusion and community living. It is important, given the pilot nature of the project and relatively short timetable, that action plans balance ambition and the drive for change with realistic and attainable goals. Reforming an entire system of care for children with individuals can seem understandably overwhelming when faced with a long tradition of residential care for vulnerable children and the segregation of individuals with disabilities. Often, the most difficult aspect of this large scale reform is making a start.

National Working Groups will come together five times in total over the fifteen months of planned activities: approximately once every three months. Three meetings of each National Working Group will be convened in-country and all three working groups will also come together for two transnational meetings." (TWIA Project Description).

Implemented

Please describe the activities and deliverables in the action

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 a 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 met at least four times in their own country and at two transnational meetings. The meetings involved government officials, policy experts, practitioners, self-advocates, parents and the two members from the Child Participation Group.

Child participation mechanisms were built into the way the groups worked, so that the three National Working Groups themselves learnt and modelled good practice in addressing the participation of children with intellectual disabilities in planning services and policy making. This served to increase their capacity and commitment to further include the views of excluded children in all aspects of their future work.

As outlined in the project description, an Expert Mentor was identified in each country. Each actively supported and steered the work of the National Working Group, shared national experiences at transnational workshops, participated in Steering Committee meetings and provided input to the various project outputs. Two of the three expert mentors had been involved in the original WHO-led process to draft the BHBL Declaration, so were able to offer clarity about the intent of the Declaration's various priorities.

In line with the project design, each National Working Group went about its work in different ways depending, for example, on whether it proved possible to gain any mandate for this work from government or whether the drafting of a new National Action Plan would be politically possible or appropriate. Once each group had been formed, it thoroughly reviewed the legislative landscape as it applied to children with intellectual disabilities and the services they access. This included any applicable national strategies, policies and action plans across key areas such as healthcare,

education to social protection. Each group was then able to assess what the most appropriate form of action would be in their national context. These national experiences are described in detail below.

National Working Group in Bulgaria

The appointment of members to Bulgaria's National Working Group aimed to ensure broad representation across key areas to maximise the impact of the Group's work. Members included: senior officials from the Ministry of Labour and Social Policy; the Ministry of Education (the Inclusive Education Expert) and the Ministries of Health and the Interior; local UNICEF and WHO representatives and a number of relevant, national-level NGOs, including the Karin Dom Foundation; the parents of children with intellectual disabilities from Varna and two young self-advocates from the Child Participation Group.

Whilst not mandated by government, Bulgaria's National Working Group secured significant governmental approval and involvement from the outset and functioned as a forum for discussion, advocacy and the coordination of initiatives. The State Agency for Child Protection of the Ministry for Labour and Social Policy (both the outgoing and the incoming Chairs of the Agency joined the Working Group and attended transnational meetings) and the Ministry of Education were both highly active partners.

The Expert Mentor, based in Sofia, focused on negotiations with government ministries and other potential partners and facilitated the work of the Bulgarian National Working Group.

The group held three full coordination sessions in Sofia, and also hosted a transnational workshop. Its main work was effected through the delegation of tasks, individual ad-hoc meetings and on-going email communication. The Group conducted a policy review, explored existing good practices, provided a forum for interaction between policy makers and service users and developed a set of proposals for action designed to ensure adequate and appropriate implementation of the Declaration.

The two main areas on which the group focused activities were: empowering children and young people with intellectual disabilities to contribute to decision-making about their lives and building capacity and commitment to change within the relevant institutions and workforce.

The conclusions of the initial policy review were:

- a formal national action plan is not needed, as an adequate policy framework already exists regarding children's rights and deinstitutionalisation. However there is insufficient clarity on the position of children and young people with intellectual disabilities within those policies
- where good policy does exist, it is not linked to practical measures or consistent implementation mechanisms. This has resulted in a fragmented system and discrimination in practice
- a number of targeted interventions are required to improve individual laws in different fields to ensure that the situation on the ground could and would be changed in line with the Declaration.

A set of priority actions was drawn up in cooperation with the relevant ministries and government agencies. Each priority action was entrusted to the stewardship of the most appropriate member of the group. The main areas of policy and legislation identified as needing intervention were:

- the Regulations on Criteria and Standards for Social Services for Children
- the New Law on Primary and Secondary Education and the National Education Standards
- the Ministries' internal regulations
- the by-laws governing school councils.

In particular, the group looked at the readiness of mainstream schools to genuinely integrate children once the deinstitutionalisation process is fully underway, as the Group was of the opinion that there had been

little practical preparation and no system of practice had been specifically approved. The Ministry of Education agreed to integrate child participation and inclusive education into the planning and implementation of its new Education Act and to ensure public scrutiny of the new national education standards. More specifically, the Working Group called for a thorough review of the standards for inclusive education, professional training, inspection and curricula from the perspective of the needs and rights of children with intellectual disabilities and their participation. The group also looked at participation by students with intellectual disabilities on school councils. Following the Child Choice Event, the State Agency for Child Protection has committed to integrating child participation for children with disabilities into its practices at national level and ensuring child self-advocates with intellectual disabilities are included in the National Youth Parliament.

KAP Survey Result: A change in practice of practitioners, service providers and carers in Bulgaria was noted during the project. For example, at the beginning of the project, 70% said that in their practice, 'children's privacy was respected'. This had risen to 90% by the end of the project. Similarly, at the beginning of the project 24% said that they never 'allow children to choose what to eat for their meal', a figure which had dropped to 0% by the end of the project. It can therefore be said that the involvement of service providers and carers in both the child participation groups and the National Working Group in Bulgaria had a direct impact on the way they and their colleagues worked with children.

National Working Group in the Czech Republic

"I was impressed by the power of the words of these young people with intellectual disabilities." National Working Group Member, Czech Republic

Working closely with the authorities in Pardubice, institution management and staff, the local coordinator took the lead in setting up both Child Participation Groups and the National Working Group, with technical support from the Expert Mentor, who was based in London and the Lumos office in Prague.

The National Working Group consisted of representatives from local organisations, institutions, government ministries and agencies, civil society, non-governmental organisations from other parts of the country and a locally-based Senator who was also the principal of a local Special Needs school.

The breadth of high-level membership of the National Working Group provided an inbuilt mechanism to expand the activity to a national platform once a basic model had been developed. The Working Group examined the BHBL Declaration and carried out a situation analysis, both on the ground inside institutions and at a local level. The Group met four times. By the time Prague hosted the second transnational meeting in December 2012, representatives of the Ministries of Labour and Social Affairs and Education were involved in the Working Group, with deputy ministers joining the panel of that event to endorse BHBL and the TWIA project.

Taking a 'local level first' approach in the Czech Republic meant that policy and processes developed at a slower rate than in Bulgaria and Serbia. However, this approach has the potential to produce highly practical solutions based on specific situations. It is hoped that testing ideas in an institutional environment with the involvement of practitioners, professional staff, parents and children will lead greater weight to the recommendations of the National Working Group and increase the likelihood of their adoption in what can be a sceptical environment.

As detailed in section one of this report, as a direct result of the project, improvements were made in the way staff in institutions worked with children in their care. Pardubice County has subsequently committed to sharing their experiences in this project with other counties.

After the project had already begun, central government in the Czech Republic made a paper commitment to deinstitutionalisation under the 2012-2015 National Strategy to Protect Children's Rights. This may open

up the way for more fruitful action at national level, building upon the modest work done so far in Pardubice.

The members of the Working Group, including representatives of the various ministries involved, have committed to continue their work as an informal network after the end of the TWIA project, with the support of the Lumos office in Prague. The group has prepared a list of priority actions to implement the BHBL Declaration to act as the basis for further work where and when opportunities for positive change can be identified. This has been made into a simple animation using pictures drawn by the children themselves.

National Working Group in Serbia

A formal National Working Group was set up under the auspices of the Ministry of Health and was responsible for the development of an official National Action Plan for BHBL implementation. The group included members of the relevant ministries (Health, Social Policy, Education, and Local Government), the Centre for Child Rights, a number of other non-governmental organisations, institutions working with children with intellectual disabilities, family organisations and self-advocates. The Group met four times. Members were given specific tasks to perform concurrently and delivered updates at the meetings.

In the first phase, representatives of the relevant Ministries and the Child Rights Centre carried out a review of legislation, policies, programmes, departmental reports and reviews, all from the perspective of children's rights and child participation. The Expert Mentor and coordinator used these results to create a discussion paper. On the basis of this, the group determined priorities and, given the limited time available, decided to focus on reforms within the healthcare system and on the coordination of services.

The draft National Action Plan produced by the group is currently being revised by the Ministry of Health. Given the close involvement of ministry officials, some recommendations are already on ministry agendas and incorporated within policy.

All involved in the process have made clear their determination to ensure it does not stop now. The National Working Group will continue to meet formally after the end of the TWIA project to ensure the recommendations in the Action Plan are incorporated into policy and followed through in practice at an institutional and community level. The Action Plan was developed under the Ministry of Health and its recommendations for other ministries are not binding; however the group, which includes representatives of those ministries, will continue to advocate for their implementation.

Changes

Was there any variance from the original action plan?

☒ Yes
☐ No

Describe any variance from the original action plan. Describe how and why, provide justification of the change(s) made and impact on project implementation.

The project design allowed for a different approach to national action to be taken in each country with each National Working Group empowered to identify specific priorities and to focus their work on different aspects of social inclusion and community living as contained in the BHBL Declaration in line with what was deemed possible or appropriate in each national context. As outlined, by the project evaluator in his contribution to this report, the term, "National Action Plan" as used by the WHO in the texts accompanying the Declaration was not clearly defined.

During the project period, this lack of clarity did at times prompt questions among National Working Group members that the objective of a National Action Plan was undefined however as detailed in the project description, "reforming an entire system of care for children can seem overwhelming [...] the most difficult aspect is making a start". Each group therefore focused their work on what was achievable and would have the most potential for impact. In Serbia, this was indeed a National Action Plan

emanating directly from the project. In Bulgaria, a relevant national action plan already existed so the group focused instead on influencing it and other policies. In the Czech Republic, the group focused first on changing practice at the local level which would later be demonstrated at a national level.

Given that the Ministry of Health has committed itself to taking forward the National Action Plan in Serbia and ensuring that it has formal government endorsement, the draft of this text is currently being finalised in its internal processes which are out of the control of the project team. It is therefore not appropriate to share this publicly at this time. Once this document has been formally adopted, it will be added to the web site.

Given that finalised National Action Plans are not yet available and the objective of a national action plan was in fact in the Czech Republic and Bulgaria delivered through specific national actions, as detailed in section one of this report, a decision was taken to produce a single output which combined the Guide to National Planning, an assessment of each country's situation, the national action taken in each country and also the experience of child participation, all linked to the project's overarching aim, to turn the BHBL Declaration's words into action. It was felt that such a combined publication would more accurately reflect the experiences of the three countries and also be a more useful guide to other countries and the EC in supporting similar actions in the future.

In line with the project description, this publication was first drafted by a member of the Steering Committee following interviews with project participants. However, the publication has required significant editing and proof reading and was not able to be finalised in time for the end of the project on 19 June 2013. Lumos has therefore committed to funding the final design, printing and translation costs from its own funds. This publication will be available on the Lumos web site in autumn 2013 to coincide with this report and will be widely disseminated (see below for details of the dissemination plan).

Activity

Planned

Please shortly present your project plan/activity plan as outlined in the approved action grant agreement.

Social Experimentation

"One of the primary outputs of this project, described below, is the development of a simple and user friendly self monitoring and evaluation tool on the degree to which full inclusion for children with intellectual disabilities has been obtained in policy and practice. This tool will provide a set of easily interpreted indicators for each of the 10 Priorities in the Better Health, Better Lives Declaration. Progress towards social protection and social inclusion of children with intellectual disabilities in national policy and programmes over the duration of the proposed project will be measured in each of the project countries using this self-evaluation tool prior to, and upon completion of, project activities. By using this same self-evaluation tool to evaluate the baseline progress of control countries not participating in project activities, this tool will further serve as a method of social experimentation. Given the pilot nature of this experimentation, up to three additional European nations will complete this tool. Countries with similar geographic, socio-cultural and economic profiles to the project countries will be identified at the beginning of the project.

A Knowledge, Attitudes and Practice (KAP) survey will be undertaken at the beginning and end of the project to assess the degree to which this project is able to meet the above objective. KAP studies allow insight into what people know and how they feel and behave around a given topic. This analysis, before and after project activities, will allow for an assessment of the changes this project results in for these three dimensions of human experience with regards to children with intellectual disabilities. This will then allow future social experimentation and project replication which is best suited to meet its aims." (TWIA Project Description).

Implemented

Please describe the activities and deliverables in the action

The TWIA project explored innovative ways of building an inclusive process through which some of the commitments in the BHBL Declaration could be turned into action. It was hoped that this experiment would demonstrate what happens when children with intellectual disabilities are co-producers of policy and practice change, together with adult decision-makers.

In line with the original Project Description, 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. Social experimentation requires quantifiable measures that show the difference new methodologies make. What was measured here was the extent to which participants' knowledge and attitudes about children and young people with intellectual disabilities - and their capacity for meaningful inclusion in such processes - changed.

Participants were surveyed before and after the project. A different group of questions specifically for the children and young people involved was also used in order to capture some of the experiences and views of the young people themselves. A selection of results of this survey have been included throughout this report.

The KAP survey demonstrated: an increase in confidence and self-esteem of the children and young people involved in the project; changes in attitude among National Working Group members of the capacities of children with intellectual disabilities; changes in practice for those working directly with children and changes in attitude of children and adults alike towards institutions and towards government policies for children with intellectual disabilities. The survey was filled in by a relatively small number of people, all of whom were involved in the project. It can therefore not be taken to be indicative of any change in attitude of the wider population in the three countries. However it clearly demonstrates the impact of the participative methodology of the Turning Words into Action on those involved.

A web-based self-evaluation tool has been developed to help National Working Group members and others assess a country's level of implementation of the BHBL Declaration in policy and practice. Originally intended to be developed at the beginning of the project and also act as a project monitoring tool, it was developed over the course of the project incorporating the learning from the National Working Groups and the Transnational Workshops with a view to it having sustainable impact after the project. It has been tested in Serbia, Czech Republic and control country, Moldova and will be tested in Bulgaria before being finalised in autumn 2013. These tests were intended to test the usability of the tool both in terms of content and technical aspects. Following the tests, the questions posed in the tool will be simplified and some small changes to navigation within the tool will be made.

Lumos is committed to developing this tool as an aid for those who wish to identify gaps in policy and practice related to the rights of children with intellectual disabilities. The tool has been translated into six languages and will be disseminated widely after being finalised. Screenshots of current drafts of the tool will be disseminated together with this report.

Changes

Was there any variance from the original action plan?

☒ Yes
☐ No

Describe any variance from the original action plan. Describe how and why, provide justification of the change(s) made and impact on project implementation.

Progress towards social protection and social inclusion of children with intellectual disabilities in national policy and programmes over the duration of the proposed project was planned to be measured in each of the project countries using the newly developed Self-Evaluation tool prior to and upon completion of project activities.

The experimental nature of this project meant that the self-evaluation tool was developed and improved over the course of the project reflecting learning about the participation of children with intellectual disabilities in consultative policy making processes. The complexity of the many policy areas which fall under the BHBL meant that such a tool needed to cover all of these areas and yet still be practical. Various drafts of this tool were trialled by the National Working Groups and each one led to further improvements.

As the project evolved, however, it became clear that the best measure of the progress of the project would be to capture the interactive dialogue and expressions of opinions which it had enabled. This would be a more qualitative than quantitative approach to evaluation. Developing a tool that reflected both quantitative changes in policy and practice as well as qualitative changes during the project presented a major challenge so a change in approach was agreed.

The project team decided that the KAP survey should instead act as the main baseline measure for the project's impact and that the self-evaluation tool should incorporate the experiences of the project and be tested in each of the project countries plus one additional country. The tool would be used after the project, as a useful way to share and further develop usable indicators of BHBL implementation which can have real sustainable usefulness after the project and as a means of assessing the inclusion of children with intellectual disabilities in policy and practice.

Following input from several Steering Committee members and the External Evaluator of the project, the new web-based Self-monitoring and evaluation tool has been developed and translated into Five European languages.

Russian was selected as one of these languages because of its usefulness and potential impact in Moldova and other European neighbouring countries where progress on the rights of children with intellectual disabilities and on deinstitutionalisation is urgently required. It is hoped that this tool will be especially timely as countries across Europe must report to WHO in 2015 on the progress they have made in implementing the Declaration.

This tool will be made available on the Lomos website www.wearelomos.org and will be widely disseminated and shared with WHO Europe to explore the possibility of the tool being endorsed and promoted through their networks.

Transnational dimension

Has your project had a transnational dimension?

☒ Yes
☐ No

Describe the transnational dimension of the action.

'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. As such, the results of the transnational activity have been detailed in the first section of this report. A summary of the main transnational aspects of the project follow:

To meet this objective, as envisaged in the Project Description, a Steering Committee was officially established at the beginning of the project. This committee was made up of international experts who had been involved with the drafting of the BHBL Declaration, representatives of the project partners, young people with intellectual disabilities and family members.

The committee met three times during the life of the project. On each occasion, CHANGE offered support and guidance to ensure that the young self-advocates were prepared and that the agenda would enable their meaningful involvement.

Steering Committee members provided technical expertise and advice to the project team on the implementation of the project. Two members of the

Committee provided their technical support to National Working Groups as Expert Mentors. The Bulgarian expert mentor, whilst not officially a member of the Steering Committee, also attended the meetings.

When implementing international standards, much can be gained from sharing experiences across borders. Taking its inspiration from the BHBL Declaration which was itself agreed by 53 countries, the TWIA project set out to ensure that learning was shared between the three countries. It did this through organising two Transnational Workshops where self-advocates and other members of the three 'National Working Groups' could come together and discuss progress.

The first such workshop was held in Sofia in September 2012 and focused on four key areas: sharing and learning from each other, key elements of policy and practice, promoting child participation and how to make change happen.

The second workshop in Prague in January 2013 included presentations about the Child Choice events and their impact on the children, on policy makers and on the public. This meeting was attended by eight senior government officials and representatives of the European Commission, as well as by Baroness Sheila Hollins, Chair of both the Steering Committee for the BHBL initiative and of the TWIA Steering Committee.

Progress between the two events was very marked. At the Sofia workshop, there were both parallel and joint sessions, with self-advocates and adults working separately at times. In Prague there was no need for separate sessions because a common agenda with a common approach to working together had been agreed. In advance of each workshop, CHANGE worked intensively with the self-advocates to prepare them for the joint sessions and supported them to prepare and deliver their presentations. Pictures, mimes and simple slogans were used to overcome language barriers and demonstrate the common concerns of children with intellectual disabilities across the three countries.

The transnational dimension of the project has also been assured in the project outputs, each of which brings together the different national experiences and perspectives into a common summary of the project and its impact, the demands of the children and young people involved and common perspectives on the BHBL Declaration. The publications and the self evaluation tool have been translated into the various project languages plus English and French. Romanian and Russian versions have also been produced of the Our Words Our Actions publication and the Self Evaluation Tool to ensure that the messages of the project reach as many people as possible in those EU and neighbouring countries where institutionalisation of children remains a serious challenge to policy makers and where participatory models of consulting children with intellectual disabilities on their rights as modelled by this project remain in their infancy.

Partners or stakeholders

Were there any partners or stakeholders involved in your project?

☒ Yes
☐ No

Please list here all partners or stakeholders and describe the contribution they made to the action. 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 provided 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 contributed by providing their expertise to the project implementation and National Working Group meetings. They also facilitated one of the sessions at the first Transnational Workshop.

<http://karindom.org/english/>

Pardubice County, also a project partner, is a local authority in the Czech Republic, which is undergoing reform of its residential system of care for children with disabilities through the development of community based services. They provided 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 special schools. They provided a working space for the Local Coordinator and supported her in her everyday work. They also attended the Steering Committee meetings. 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.

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 as partners 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 implemented 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 (no Serbian partner had been identified in the project description).

<http://www.cpd.org.rs/>

CHANGE is a leading international human rights organisation based in the UK. CHANGE employs people with intellectual disabilities to campaign, run projects, research issues, deliver training and co-produce easy read resources about issues that affect the lives of people with intellectual disabilities. To promote involvement of self-advocates in the project it was vital that they were provided with information which was easy to read and accessible for people with intellectual disabilities. CHANGE was best-placed to facilitate this important piece of the project work and ensured that the participation of young self-advocates was sincere. As outlined in section 2 of this report, this collaboration with CHANGE was not envisaged in the original project description.

<http://www.changepeople.org/>

Equality

How did you make sure that equality considerations were taken into account in your work? 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 in society. Growing up in institutions increases this segregation from society. This project aimed to include all children by making its activities accessible and actively seeking their views. At every stage, we sought to provide equal opportunities for boys and girls, Roma children and children with varying communication and accessibility needs. We paid particular attention to ensuring that children living in institutions had the preparation they need to be able to participate fully in the child participation activities.

Each of the local co-ordinators paid specific attention to engaging with those children who were less able to participate in the group activities due to the severity of their disabilities. For example child participation activities for younger children with severe communication difficulties were organised in the Czech Republic and children in Bulgaria were encouraged to see themselves as advocates for those less able to participate. It would be of benefit if future projects of this nature could focus on developing methodologies to allow for the meaningful participation of children with severe intellectual or physical disabilities and communication difficulties. This suggestion was also made by the young self-advocates themselves at the second Transnational Workshop in Prague.

The composition of the National Working Groups provided opportunities for representatives of various backgrounds to contribute to social policy and decisions. The Steering Committee also had a diverse membership of policy makers, academics, civil society experts, service providers and beneficiaries. The steering committee membership was made up of ten women and five men, from at least seven different European nationalities. Of these, three were self-advocates with intellectual disabilities and at least one was a parent of a child with a disability.

Continuity

Is this action (or a related new action) to continue after European Union's financial support has come to an end?

☒ Yes
☐ No

Please explain the next steps.

As described in the Project Description, the root and branch reform of the system of care of children from a state-led, institution-based model to one designed around the individual needs and rights of all children can be a daunting task and "often the most difficult aspect of such large scale reform is making a start." This project was therefore always intended to aid the three countries involved to build a foundation for further action beyond the timescale of this relatively short and small-scale project.

Child Participation: The project established a way of seeking the input of children with intellectual disabilities in policy and practice by supporting and enabling their genuine participation. Lumos is developing a long term strategy to build on the progress and activities started by the TWIA project and help to make them sustainable.

The positive impact on the lives of the children, young people and parents involved in this project in a relatively short time, as demonstrated elsewhere in this report, was something that everybody involved in the project felt a moral obligation to maintain. A notable feature of the second transnational workshop was that it ended with a public commitment from all of the project team, steering committee members and national working group members to continue supporting the work of the child participation groups after the end of the project.

Both of the Lumos local co-ordinators recruited for this project will continue their work as dedicated full time child participation officers in the Lumos teams in Prague and Sofia. Their roles will be to ensure the sustainability of the child participation groups established by the project and to support those children and young people involved to have new opportunities and build on their experiences from the project. They will also ensure that the learning and methodology of this project is fully captured and used in other areas of Lumos' work with children and policy-makers, for example listening and acting on children's views when preparing children for life outside of institutions or supporting children to speak out at public events. Lumos intends to include children with more complex needs and communication impairments in this work in the future and is developing a strategy to best achieve this.

The Child Rights Centre in Belgrade has also continued to support the child participation group in Serbia since the end of the project and has committed to integrating this group into its future plans and projects.

In July 2013, Lumos organised for a group of two Serbian and four Bulgarian children and young people with intellectual disabilities from this project, plus two of the local co-ordinators and some parents to take part in a major global workshop in Switzerland on child participation. This event, entitled "Children as Actors for the Transformation of Society" was organised by Initiatives of Change and the Child to Child Trust. This delegation from the Turning Words into Action project were the only participants with intellectual disabilities and they presented this project and also raised awareness among the other children of how to include children with intellectual disabilities. Lumos plans to take part in this event again next year and will work with the organisers to ensure that the event is accessible as possible to children with intellectual disabilities.

In addition, Lumos will use the experience of the project to develop child participation methodology in Moldova, a country with an on-going successful deinstitutionalisation programme but as yet with little experience of the kind of participative policy making demonstrated by this project. Project outputs were prepared in Romanian (and Russian) and will be widely disseminated in Moldova. Children with disabilities are currently being prepared by Lumos in Moldova to participate at an international conference on inclusive education organised by Lumos and the Moldovan Ministry of Education in Autumn 2013, using some of the methods trialled in this project.

National Action:

It is hoped 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. External support, for example in the form of future programmes from the European Union, for the maintenance and development of such national consultative structures may be required.

The Serbian Ministry of Health has committed to sustain and build on the work of the project by supporting the implementation of the new National Action Plan for children with intellectual disabilities and the National Working Group structure. In Bulgaria and the Czech Republic, the National Working Groups structures also have the potential to be maintained.

In Bulgaria Lumos is a founding member of a new coalition entitled *Children 2025* which seeks to keep deinstitutionalisation and child rights on the political agenda at a time of significant political instability.

The publications of this project will be used in all three countries to advocate for the rights contained in the BHBL Declaration and, by extension, better social cohesion in line with the objectives of the European Union's Social Open Method of Co-ordination.

European Union and International Action:

In order to ensure that the sustainability of the project outcomes is assured, Lumos has committed to formally engaging in another European Commission funded project entitled "Hear our Voices". This project (JUST/2011/FRA/C/AG/2735) is coordinated by Inclusion Europe and funded by the Fundamental Rights programme of European Commission Directorate General for Justice. The operating partners are Eurochild, The Cedar Foundation - Bulgaria, QULP- Association for Change - Czech Republic and the Down Syndrome Foundation, Spain.

The main focus of this project is to gather together expertise in child participation for children with intellectual disabilities, to support groups of children in each country to advocate for their rights and advocate at the European Union level for improvements to child participation policy and practice. It is hoped that formally sharing the outcomes of TWIA through this project and dissemination of outputs through the wide European networks of the participating organisations will both ensure sustainability and broaden the project's impact.

A joint seminar targeting European policy-makers will be organised in Brussels in late autumn / winter 2013 to both showcase the work of the Turning Words into Action project and also launch the initial research of the Hear our Voices project into good practice in the field of participation for children with intellectual disabilities. Children and young people from the Turning Words into Action project will participate at this event and also be integrated into child participation activities of the Hear our Voices project in Bulgaria and the Czech Republic. National seminars in Bulgaria, the Czech Republic and international workshops will also take place which will be an opportunity to revisit the policy demands of the Turning Words into Action National Working Groups.

Lumos will also seek to engage at the appropriate level with the World Health Organization - Europe to share the project outputs and explore ways in which they can be used to reinvigorate and support the work of the WHO to monitor and promote the implementation of its BHBL Declaration across the European Region. This reinvigoration is of particular importance given the fact that all European countries will have to report to the WHO on their implementation of the BHBL Declaration in 2015.

Lessons learned and dissemination of results

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 level policy-makers; social partners; opinion-makers including mass media, journalists; non-governmental organisations; academia, research institutions, think tanks; others where relevant)

As outlined in section 1 of this report, over the course of the project progress was made in furthering the rights of children with intellectual disabilities in each of the three countries. This progress can be summarised under the following four outcomes:

- empowerment of children and young people through meaningful participation
- action taken towards implementation of the BHBL Declaration
- children and young people with intellectual disabilities, policy makers and civil society stakeholders have had positive experiences of working together in new ways
- policy and practices have been influenced in each country

The key outcomes of this project are however best expressed by the recommendations of the children and young people themselves, in their own words, as taken from the publication 'Our Words, Our Actions':

1. *The Better Health Better Lives Declaration is very useful and practical.*
2. *Supporting children and young people with intellectual disabilities to be involved is very important.*
3. *Involving children and young people helped everyone to learn together.*
4. *Everyone is different. Every country is different. Plans must fit what will work best in each country. The most important thing is not a piece of paper with a plan on it. The most important thing is for everyone to work together to make real change happen.*
5. *It takes time to make real change happen. It is important to involve parents in everything that is done. They need support to become involved.*
6. *It is important for everyone to work together.*
7. *It is important that people who are working with children and young people have the experience and skills to work with children. They should be trained and supported to do this work.*
8. *It takes time to support children to be involved and grow in confidence.*
9. *More children without disabilities should be included and have a chance to work together with children with disabilities.*

Lessons Learned in Child Participation

The following are a selection of some of the most important lessons learned by the project team in delivering the child participation activities. Some of the methods used by the team have been collated in the online resource "Listening Together." Whilst not an exhaustive list of tools, it is hoped that this will provide useful examples to NGOs and governments alike as they seek to engage meaningfully with children with intellectual disabilities.

1. Involve children and young people in designing activities

Everyone involved in the TWIA project agreed that the equal involvement of the children and young people in the actual design of the participation activities was key. The actual experience of co-producing activities built their confidence in the process and also ensured that the views expressed were genuinely those that they most wanted to share. In turn, this ensured that the views expressed highlighted what policies and practices most urgently needed to change to meet their needs. Because the activities were developed together with the children and young people, the pace matched their needs and capacities and built up over time in a sustainable way.

Many activities focused on building opportunities for the children to express their thoughts about their daily lives, their dreams and their worries. Initially these opinions were largely about their individual concerns. Over time, however, a sense of group identity was built up and they began to express

their opinions and wishes for all children and young people with intellectual disabilities, in their own countries and around the world.

2. Ensure adequate time to prepare the children for meetings

Enough time was given to prepare the children and young people before every meeting at which they might be sharing their views with others. National Working Groups and Transnational Meetings were organised according to the environment and structure most appropriate to the needs of the self-advocates, not the conventions and convenience of the 'adult world'.

3. Create a supportive environment

A friendly environment, an inclusive culture and firm political commitment are essential for child participation. Such a culture change takes time. It requires understanding and a commitment at all levels to explore new ways of working with children, starting with carers, families, professionals and policy makers.

4. Involve parents, families and carers

Just as children and young people need to be prepared to participate in new and inclusive processes, so must their family members and carers, whose role in supporting day-to-day inclusion in the community is so important. The experiences and observations of parents and carers about the services their children access and their own needs will be vital in reforming services.

"To be honest, in the beginning [the parents] were coming only to support their children. Then they started to work on their own and became very supportive and engaged. Two of them participated in Working Group and transnational meetings (which was helpful as they could see that there are many other people trying to help). These parents confessed that in the beginning they were with us only because of their children, but now they wanted to get engaged in a broader sense - for all children."

Lumos local coordinator, Bulgaria on parent participation

5. More work is needed to prepare and engage with children with severe intellectual disabilities and communication difficulties.

There is a risk that child participation work naturally puts forward the children who are most able to communicate to the detriment of those less able to participate without support. Special attention is needed to work with those children with disabilities who require more time to develop their communication skills or to express opinions, many of whom have grown up in institutions without adequate mental stimulation or support so are particularly vulnerable. Without this, they risk further isolation and social exclusion.

Future European Union funded initiatives of this type, should seek to build expertise, knowledge and good practice in this field and allow enough time for them to be developed. Any national government seeking to put in place systems for consulting with children with intellectual disabilities needs to ensure that all children with intellectual disabilities are included in these processes.

Lessons Learned in Implementation of the BHBL Declaration

1. The Structure of the Declaration is Helpful

As outlined in the very first recommendation of the children involved in this project, those involved found the BHBL Declaration to be a useful tool. By expressing human rights for one specific target group in ten easy to explain priorities, the Declaration lends itself well to self-advocacy of the type explored by this project. It is also relatively easy to translate these ten priorities into easy-read statements which the children were able to understand as promises, which their governments had made to them. The BHBL Declaration therefore lends itself well to participatory consultation processes involving children with intellectual disabilities of the kind trialled in this project.

2. The importance of ownership and raising awareness

It is important for international human rights agreements of this type to be well publicised so that the target groups are aware of the commitments that they contain so that they can hold policy makers to account. Without this

project, many of the stakeholders, children, young people and parents involved would not have been aware of its existence or its potential as a lever for policy change. Future initiatives of the European Union could seek to promote awareness of such international human rights instruments at the national level and provide support to countries to put in place sustainable national mechanisms for involving beneficiaries in monitoring their implementation. The National Working Groups of this project could provide a model for such mechanisms.

Lessons Learned in Working Together

1. Everybody benefits from new ways of working

The project brought together groups who had little or no experience of working together before. The children, young people and parents were able to express their views directly to the policy makers and policy makers were able to directly hear the views of these beneficiaries expressed in their own words, often in a non-formal way. This informality was refreshing for all involved and helped those involved to understand what the most urgent changes to policy and practice should be. In the words of the children's own recommendations "young people helped everyone learn together".

2. New ways of working together take time to establish

Designing a participatory process for dialogue between children with intellectual disabilities and policy makers takes time and preparation. This design process should include everybody and, as identified by the children themselves in their recommendations, enough space and time should be given to enable the children involved to grow in confidence. Conversely, policy makers also need time to adapt to non-traditional ways of working.

Lessons Learned in National Action

1. International agreements need to be made relevant to national contexts

As outlined in Sections 1 and 2 of this report, after analysing the national policy environment, the national working groups in each country pursued different paths to try to influence national policy processes in line with the BHBL. This flexibility was important and ensured that progress could be made in each country even during a short project.

2. Public support is important

In each country, the child choice event sparked positive media coverage about the rights of children with intellectual disabilities and each event reached out to the community as a matter of priority. As noted by the expert mentor in the Czech Republic, national action can only be successful and sustainable if there is public support for it and greater awareness of the lives and challenges of children with intellectual disabilities.

"Of course, large-scale change in children's lives requires national action expressed in legislation, better policies and the allocation of resources to implement these. But the transformation towards equal citizenship for disabled children and young people - more simply 'ordinary lives' like their non-disabled peers - cannot be delivered only or mainly from the top down in Czech society. 'Policy push' must be complemented, and indeed driven by 'community pull'."

Dr [REDACTED], Expert Mentor, Czech Republic - speaking at the end of the project

Sustained public campaigns should therefore be organised across the Region to increase the visibility of people with disabilities in communities and raise awareness of the challenges they face.

3. National working groups benefited from transnational experiences

The two transnational workshops provided valuable opportunities for participants to share their perspectives and experiences on implementing the BHBL Declaration at the national level with peers from similar countries. As countries across the Region prepare to report to WHO Europe on their national implementation of BHBL in 2015, further forums should be organised where countries can share their experiences so far and renew their commitment to implementing the BHBL Declaration.

Evaluation of the action

Did you carry out any evaluation of the action performed?

- ☒ 4 Yes, external evaluation
☐ Yes, internal evaluation
☐ No

Please outline the key findings and conclusions of such evaluation.

External Evaluation

The role of the external evaluator was outlined as follows in the Project Description: "An external evaluator is required to ensure that objective and independent feedback to the project is provided throughout. [REDACTED] had been identified to fulfil this role for this project. [REDACTED] enabled independent monitoring of the quality of the project and the achievement of activities according to the project timescale. [REDACTED] is a senior practitioner with significant experience in both policy arenas and in including people with intellectual disabilities in the planning process. For objectivity, [REDACTED] did not engage directly with national or transnational action and child participation activities but acted as an observer and "critical friend" to these activities and to the Steering Committee. Evaluation was an embedded, interactive process throughout the project and the evaluator therefore attended Steering Committee meetings to observe and make on-going recommendations." (TWIA Project Description).

[REDACTED] attended each of the steering committee meetings of the project, both transnational workshops in Bulgaria and Czech Republic and also met with the Serbian National Working Group in Belgrade. He was therefore able to visit all of the project countries once. [REDACTED] provided invaluable feedback and advice at each event and regular input and support to the project team. He concluded his work with a presentation at the final steering committee meeting in June 2013. His final thoughts are detailed, in his own words, below.

"The fundamental challenge in this project is, as simply described in the title, one of how to turn the words and rhetoric of declarations and conventions into tangible and demonstrably beneficial results for children and young people with intellectual disabilities and their families. The rights and values base contained in the principle of empowering children and young people with intellectual disabilities to contribute to decision making about their lives, is of little value whilst they remain as words on a page. It is only when these words act as a prompt or trigger to effective action that their value is realised. What is not clear, and what this project has endeavoured to explore and validate, is what the contribution of children and people should look like. How can they be most effectively engaged and in what? What exactly is the added value in terms of processes or outcomes that is brought about by this involvement and what types of involvement are most effective in what circumstances.

Another challenge has been one of language. Not just the obvious differences in the spoken language of the participants but the language of cultures, societies, histories, expectations, politics. Finding common language and understandings both at a local level and in the transnational working groups has consumed a considerable amount of time and energy. One of the first realisations of these challenges was in the varied and sometimes incomplete understandings of what people thought they meant by "national action plans". This is not solely a problem for this project, the WHO declaration uses the term repeatedly but does not clarify what a "national action plan" is and we have to assume that it does not refer to the specific but to a generalisation with regard to plans, strategies, policies and the resources required to implement them that may exist at different levels of state organisation, administration and legislation.

One of the benefits of the involvement of children and young people would appear to be that being a child allows one to communicate in uncomplicated, unveiled and more honest ways that more readily lead to the sharing of simple yet fundamental concepts that are quickly understood and shared across national and individual boundaries.

Towards the end of the project there emerged a growing sense of the need to find some model beyond that of child participation that could adequately

describe what was being discovered and achieved both individually and collectively. Some of the principles of 'co-production' were able to bring this coherence and to 'validate' what, up to that point, was beginning to feel in some ways undefined, at times ephemeral and concerning when thinking about sustainability and the need for much more future development of the footholds and achievements gained.

In this model, the principles of working in genuine partnerships, of seeing children and young people with intellectual disabilities and their families as resources, as bringers of skills, experiences and insights rather than those who need to be always in receipt of the 'wisdom' and guidance of others, bring a strength to the project's collective thinking and to the future direction.

This has been a shared and iterative process and therefore it is only to be expected, albeit sometimes with the benefit of hindsight, that the purpose and direction of the project has in many ways evolved as it progressed and the ending point may in some ways be different to that which was originally expected. Yet this is perhaps the most important contribution that the children and young people and their families have made. Their very presence and collaboration has allowed greater exploration and "play" with our original ideas and concepts and have shaped the activities in each country, and across countries, in such a way that there is arguably a more healthy and robust platform of experience, of shared knowledge, of new partnerships and relationships of influence and, above all a greater presence in the public domain, that can continue to be built upon and strengthened in the future."

May 2013

In addition, in line with the Project Description an external audit of the budget and financial report of the project took place on 31 July 2013. The results of this audit confirm that the, "costs presented in the financial statements are accurately recorded and eligible and that all receipts have been declared in accordance with the agreement." This has been included in annexe to the financial report.

Internal Evaluation:

In line with the Project Description, the following internal processes were followed throughout the project to evaluate the action.

- Regular meetings were held between Project Manager, Project Coordinator and Finance and Administration Officer discussing the implementation of the project.
- The Project Coordinator had regular teleconferences and meetings with the Local Coordinators in the three countries monitoring that activities were going according to the project plan and also discussing any practical challenges.
- Planned and ad hoc meetings were undertaken between the Project Management Team and members of the Steering Committee.
- Three Steering Committee meetings took place to evaluate the implementation of the project. The committee met three times during the life of the project. They provided technical expertise and advice to the project team on the implementation of the project. Two members of the Committee provided their technical support to National Working Groups as Expert Mentors in Serbia and the Czech Republic and the Bulgarian Expert Mentor also participated in these meetings.
- The three Expert Mentors provided on-going technical support to the work of the National Working Groups.

News/success/best practices

We are very keen to hear about any success or good news from the actions that we fund. Please use the space below to tell us about any such news 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 or explain where others can access it (e.g., website)

The successes and learning from the project have been documented in four main project outputs and various additional outputs each one tailored for a slightly different audience. They will be subject to the post-project dissemination strategy and are summarised in Section 4 below.

Dissemination of findings

Adequate dissemination of findings and lessons is essential in ensuring the EU added value of the action.

Therefore, please explain and describe how you involved relevant stakeholders during the action and whether there was any feedback.

In all dissemination, special attention will be paid to ensuring that no child is placed in harms way by any external communication and Lumos will apply its policies in this area.

Given the experimental nature of the work and the vulnerability of the children and young people involved, we have taken more time than originally envisaged in the project description to finalise and publicly disseminate the various outputs of the project so that they accurately reflect the experiences of the children and those working with them. In so doing, we aimed to ensure that they will be useful as possible sources of advice and inspiration to others long after the project ends.

During the project, internal dissemination of project progress has taken place at steering committee meetings, national working group meetings and transnational workshops. The Child Choice Events have, in each case produced materials, designed by the children themselves, which were circulated to the general public. After the end of the project, representatives from Serbia and Bulgaria presented the project to participants from around the world at the Children as Actors for the Transformation of Society Conference in Switzerland (see the *continuity* section above for more details).

Summary of Project Outputs:

· **"Turning Words into Action"** is a guide to national planning which is intended to inspire and assist civil society and governments in translating the Better Health Better Lives Declaration's words into national action. It also features more information about the project in each country and the impact on national policies and practice. In the original project description this was envisaged as two separate outputs: An Updated National Action Plan and a Guide to translating the BHBL into Action. It was combined to best reflect the realities of the national action aspects of the project and to summarise the learning in one document. Following feedback from steering committee members following its presentation at the final steering committee meeting in June 2013, this publication is being finalised during August 2013 with a view to it being published and translated in the autumn.

· **"Listening Together"** provides a summary of processes, learning and tools used by the project teams to help develop an environment conducive to the participation of children and young people with intellectual disabilities. This publication will be available online at Lumos' website in Autumn 2013 and is intended to offer practical advice and ideas. It corresponds to the Guidance Manual on the Participation of Children with Intellectual Disabilities listed in the project description. In order to make this resource as useful as possible for practitioners, it will be a web-based resource and will be regularly improved and adapted to include new learning and experiences.

· **"Our Words, Our Actions"** is an easy read publication written by children and young people with intellectual disabilities and tells the story of the project from their perspective. It summarises their views on each of the ten priorities of the Declaration and concludes with their most urgent recommendations. This report is for politicians, for parents, for people who care for children with intellectual disabilities and for children and young people with intellectual disabilities, to give them ideas about how they can get involved and push for change. This report will be published and distributed widely at upcoming Lumos events. It has been translated into French, Bulgarian, Czech, Serbian, Romanian and Russian and edited to ensure that the language is easy to understand. In the original project description it was envisaged to have easy read versions of all project publications. On advice from CHANGE, however, it was decided to produce a single easy read publication which captured all aspects of the project, notably the children and young people's views on

the BHBL Declaration, their key recommendations to policy makers and the highlights of the project from their perspective.

• **Self-Evaluation Tool:** A new web-based tool has been developed in 5 PROGRESS Country languages and will be made available on the website in autumn 2013, when finalised. It will also been made available in Russian because of the potential impact such a tool could have in pre-accession and European neighbouring countries. This tool is intended to be useful to civil society, academics and governments in assessing their country's level of implementation of the BHBL Declaration. It also features examples of good practice for each of the Declaration's priorities. The final product is a result of input and feedback from steering committee members and the external evaluator. Following testing in Serbia, Bulgaria, the Czech Republic and control country Moldova, final changes are being made to the tool during summer 2013. Please see the *social experimentation* chapter of section two for more detail.

In addition to the main outputs outlined above, the following publications and outputs have also been produced to showcase different aspects of the project and will also be widely disseminated in line with the post-project dissemination strategy outlined below.

• Once finalised by the Serbian Ministry of Health, the National Action Plan produced by that National Working Group will be uploaded onto the Lumos web site.

• Videos and animations produced during the project will be available for the wider public at Lumos website. The subjects of these films are as follows:

1. Bulgarian parents speaking about the impact of the project on their children and what the BHBL Declaration means to them. (This was first shown at the transnational workshop in Sofia in September 2012 and demonstrates the impact on parents of the project.)

2. Czech National Working Group's priorities for a National Action Plan. (This was shown at the third steering committee meeting in June 2013 and demonstrates a way of sharing policy demands in an easy to understand way.)

3. Voices of children sharing their dreams and interpretation of the rights in the BHBL Declaration. (This was first shown at the third steering committee meeting in June 2013 and links pictures drawn by the children with their voices.)

4. A film made by a local co-ordinator in the Czech Republic and a child with an intellectual disability showcasing a participative approach to sharing the voices of children with communication difficulties. (This has yet to be shared beyond the project team.)

5. A film showing the Czech Child Choice event featuring interviews with participants about their views of the TWIA project. (This was shown at the transnational workshop in Prague in January 2013.)

6. Tour of Dreams /Child Choice Event Animation. This features the actual messages of children involved in the project and is voiced by one of the Bulgarian children who took part. (This is being finalised in August 2013.)

• Leaflets, posters and general advocacy materials were produced in each country to support the messages of the child participation activities and Child Choice events advocating for the rights and needs of full inclusion for children with intellectual disabilities. They were widely disseminated at each Child Choice Event. Examples of these materials have been sent to the Lumos office and where possible examples have been sent together with this report.

A post-project dissemination strategy is being developed to use these project publications and outputs strategically. This will begin in earnest with the launch of the project web site in September 2013 and continue with an event in Brussels, linked to the Hear our Voices project targeting policy-makers later in the year (See section 6 above for more detail). Further events in 2013 and 2014 will also be used to disseminate the publications to a wide audience.

• **September 2013: Launch of project web pages with all project outputs**

The dedicated web pages will contain PDF versions of each of the outputs in all language versions and links to the Self Evaluation Tool in various languages. It could, subject to discussions with WHO Europe, also potentially serve as a central point of information for the implementation of the SHBL initiative in the future. These web pages are currently being developed and will be hosted on the Lumos website www.wearelumos.org

5 November 2013 (Date tbc): Turning Words into Action Dissemination event in the European Parliament, Brussels. (Linked to the Hear our Voices EC funded project led by Inclusion Europe)

This event will be organised to share all of the project outputs from Turning Words into Action and target European policy makers. It will be a joint event together with Inclusion Europe and also launch the initial research of their EC funded project "Hear our Voices" into good practice in child participation with children with intellectual disabilities. Lumos is formally collaborating with this project to ensure as broad as possible dissemination of the findings of the TWIA project and sustainability of the learning (see the continuity section above for more information). During 2014, under the "Hear our Voices" project, seminars on the rights of children with intellectual disabilities will be planned in Switzerland, Brussels, Bulgaria, Czech Republic and Spain. TWIA materials will also be widely disseminated at these events. If meaningful participation can be assured, children who participated in the project will be supported by Lumos to contribute to these events.

6 November 2013: From the Kennedy Law to the Berlin Wall: Ending the Institutionalisation of Children, European Parliament, Brussels

This event will be co-hosted by Lumos and the Chair of the European Parliament Disability Intergroup Adam Kosa MEP. This event is intended to mark the 50th anniversary of the US Kennedy law that began the deinstitutionalisation process in the USA and one year before the 25th anniversary of the fall of the Berlin wall, which sparked a wave of deinstitutionalisation across Central and Eastern Europe. If meaningful participation can be assured, children who participated in the project will be supported by Lumos to contribute.

13-15 November 2013 (Date tbc): Lumos and Ministry of Education International conference on inclusive education, Chisinau, Moldova

Romanian (and Russian) language versions of the project publications will be disseminated. Children will be prepared and supported to take part in this event to showcase child participation methodology.

Social Media: The two events in Brussels will be promoted on social media, coupled with a strong message of the importance of ending the institutionalisation of children across Europe. Lumos has access to a significant number of followers and supporters on social media around the world. This would ensure an immediate global reach for the publications and the other project outputs.

Other opportunities: Lumos is a founding member of the Bulgarian coalition Children 2025, the European Expert Group on the Transition from Institutional to Community Based Care, the UNICEF Global Partnership for the Inclusion of Children with Disabilities in Development and participates at major conferences and summits around the world. Every appropriate opportunity will be taken to disseminate the project outputs at these forums among the other stakeholders involved. Special attention will also be paid to seeking an opportunity with the World Health Organization where the outputs and outcomes of this project could be formally and publicly presented. This renewed focus on the BHBL Declaration could be particularly timely given that countries are due to report to WHO on their implementation of the Declaration in 2015.

EU visibility in the form of the EU flag and the appropriate text has been assured at all events and in all project publications. That the project was funded by the European Union was also announced at all National and Transnational meetings and printed on meeting documentation. 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 therein.



SUMMARY OF QUANTITATIVE INFORMATION

Please note that quantitative performance information must be submitted in relation to all outputs delivered during the implementation of the action grant.

Reports

Were there any REPORTS (which include written outputs such as reports, analyses, studies, reviews, manuals, working papers, toolkits, etc.) produced as part of your action?

☒ Yes
☐ No

Total number of reports

14

Please provide the total number of independent written outputs, irrespective of whether they were published or not. An output produced in several languages counts as a single output.

Next please disaggregate the total number into the subcategories provided according to the written output's primary objective. A single output may fall into several categories (e.g., a study may aim at produce policy advice and at the same time to identify good practice).

Reports aimed at providing policy advice, research and analysis

7

Reports aimed at identifying good practices

3

Monitoring and assessment reports on the implementation of laws or policies

2

Reports aimed at the development of appropriate statistical tools, methods and indicators

2

Scope of dissemination

Have the reports been actively distributed?

☒ Yes
☐ No

Total number of material copies distributed

1000

Please provide a total cumulative number for all the reports.

EU-level policy and decision-makers

50

National/regional/local-level policy and decision-makers

90

Social, economic/business partners

0

Civil society, NGOs

90

Academia, experts, think tanks

90

Media, Journalists

90

If the reports have been published online, please also provide the total number of their downloads by unique users

90

Information / promotional material / website

Were there any INFORMATION/PROMOTIONAL MATERIALS (including leaflets, brochures, newsletters, websites, articles in media, video material, etc.) produced as part of your action?

☒ Yes
☐ No

Total number of pieces of such information and promotional material

12

Please provide the total number of various information and promotion materials, irrespective of their form/type of publishing (video, electronic document, printed on paper, etc.). An output produced in several languages counts as a single output.

Total number of printed material copies

1100

Number of copies in easy-to-read language for disabled people

1100

Number of copies in each language

Language

- Select a language --
☒ English
☐ French
☐ German
☐ Other languages

Copies

200

Language

- Select a language --
☐ English
☒ French
☐ German
☐ Other languages

Copies

200

Language

- Select a language --
☐ English
☐ French
☐ German
☒ Other languages

Copies

700

Scope of dissemination

Next please provide the total cumulative number of the disseminated copies of these materials (e.g., printed/published copies distributed to your target audiences, number of downloads of the electronic copies published on websites, number of unique visitors to your information/promotional website(s), etc.).

Total number of material copies distributed

600

EU-level policy and decision-makers

50

National/regional/local-level policy and decision-makers

110

Social, economic/business partners

0

Civil society, NGOs

110

Academia, experts,
think tanks

110

Media, Journalists

110

Total number of visits to websites related to
information and promotional (e.g., the website
of your action). The average no. of unique visits
per month during the reporting period.

110

Training / mutual learning

Were there any TRAINING/MUTUAL LEARNING
EVENTS (which include various trainings, peer
reviews and other forms of mutual learning)
organised as part of your action?

☒ Yes
☐ No

Number of trainings sessions, peer
reviews and other mutual learning
events

16

Total cumulative duration of these
events

18

Please sum up duration of the above events,
converted into full working day equivalent, i.e. 8
hours. For example, 1 four-day training (4 days) and
1 half-day round-table discussion (0.5 day) result in
total cumulative duration of 4.5 days.

Number of individuals who participated
in these events

291

Number of women among these
participants

204

Survey results

You were asked to carry out a short on-the-spot participants' satisfaction survey for each event organised. Please report on the survey results.

Event

Title of the event

Transnational Workshop

Total number of participants

63

Total number of participants
responding to at least one compulsory
question

52

Next please report on participants satisfaction obtained from the standardised questionnaire.

Did the event match your needs?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

62

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

36

Did you gain relevant knowledge and information?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

60

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

37

Will you be able to apply such knowledge and information in your work?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

61

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

26

Event

Title of the event

Follow Up Transnational
Workshop

Total number of participants

65

Total number of participants
responding to at least one compulsory
question

37

Next please report on participants satisfaction obtained from the standardised questionnaire.

Did the event match your needs?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

85

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

10

Did you gain relevant knowledge and information?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

76

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

15

Will you be able to apply such knowledge and information in your work?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

78

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

8

Event

Title of the event

National Working group meetings

Total number of participants

Total number of participants
responding to at least one compulsory
question

Next please report on participants satisfaction obtained from the standardised questionnaire.

Did the event match your needs?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

Did you gain relevant knowledge and information?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

Will you be able to apply such knowledge and information in your work?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

Other information and communication events

Were there any OTHER INFORMATION AND
COMMUNICATION EVENTS (which include various
seminars, conferences, round tables, networking
events, etc.) organised as part of your action? ☒ Yes
☐ No

Number of information and
communication events

Total cumulative duration of these
events

Please sum up duration of the above events,
converted into full working day equivalent, i.e. 8
hours. For example, 1 four-day training (4 days) and
1 half-day round-table discussion (0.5 day) result in
total cumulative duration of 4.5 days.

Number of individuals who participated
in these events

Number of women among these
participants

Survey results

You were asked to carry out a short on-the-spot participants' satisfaction survey for each event organised. Please report on the survey results.

Event

Title of the event

Steering Committee meeting

Total number of participants

14

Total number of participants
responding to at least one compulsory
question

8

Next please report on participants satisfaction obtained from the standardised questionnaire.

Did the event match your needs?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

90

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

10

Did you gain relevant knowledge and information?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

90

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

10

Will you be able to apply such knowledge and information in your work?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

80

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

20

Event

Title of the event

Steering Committee Meeting

Total number of participants

25

Total number of participants
responding to at least one compulsory
question

19

Next please report on participants satisfaction obtained from the standardised questionnaire.

Did the event match your needs?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

75

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

15

Did you gain relevant knowledge and information?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

76

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

12

Will you be able to apply such knowledge and information in your work?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

46

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

37

Event

Title of the event

National Working Group meetings

Total number of participants

37

Total number of participants
responding to at least one compulsory
question

32

Next please report on participants satisfaction obtained from the standardised questionnaire.

Did the event match your needs?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

72

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

12.5

Did you gain relevant knowledge and information?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

73

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

13

Will you be able to apply such knowledge and information in your work?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

47

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

12.5

Event

Title of the event

Steering Committee meeting

Total number of participants

21

Total number of participants
responding to at least one compulsory
question

20

Next please report on participants satisfaction obtained from the standardised questionnaire.

Did the event match your needs?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

80

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

20

Did you gain relevant knowledge and information?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

80

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

20

Will you be able to apply such knowledge and information in your work?

Share of
respondents having
responded as 5 "yes,
agree strongly", per
cent

64

Share of
respondents having
responded as 4 "yes,
somewhat agree",
per cent

30

EXECUTIVE SUMMARY

With a view to disseminating all results obtained and outputs delivered under the grant agreement, all beneficiaries are requested to provide an Executive Summary which will be posted on the website of the Directorate-General for Employment, Social Affairs and Inclusion.

Upon a reasoned and duly substantiated request by the beneficiary, the Commission may agree to forgo such publicity, if disclosure of the information indicated above would risk compromising the beneficiary's security or prejudicing his commercial interests.

Such a summary should be written in English. It should be a stand-alone summary of the action and its implications. Thus it must be well thought out and presented as it may be a unique opportunity to publicise your work and your organisation.

Short description of the action

A concise description of the context in which the action was carried out, the target group(s) of the action as well as the key activities and deliverables.

1/2 page maximum.

Executive Summary - Turning Words into Action: *Enabling the Rights and Inclusion of Children with Intellectual Disabilities in Europe*

- **Name of Project:** Turning Words into Action (TWIA)
- **Duration of Project:** 19 September 2011 to 19 June 2013
- **Agreement Reference:** VS/2011/0161
- **Application Reference:** VP/2010/007/0035
- **Lead Agency:** Lumos Foundation
- **Partners:** Child Rights Centre/ Centar za prava deteta, Serbia, Karin Dom Foundation, Bulgaria and Pardubice County, Czech Republic.

Summary

The TWIA project brought together children and young people with intellectual disabilities, their parents, policy makers and health and educational professionals in Bulgaria, the Czech Republic and Serbia with the aim of bringing the World Health Organization's 'Better Health Better Lives' (BHBL) Declaration to life through meaningful and effective child participation activities and outcomes.

Acknowledging the multiple discrimination and exclusion faced by children with intellectual disabilities across Europe, the BHBL Declaration built on the rights contained in the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD). This Declaration, signed by 53 countries in 2010 that are committed to implement this, coupled with the EU Disability Strategy provide the foundation upon which children with disabilities can better participate fully in European society. The TWIA project has provided a template for other countries to follow which will ensure that children, their families and professionals all work together to identify and design services that meet their needs and which support them to achieve their potential. This was done in the following ways:

- 1. Establishing National Working Groups**, that met regularly to discuss the steps required for implementation of the BHBL Declaration and consisting of government officials, representatives of UN agencies such as UNICEF and WHO, civil society, policy experts, practitioners, self-advocates, parents and in every case two children or young people from the child participation group
- 2. Child Participation Activities** through groups in each country with the objective of building the confidence, capacities and skills of children so that they could express their views and advocate for change. Activities in each country culminated in three 'child-choice' events which were designed and organised by the children themselves - each with the objective of reaching out to their communities.

Key Deliverables

Various publications have been produced, and will be made available in several languages on line at www.wearelumos.org during autumn 2013. These include:

- 'Turning Words into Action' a guide to using the BHBL Declaration for National Planning involving children with intellectual disabilities which contains a summary of how the project influenced policy in each country;

- 'Our Words, Our Actions', a children's publication in easy read format sharing the children's view of the BHBL Declaration, their experience of the project and their messages to policy-makers;
- 'Listening Together', a web based resource containing practical advice and ideas for creating a suitable environment for child participation;
- 'Tour of Dreams': A short animation about the project featuring views of the children involved, narrated by one of the children from the Bulgarian group;
- A web-based self-evaluation tool has been developed to help national representatives assess a country's level of implementation of the BHBL Declaration in policy and practice.

Main objectives of the action

1/2 page maximum.

The aim of TwiA was: To improve the life chances, inclusion, access to rights and social participation of children and young people with an intellectual disability in Europe through meaningful child participation activities which can support the development of services and national policies.

Key results

- Results/outcomes of the action, including benefits for main actors and target group(s)
- Added value of the action, i.e. the lasting impact and/or multiplier effect.

1 page maximum.

1. Empowerment of children and young people through participation

Forty nine children and young people with intellectual disabilities who participated in the groups set up by this project were able to learn more about their rights, support their younger peers and to express their need for quality healthcare, community living, employment, lifelong training and education opportunities based on their own personal experiences. The impact on the self-esteem and confidence of the children to express their own thoughts and ideas has been noted by the children themselves, parents, staff who work with the children, the external evaluator, policy-makers and in the Knowledge, Attitude and Practice (KAP) survey which was carried out to assess the impact of the project. The opinions, ideas and experiences of the groups and their facilitators have formed the core part of two publications 'Our Words, Our Actions' and 'Listening Together'.

2. Preliminary action towards implementation of the BHBL Declaration through influence on policy and practices

The TwiA project was able to start the process of influencing policies and practices (or at least promote commitments to future action) in each of the three countries. They include the development of a National Action Plan focussed on BHBL in Serbia with cross-ministry support and officially mandated by the Ministry of Health; a commitment from the Ministry of Education in Bulgaria to include measures relating to inclusive education and child participation in the forthcoming National Education Act and to establish a working group to develop a new programme on independent living for young people with disabilities; a commitment from Pardubice County in the Czech Republic to further build child participation practices into the current preparations to reintegrate young people from institutions in the community and to share their experiences with other counties. A summary of how the project influenced policy in each country can be found in the publication, 'Turning Words into Action.'

3. New ways of working: positive experiences of working together

The environment and framework for the meetings, supported by UK-based human rights organisation CHANGE, were always designed to encourage the participation of the young self-advocates: it was not simply a case of opening adult meetings up to child participation. The children and young people in the project had no previous experience of participatory engagement or public speaking, they lacked confidence and had previously experienced occasions in which they had not been expected to express their points of view or be listened to. A KAP survey measured the positive changes they experienced through the project.

This project represented a significant step forward. It is hoped that the experiences and processes it trialled will inform others working to implement

policy and practice change for children and young people with intellectual disabilities through meaningful child participation activities. In particular, it is hoped that 'lessons learned' from this project will help countries seeking to advance or develop their own action plans to implement the BHBL Declaration or other similar human rights agreements.

For Further Information please contact:

Georgette Mulheir

Chief Executive

Lumos Foundation

12-14 Berry Street

London EC1V 0AU

United Kingdom.

Telephone:- 44 (0)20 7253 6464

info@lumos.org.uk

www.wearelumos.org

Translations

You can now add the translations of the executive summary entered before. This information will also be published on the website allowing more people to know about your action.

COMPULSORY MENTIONS OF EUROPEAN UNION SUPPORT

In accordance with the General conditions, all beneficiaries are under the obligation to acknowledge that the present activity has received funding from the Union in all documents and media produced, in particular final delivered outputs, related reports, brochures, press releases, videos, software, etc. including at conferences or seminars. In the context of the European Union Programme for Employment and Social Solidarity - PROGRESS, the following formulation shall be used:

This (publication, conference, training session etc) is supported by the European Union Programme for Employment and Social Solidarity - PROGRESS (2007-2013).

This programme is implemented by the European Commission. It was established to financially support the implementation of the objectives of the European Union in the employment, social affairs and equal opportunities area, and thereby contribute to the achievement of the Europe 2020 Strategy goals in these fields.

The seven-year Programme targets all stakeholders who can help shape the development of appropriate and effective employment and social legislation and policies, across the EU-27, EFTA-EEA and EU candidate and pre-candidate countries.

For more information see: <http://ec.europa.eu/progress>

For publications it is also necessary to include the following reference: "The information contained in this publication does not necessarily reflect the position or opinion of the European Commission".

With regard to publication and any communication plan linked to the present activity, the Beneficiary will insert the European Union logo and mention the European Commission as the Contracting Authority in every publication or related material developed under the present grant agreement.

SIGNATURE

Declaration

Title

Ms.

First name

Georgette

Surname

Mulheir

Position held in the organisation

Chief Executive

Organisation name

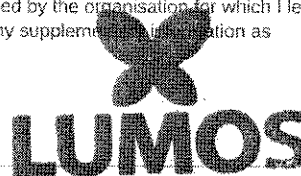
LUMOS Foundation

I confirm that I am duly authorised to sign this declaration on behalf of the organisation named. I certify that the information given in this report is correct, and confirm that the enclosures are current, accurate, and adopted or approved by the organisation for which I lead. I understand that you may contact me to clarify any details in this report, including providing any supplementary information as applicable. I confirm that I am authorised by the organisation for this purpose.

On behalf of the organisation: date and signature



13/09/13



Working to transform the lives
of disadvantaged children

Registered company number: 5611912

Check List

- ☒ Have you responded within the required deadline?
- ☒ Have you made sure that all your published material acknowledged support from the EU?
- ☒ Have you attached the documentation as required in your grant agreement:
 - The print-out of the duly completed, validated and submitted on-line final budget form SWIM which stands as your financial report;
 - Executive summary of your work in English in no more of 2 pages (see proposed structure). As indicated below, the Executive summary must contain a 1-page section on "Key results" of the action. The key results should be concise, sharp and easily understandable;
 - Printed and electronic copies of information and promotional materials funded by the grant (articles, leaflets, brochures, programme, stickers, posters, tapes, calendars, etc);
 - Printed and electronic copies of the reports, analyses, studies, reviews, manuals, working papers, attendance lists, toolkits, computer discs with information if available etc.) produced under your work;
 - For all events, the list of participants with original signatures of all participants.
- ☒ Have you completed the declaration with the correct signatories?
- ☒ Have you submitted ONE original and ONE hard copy of the final activity and financial reports as well as the supporting evidence and ONE electronic copy of all documents?



European
Commission

EUROPEAN COMMISSION

DG Employment, Social Affairs and Inclusion

Employment, social affairs and equal opportunities

Inclusion, socio-political aspects of migration, social integration policies

Call for proposals:

Call for proposals for Social Experimentations

Reference:

VP/2010/007

Budget Heading:

04.04 01 02

FINAL FINANCIAL STATEMENT

Application reference: VP/2010/007/0035

Agreement ref.: VS/2011/0161

SI2.598413

A handwritten signature in black ink, appearing to be "Lm".

Budget

Total cost of the action	218 833.14
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Total eligible costs (D + I)	218 833.14
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Total eligible direct costs (D)	209 661.73
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Heading 1 - Staff costs

Management.....	37 843.49
Administration.....	42 637.65
Secretariat.....	0.00
Accounting.....	7 985.60
Other staff.....	7 265.45
Total - Staff costs.....	95 732.19

Heading 2 - Travel, accommodation and subsistence allowances

Travel.....	43 669.27
Subsistence allowances (accommodation, meals, etc.).....	17 472.26
Total - Travel, accommodation and subsistence allowances.....	61 141.53

Heading 3 - Costs of services

Information dissemination.....	2 244.00
Translations.....	8 161.61
Reproductions and publications.....	16 393.09
Specific evaluation.....	0.00
Interpretations.....	6 895.93
External expertise.....	0.00
Other services.....	0.00
Total - Costs of services.....	33 694.63

Heading 4 - Administration costs

Depreciation for purchase of equipment.....	0.00
Hire of rooms.....	1 429.25
Hire of interpreting booths.....	4 735.29
Audits.....	1 168.63
Financial services.....	0.00
Other administrative costs.....	11 760.21
Total - Administration costs.....	19 093.38

Heading 1 - Staff costs

Management/Coordination (transnational and national)

Name	Name of organisation and function within the organisation	Status	Daily Salary cost	Number of days	Total	Comment
Project Coordinator (To be hired for this project if grant awarded)	Lumos, Project Manager: Words into Action	.5 time (17.5 hrs/week) for 16 months. Temporary Part-Time position for purposes of this project	181.04	143.00	25 888.72	
Three Steering Group Members to act as expert mentors to local working groups	One mentor per country to attend local working group meetings and provide distance support. Assignment of Steering Group Members as expert mentors will occur in consultation with local working groups at the beginning of the project- see description of action for additional details	(At least) 7 mentor days per country. Total 30 days	173.69	30.00	5 210.70	One mentor per country to attend local working group meetings and provide distance support. Assignment of Steering Group Members occurred in consultation with local working groups at the beginning of the project- D Towell (Czech Republic), V Ispanovic (Serbia) & Haralan Alexandrov (Bulgaria) see description of action for additional details
Two Steering Group Members to facilitate transnational workshops	All project partners and steering group members will participate in planning and designing the workshops, 2 Steering Group members will facilitate the first transnational 4 day workshop, 1 Steering Group member will facilitate the 2-day follow up transnational meeting. Both meetings will also be supported by the with Project Manager	transnational meeting: 3 days (2 people) 1 day at follow up meeting.	286.31	7.00	2 004.17	2 Steering Group members () facilitated the first transnational 4 day workshop and Apostolo Apostolov headed 1 session, 1 Steering Group member () facilitated a further meeting.
Steering Group Members and Project Partners to contribute to production of outputs and reports	All Steering Group Members and Project Partners to contribute-1 day to project outputs/publication.	days in total 22	215.45	22.00	4 739.90	() consultant prepared the first draft of the Self Evaluation Tool (2 days). (), steering group member researched and drafted the Guide To National Planning/ (Entitled: "Turning Words into Action") - 20 days
Project Manager, ()	Lumos, Director of Operations	1 day per month time to manage project over 18 months- Part of Lumos Contribution to funding	350.00	0.00	0.00	not used

Total cost of Management/Coordination..... 37 843.49

Administration/Implementation of the project

Name	Name of organisation and function within the organisation	Status	Daily Salary cost	Number of days	Total	Comment
Local Coordinator Bulgaria-post to be filled:	Lumos, Local Coordinator Bulgaria: Words into Action Project	Temporary Full-Time position for purposes	54.59	366.05	19 982.67	extended for 3 additional months to continue

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Total eligible indirect costs (I)	9 171.41
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Heading 5 - Overheads

Overheads.....	9 171.41
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Total eligible Indirect costs (I).....	9 171.41
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Total revenue of the action	218 833.14
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Income	218 833.14
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Income

Beneficiary's contribution in cash (C).....	43 855.00
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Revenue generated by the action (R)	0.00
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Union Grant (S).....	174 978.14
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Total Income = C + R + S.....	218 833.14
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am

see description of action section 3.6.2 for details		of this project. Full Time (35 hrs/week) for 15 months				support to children after 12 month contract
Local Coordinator Czech Republic- post to be filled; see description of action section 3.6.2	Lumos, Local Coordinator Czech Republic: Words into Action Project	Temporary Full-Time position for purposes of this project. Full Time (35 hrs/week) for 12 months	54.55	213.63	11 653.52	
Local Coordinator Serbia- post to be filled; see description of action section 3.6.2 for details	Lumos, Local Coordinator Serbia: Words into Action Project	Temporary Full-Time position for purposes of this project. Full Time (35 hrs/week) for 12 months	54.46	202.01	11 001.46	Tasks of role split into 3 posts, no budget implications.

Total cost of Administration/Implementation of the project..... 42 637.65

Secretarial costs [No data entered]

Total cost of Secretarial costs..... 0.00

Accounting

Name	Name of organisation and function within the organisation	Status	Daily Salary cost	Number of days	Total	Comment
Finance and Administration Officer - post to be filled with project funds	Lumos, Finance and Administration Officer, Words into Action Project	Temporary part-time position for purposes of this project. .25 time (8.75 hrs/ week) for 14 months	114.08	70.00	7 985.60	Post was recruited in April 2012. 14 months contract. (Not 16 as in project description.)

Total cost of Accounting..... 7 985.60

Other staff

Name	Name of organisation and function within the organisation	Status	Daily Salary cost	Number of days	Total	Comment
	5 days total time for project partner local staff to assist with national and child participation activities locally. Also to include assistance with data collection, evaluation and social experimentation	5 days total over duration of project	150.00	4.80	720.00	
	5 days total time for project partner local staff to assist with national and child participation activities locally. Also to include assistance with data collection, evaluation and social experimentation	5 days total over duration of project	150.75	5.00	753.75	
	Lumos Consultant, External Evaluator for the project	17 days: includes Steering Committees, transnational mtgs, national meeting Serbia etc	305.08	17.00	5 186.36	17 days in total. Meetings plus ad hoc advice and reporting.
Carers/support workers	The individual carers and support workers of children and self-advocates will necessarily provide support at Steering Committee, National and Transnational Meetings	Support workers/carers of specific children. Hired as needed for	100.89	6.00	605.34	2 Support workers for participation at project meetings in Serbia

		days of support services by Lumos				
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Total cost of Other staff 7 265.45

Total staff costs 95 732.19

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Heading 2 - Travel, accommodation and subsistence allowances

Travel, accommodation and subsistence allowance

Please enter in "Daily cost per person" accommodation and daily subsistence allowance (DSA) costs

Purpose of the travel	Place of the event	Average travel cost per person	Number of people	Travel sub-total	Daily Cost per person	Number of people	Number of days	Subsistence and accommodation sub-total	Total	Comment
3 in-country working group meetings. Each meeting will host 10 local delegates for 1 day, travel included in DSA	Bulgaria	280.87	8.00	2 246.96	29.99	2.00	3.00	179.94	2 426.90	
3 in-country working group meetings. Each meeting will host 10 local delegates for 1 day	Czech Republic	227.10	3.00	681.30	19.47	2.00	3.00	116.82	798.12	
3 in-country working group meetings. Each meeting will host 10 local delegates for 1 day	Serbia	251.26	1.00	251.26	30.00	0.00	3.00	0.00	251.26	
Attendance at in-country working group meetings for 1 international delegates/ facilitator per meeting (9 in total, 3 per country)	3 meetings each in Bulgaria, Czech Republic and Serbia	210.25	2.00	420.50	128.55	1.00	10.00	1 285.50	1 706.00	
Attendance at in-country working group meeting for external evaluator to attend 1 meeting per country over project (3 in total)	1 meeting in Serbia	302.67	2.00	605.34	130.00	0.00	3.00	0.00	605.34	Bg and CZ visits covered by transnational workshops
Steering group meetings. 3 in-person meetings over the 18 month project for 10 steering group members + 2 carers/supporters for persons with disabilities).	London	254.00	45.00	11 430.00	20.00	45.00	3.00	2 700.00	14 130.00	
Transnational action planning workshop. Meeting participants include 10 local delegates (travel included in DSA) and 24 international delegates (10 each from Czech and Serbia working groups, facilitators and 1 external evaluator)	Bulgaria	297.11	46.00	13 667.06	30.00	60.00	3.00	5 400.00	19 067.06	
Follow up transnational workshop. Meeting participants include 10 local delegates (travel included in DSA) and 23 international delegates (10 each from Bulgaria and Serbia working groups internal facilitators and 1 external evaluator)	Czech Republic	294.93	45.00	13 271.85	37.50	60.00	3.00	6 750.00	20 021.85	
Project Coordinator to visit each country to meet with Local Coordinators and monitor and support project activities. 2 visits per country for 2 days each over project duration	3 visits in addition to travel for transnational workshops	273.75	4.00	1 095.00	104.00	2.00	5.00	1 040.00	2 135.00	Bulgaria, Serbia and Brussels for EC Conference on Social Experimentation

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Travel for Disabled Steering Group Members to attend teleconference meetings in person with PMT to ensure accessibility and their meaningful inclusion	London	200.00	0.00	0.00	130.00	0.00	3.00	0.00	0.00	Not used
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Total of travel costs..... 43 669.27

Total of subsistence and accommodation costs..... 17 472.26

Total - Travel, accommodation and subsistence allowances..... 61 141.53

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Heading 3 - Cost of services

Information dissemination

Nature of costs	Quantity	Unit cost	Total	Comment
Website, to be hosted on Lumos' site (www.lumos.org.uk) cost for 4 days production and associated fees	0.00	250.00	0.00	All project outputs will be hosted on the Lumos web site. No cost to project.
Production of easy read documents- to ensure all information and results are accessible to children and to individuals with disabilities	2.00	1 029.00	2 058.00	This is an average. It is split between an easy read animation about the Bulgarian child choice event and easy read version of the BHBL Declaration produced in Serbia.
Production of CD-ROM's with all document outputs, child participation tools, reports and additional materials available in all project languages	0.00	0.50	0.00	
leaflets/posters for child participation activities to increase visibility & inclusion in community (500 per country)	372.00	0.50	186.00	Leaflets and posters disseminated at the child choice events in Serbia and editing of a video of parents in Bulgaria talking about the project.

Total information dissemination..... 2 244.00

Translations

Total number of languages (the document is translated to) , Cost per page (1 page=1500 characters without blanks)

Description of documents to be translated	Languages from ... to ...	Total number of language	Cost per page	Number of pages	Total	Comment
Guide to national planning: a pragmatic guide to national planning using the Better Health, Better Lives Declaration as a framework, sharing of experiences, reporting on the process, highlighting innovative aspects in planning and implementing change for children with intellectual disabilities.	English - Bulgarian English - Serbian English - Czech	3.00	20.74	20.00	1 244.40	Used for translation of materials and documents at National Working Group Meetings. This publication, to be called "Turning Words into Action" is being finalised after the the project and will be translated into BG, FR, CZ & Serbian using Lumos' own funds.
An Easy Read Version of the above project report to ensure all results and information are accessible to children and individuals with intellectual impairments. The EasyRead version will have significantly less words per page, reducing the pages costed for.	English - Bulgarian	1.00	25.77	1.00	25.77	Bulgarian translation of easy read materials about the BHBL Declaration used at NWG meetings. 1 invoice
A guidance manual and training module on how to ensuring the effective participation of children and young people with intellectual disabilities in national planning and decisions regarding their lives. To include the process followed during this project and lessons learned.	English - French English - Bulgarian English - Serbian English - Czech	0.00	15.00	50.00	0.00	These experiences will be captured in the Turning Words into Action publication (which will be translated using Lumos funds) and an online resource "listening together".
An Easy Read Version of the above guidance manual focused on how children can be included and what to expect in this process. The EasyRead version will have significantly less	English - Bulgarian	1.00	15.40	11.00	169.40	Used to translate easy read materials for child participation meetings. January 2013 Bulgaria. Easy read guidance incorporated into child

words per page, reducing the pages costed for.						publication below on advice of easy read experts
A child written publication demonstrating their thoughts and feedback on the Declaration. This will largely take the form of pictures or drawings or video with few words needing translation.	English - French English - Bulgarian English - Serbian English - Czech	4.00	15.08	24.00	1 447.68	Translation into project languages plus French. (Based on average costs) Document closer to 50 pages but pages have few words.
A self-evaluation monitoring and evaluation tool which provides a set of indicators for each of the 10 priorities in the Better Health Better Lives Declaration and allows countries to track their own progress and plan next steps.	From English to French, Romanian, Bulgarian, Serbian, Russian, Czech	6.00	17.94	49.00	5 274.36	Permission received from EC to reduce number of translations in line with project realities and where tool can have most impact
translation of draft action plans from project country language into English for review by steering committee and PMT.	Bulgarian- English Czech-English Serbian- English	0.00	15.00	30.00	0.00	Not used

Total translations..... 8 161.61

Reproductions and publications

Document	Number of pages	Unit cost	Total	Comment
Guide to National Planning; 100 copies each BG, CZ & SRB, 200 copies EN, FR (total 700)	30.00	48.75	1 402.50	This document has been edited in advance of publication entitled, "Turning Words into Action". (2 days editing at £600 per day)
child participation manual; 100 copies BG, CZ & SRB, 250 copies EN, FR (total 800)	30.00	6.80	204.00	This document has been proof-read in advance of being finalised. (Fee of £175)
self-assessment M&E tool; 100 copies all EU lang, 50 copies remaining PROGRESS lang (total 2800)	48.00	170.59	8 358.91	Development of Self evaluation tool into an interactive web based resource. Also includes testing of the tool by the National Working Group in Serbia June 2013
50 colour copies of each EasyRead action plan for 3 project countries (total 150)	3 000.00	0.00	0.00	
colour copies of child publication 50 copies BG, CZ & SRB, EN, FR(1000 total)	42.00	153.04	6 427.68	Will be printed in 5 languages. Figures based on average of invoices.44000 printed pages in total
colour copies of EasyRead guidance manual 50 copies BG, CZ & SRB, 100 EN, FR(total 350)	7 000.00	0.00	0.00	incorporated into the child publication
50 copies of each action plan for children with intellectual dis. BG, CZ & SRB (total 150)	3 000.00	0.00	0.00	incorporated into the Turning Words into Action publication to be printed with Lumos own funds

Total reproductions and publications..... 16 393.09

Specific evaluation [No data entered]

Total specific evaluation..... 0.00

AM

Interpretations

Meeting	Languages	Number of interpreters	Number of days	Daily cost per interpreter	Total	Comment
3 local working group meetings, 1 day per meeting - Bulgaria	Bulgarian-English	1.00	1.00	201.01	201.01	
3 local working group meetings, 1 day per meeting- Czech Republic	Czech-English	0.00	3.00	200.00	0.00	
3 local working group meetings, 1 day per meeting- Serbia	Serbian-English	0.00	3.00	200.00	0.00	
Transnational Action Planning Workshop	English - Bulgarian English - Serbian English - Czech	6.00	3.00	231.32	4 163.76	
Transnational Follow up Workshop	English - Bulgarian English - Serbian English - Czech	6.00	2.00	210.93	2 531.16	

Total interpretations..... 6 895.93

External expertise [No data entered]

Total external expertise..... 0.00

Other Services [No data entered]

Total other services..... 0.00

Total - Costs of services..... 33 694.63

CM

Heading 4 - Administration costs

Depreciation for purchase of equipment [No data entered]

Total depreciation..... 0.00

Hire of rooms

Meeting	Number of days	Unit cost per day	Number of rooms	Total	Comment
Steering group meetings	2.00	227.89	1.00	455.78	Used for meetings to prepare self advocates and group members for the steering group meetings. (Average of 2 invoices)
Transnational Action Planning Meeting- Czech Republic	3.00	324.49	1.00	973.47	Held in Bulgaria
Follow up transnational meeting- Bulgaria	0.00	250.00	1.00	0.00	Held in Czech Republic - included in overheads

Total hire of rooms..... 1 429.25

Hire of interpreting booths

Meeting	Languages	Number of booths	Number of days	Unit cost per day	Total	Comment
Transnational Action Planning Meeting	Bulgarian Serbia English Czech	1.00	3.00	1 188.63	3 505.89	includes interpretation of preparation activities for the self advocates.
Follow up transnational meeting	Bulgarian Serbia English Czech	1.00	2.00	614.70	1 229.40	includes interpretation of preparation activities for the self advocates.

Total Hire of interpreting booths..... 4 735.29

Audits

Auditor	Cost	Total	Comment
External audit	1 168.63	1 168.63	Conducted and paid after the end of the project

Total audits..... 1 168.63

Financial costs [No data entered]

Total financial costs..... 0.00

Other administrative costs

Description	Cost	Comment
Child participation activities: materials, transportation, support workers, etc. (2250 per country)	4 582.21	
Child-choice event budget (1000 per country)	7 178.00	

Total Other Administrative costs..... 11 760.21

Total - Administration costs..... 19 093.38

Heading 5 - Overheads

Amount..... 9 171.41

Am

Heading 6 - Income

Total Income (T) 218 833.14

Revenue generated by the action (R)..... 0.00

Union grant (S = T - C - R)..... 174 978.14

Beneficiary's contribution in cash (C)..... 43 855.00

Own contribution..... 43 855.00

Partner's contribution..... 0.00

Other information

Amount of the interest yielded by the pre-financing (Articles I.6 and II.16.4 0.00
of the grant agreement) Compulsory field: If not applicable put a "0".....

GM

Certification

I, the undersigned, authorised to represent the beneficiary, certify that:

- the financial documents submitted to the Commission comply with the financial provisions of the agreement,

- the costs declared are the actual costs

- all receipts have been declared.

Name, first name: **Mulheir, Georgette**

Title or position in the organisation: **Chief Executive**

Date: **04.09.2013**

Signature and official stamp of beneficiary:



Lumos
12-14 Berry Street
London
EC1V 0AU

6 September 2013

Our ref L0085/EAF/DT

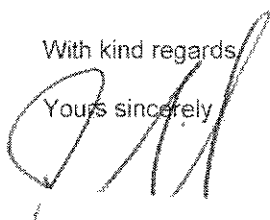
Dear

Turning Words Into Action: Enabling the Rights and Inclusion of Children with Intellectual Disabilities in Europe

I enclose our audit report on the TWIA project for the period ended 18 June 2013, for you to send to the European Commission with the final financial statement.

With kind regards,

Yours sincerely



for Buzzacott LLP

• Email

• Direct

European Commission
Directorate-General Employment, Social Affairs and Inclusion
EMPL.D.4
B-1049 Bruxelles (Belgium)

6 September 2013

Our ref O0531/ASF/DT

Dear Sirs,

Accounting No: SI2.598413

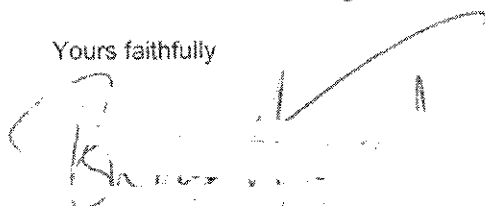
Turning Words Into Action: Enabling the Rights and Inclusion of Children with Intellectual Disabilities in Europe

We have been appointed by Lumos Foundation to audit the financial statements for the Turning Words Into Action project in accordance with article II.15.4 of the project agreement. We confirm that we belong to an internationally recognised supervisory body for statutory auditing.

We have audited the financial statements of the project for the period 19 September 2011 to 18 June 2013 in accordance with International Standards on Auditing and the provisions of the agreement. Having carried out such tests as we considered appropriate and having obtained explanations as we have considered necessary, we certify the following:

- In our opinion, the costs presented in the project's financial statements for the period ended 18 June 2013 are real, accurately recorded and eligible and that all receipts have been declared in accordance with the agreement.

Yours faithfully



A Summary statement of the receipts and expenditure of the TWIA project.

Budget by: Lynda Agboola

Heading 1 - Staff costs	Status	Daily Salary Cost	Number of Days	Total	Summary of receipts and expenditure	Comment
Management Coordination				37,843.87 €		
Project Coordinator	0.5 time (17.5 hours per week) for 16 months.	181.41	143	25,888.74 €	€1303.12 salary per month for 17 months (November 2011 - March 2013)	
3 SGM mentors to national working groups	(At least) 7 mentor days per country provided. (Total 30 days)	173.69	30	5,210.94 €	Invoices Sept 12 - £489.71, Nov 12 - £485.40 Invoices Dec 12: £1418 & Apr 13: £346 Dec 12: £1729	
2 SGM facilitators to transnational meetings	transnational meeting: 3 days (2 people) 1 day at follow up meeting.	286.31	7	2,004.21 €	Invoices Sept 2012: £881.29 & April 2013 - £342 Oct. 12 - 286.32 Oct. 12 - £246.59	
SGM & partners contribute to outputs & reports	22 days in total	296.24	16	4,739.88 €	Invoice Dec 12 - £600 Invoice May 13 - £3456.32	
Project Manager	1 day per month - Lumos contribution to funding	350.00	0	0.00 €	Not used	
Administration, Accounting and other staff costs				57,888.28 €		
Bulgaria local coordinator	temporary full time position, 12 months + 3 months	54.59	366	19,982.47 €	Salary from Jan 12 - March 13	
Czech Republic local coordinator	temporary full time position, 12 months	54.55	214	11,653.62 €	Salary from March 12 - February 13	
Serbia local coordinator	temporary full time position, 12 months	54.46	202	11,001.52 €	Salary from May, June, Sept, Nov, Dec 2012 & Feb 13 = €5244 Salary from Mar, May, June, Sept, Nov, Dec 12 and Feb 13 - €2271 Salary from Mar, May, June, Sept, Nov, Dec 12 and Feb 13 - €3486	The amount incurred is shared among 3 co-ordinators as listed.
Finance and administration officer	temporary part time position 25 time (8.75 hrs/week) for 14 months.	114.08	70	7,985.27 €	Monthly Salary from April 12 to June 13	May 2012 increased due to missing payroll cut off date as staff member started April 17 and June 2013 salary was more with unpaid holiday pay added. 14 months contract from April 2012.
Partner 1: [REDACTED]	5 days	150.00	5	719.88 €	Invoice of November 2012	€616GBP
Partner 2: [REDACTED]	5 days	150.75	5	753.77 €	Invoice of May 2013	€645GBP
External evaluator	17 days: includes Steering Committee mtgs, transnational mtgs, national meeting in Serbia, advice and reporting	305.08	17	5,186.40 €	Invoices from D s - Dec 12: £2563 and May 13: £1875	
Carers/Support Workers	Support Workers/carers of specific children. Hired as needed for days of support services	100.89	6	605.35 €	Salary for Sept 12: 180 Euros and Nov 12: 218.13 Euros. attended in Feb 13: 230.59 Euros	Support Workers for Serbian meetings
Total Heading 1				95,732.14 €		

Key Facts

1£ = € 1.1686338 at 19/06/2013 when updating SWIM version - some difference in XR between time of recording expense in internal accounts and uploading to final report
The total is rounded up to 2 decimal places.

Heading 2 - Travel, Subsistence & Accommodation		Place of the event	Total	summary of receipts and expenditure
National Working Group Meeting Bulgaria	3 in-country working group meetings. Each meeting will host 10 local delegates for 1 day, travel included in DSA	Bulgaria	2,427.00 €	A London travel Feb 12 - £285.98, Mar 12 - £117.92, Apr.12- £6.11, May 12- ££65.37 & £297.53, June 12-£107.52, July 12 - £1065.52
National Working Group Meeting Czech Republic	3 in-country working group meetings. Each meeting will host 10 local delegates for 1 day	Czech Republic	798.18 €	June 12 London travel to CZ - £137.22, Oct.12 travel -£104.13, Nov 12 - £275.37+, Jan 13 - £52.07
National Working Group Meeting Serbia	3 in-country working group meetings. Each meeting will host 10 local delegates for 1 day	Serbia	251.26 €	Feb. 13 Serbian Bill 213-IPL-806:227.92euros, 23117 - 1.79euros, 25650-4.20 euros, 19490 - 2.86 euros, 30193 - 10.25 euros, 27919 - 8.33 euros, 189282 - 3.22 euros
International delegate attending NWG meeting (facilitator), 9 in total, 3 per country	3 meetings each in Bulgaria, Czech Republic and Serbia	Czech Republic, Bulgaria	1,706.00 €	Aug 12-£267, Sept 12-£588, Nov 12-£422 Credit note - £149, BG Aug 12- £21
External evaluator attending NWG meeting (3 in total)	1 meeting in Serbia	Serbia	605.35 €	Oct. 12 London travel & Accommodation to Belgrade - £192+251.70
Steering Group Meetings London	3 in person meetings for 10 Steering Committee Members +2 carers	London	14,130.00 €	Travel and accommodation for SC members in November 2011, April 2012 and May 2013.
Transnational Meeting Bulgaria	10 local delegates (travel included in DSA) and 24 international delegates (10 each for Cz + Serbia + facilitators + 1 external evaluator	Bulgaria	19,067.17 €	Sept 12 - £13,568 & Aug 12 - £2,501+£247 were travel costs for participants at the workshop in Bulgaria.
Follow-up Transnational Meeting Czech Republic	10 local delegates (travel included in DSA) and 23 international delegates (10 each for Cz + Serbia + internal facilitators + 1 external evaluator	Czech	20,022.17 €	Feb 13 Prague Event: £320.08, £245.4, £ 14.22, £186.72, £60.47, £14.22, £211.15, £428.81=£1481.07 and additional Travel ticket to CZ - £409.50 & Catering in Prague £770.67=£1180.17. Travel to CZ meeting - Dec 12- £2786.88+ £69.35+£2187+£36.89 and Jan 13 - £4110.70, £468.57+119.54+£4691.52
Project Coordinator Travel to countries	3 visits for 2 days each	Bulgaria, Serbia and Brussels	2,135.01 €	Nov 11 £204.53, Jan 12 - £1052.98, July 12 £92.71 & £181.60 and June 12 - £295.65 were travel between the 3 countries by Project Co-ordinator/s.
Self-advocates travel to teleconference SGM	London	London	0.00 €	
Total travel, accomodation and subsistence allowance			61,142.14 €	

Comments
A breakdown of July 2012 national spend is found in the Bulgaria folder "Financial report July 2012" 3 Countries
Breakdown is found in Financial Report/3 Countries June & Oct 12 & Jan 13
Breakdown is found in CZ Financial report. The credit note is recorded on Sage as a refund and in the relevant BG financial report.
Recorded on Sage Report - Oct 12
Transactions are found in SAGE report for November 2011, Dec 2011, March 2012, April 2012, May 2013 & June 20 13
Found in SAGE report for both August and Sept 12. (Internal Note £13,568: was originally miscoded on SAGE as 5161 when it should be 5163)
Recorded in Sage Report - Dec 12, Jan 13 & Feb 13,
Recorded in SAGE for the relevant months. Brussels travel is to attend EC Social Experimentation Workshop.

Transnational Action Planning Workshop	English-Bulgarian English-Serbian English-Czech	4163.84	Invoice (Congress Engineering) 4275 euros	
Transnational Follow-up Workshop	English-Bulgarian English-Serbian English-Czech	7531.26	C2 conference in Prague - translator fee £1128 +€437.40	Recorded on Feb 13 SAGE Report
Total interpretations		6895.11		
Total Meeting & Conf. services		33,696.58€		

Heading 4 - Administration costs	Number of Days	Unit cost per day	Number of Rooms/booths		Summary of Receipts	Comment
Hire of rooms				1,429.24 €		
Steering Group Meetings	2	200.00	1	455.77 €	Room hire on 26/03/13-TWIA planning meeting £78 invoice from Saint Luke's Centre & £312 for Serbia Preparatory Meeting	Recorded on SAGE Feb/ March 2013
Transnational Meeting	3	324.49	1	973.47 €	Room hire in BG Sept 12 - £833.33	BG Sept 12 monthly expenditure
Follow-up transnational meeting	0	250.00	1	0.00 €		
Hire of interpreting booths				4,735.29 €		
Transnational Meeting (Bulgarian Serbian English Czech)	3	1,168.63	1	3,505.89 €	Transnational event in BG Sept 12 - £3000 - included in the total £5043.71	Please see BG Sept 2012 monthly expenditure for breakdown
Follow-up transnational meeting (Bulgarian Serbian English Czech)	2	614.70	1	1,229.40 €	Split charge £1052.2 out of total invoice of £1481.07	SAGE Report on Feb 13
External Audit	1	1168.63		1,168.63 €	charge for external auditor	To be paid after June, as agreed by email
Other Administrative costs				11,759.96 €		
Child participation activities: materials, transportation, support workers, etc. (2250 per country)				4582.21	CP,65.68-CP,85.64-TNM CP,276- Local coordinator) trip to Varna,86.28-Admin & Finance,27.38-Conference	Proof SAGE, BG, CZ, & Serbia monthly Expenses
Child-choice event (1000 per country)				7178	Serbia - £2268.81 & £74.29, CZ-£564.74,475.47 & £404 and BG-£622.49, £647.23, £73 and £1011.91	Proof found in Oct 12, Nov 12 and Dec 12 monthly expenses report
Total Heading 4 - Administrative costs				19,093.12 €		

		Summary Receipts	Comments
Heading 5 - Overheads	9,171.44 €		See SAGE
London	4,581.04 €		£3,920
Bulgaria	1,762.30 €		£1,508
Czech Republic	2,624.75 €		£2,246
Serbia	203.34 €		£174
Total budget	218,835.44 €		

A Summary statement of the receipts and expenditure of the TWIA project.

Budget by Lynda Agboola

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Management Coordination				37,843.87 €		
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2 SGM facilitators to transnational meetings	transnational meeting: 3 days (2 people) 1 day at follow up meeting.	286.31	7	2,004.21 €	Invoices Sept 2012: £881.29 & April 2013 - £342 Invoices Oct. 12 - £286.32 Melita Invoices Oct. 12 - £246.59	
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Partner 1: Karin Dom	5 days	150.00	5	719.88 €	Invoice of November 2012	£516GBP
Partner 2: Pardubice County	5 days	150.75	5	753.77 €	Invoice of May 2013	£645GBP
External evaluator	17 days: includes Steering Committee mtgs, transnational mtgs, national meeting in Serbia, advice and reporting	305.08	17	5,186.40 €	Invoices from Dec 12: £2563 and May 13: £1875	
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International delegate attending NWG meeting (facilitator), 9 in total, 3 per country	3 meetings each in Bulgaria, Czech Republic and Serbia	Czech Republic, Bulgaria	1,706.00 €	Aug 12-£267, Sept 12-£588, Nov 12-£422 Credit note - £149, BG Aug 12- £21
External evaluator attending NWG meeting (3 in total)	1 meeting in Serbia	Serbia	605.35 €	Oct. 12 London travel & Accommodation to Belgrade - £192+251.70
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Transnational Meeting Bulgaria	10 local delegates (travel included in DSA) and 24 international delegates (10 each for Cz + Serbia + facilitators + 1 external evaluator	Bulgaria	19,067.17 €	Sept 12 - £13,568 & Aug 12 - £2,501+£247 were travel costs for participants at the workshop in Bulgaria.
Follow-up Transnational Meeting Czech Republic	10 local delegates (travel included in DSA) and 23 international delegates (10 each for Cz + Serbia + internal facilitators + 1 external evaluator	Czech	20,022.17 €	Feb 13 Prague Event: £320.08, £245.4, £ 14.22, £186.72, £60.47, £14.22, £211.15, £428.81=£1481.07 and additional Travel ticket to CZ - £409.50 & Catering in Prague £770.67=£1180.17. Travel to CZ meeting - Dec 12- £2786.88+ £69.35+£2187+£36.89 and Jan 13 - £4110.70, £468.57+119.54+£4691.52
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Recorded in SAGE for the relevant months. Brussels travel is to attend EC Social Experimentation Workshop.

Translational Action Planning Workshop	English-Bulgarian English-Estonian English-Czech	4103.84	Invoice (Cognate Engineer 03 4276 euro)	
Translational Follow-up Workshop	English-Bulgarian English-Estonian English-Czech	2531.29	1/2 conference in Prague - translator fee 21728	Recorded on Feb 13 SAGE Report
Total Interpretations		6635.13		
Total Meeting & Cost of services		33,666.98 €		

Heading 4 - Administration costs	Number of Days	Unit cost per day	Number of Rooms/booths		Summary of Receipts	Comment
Hire of rooms				1,429.24 €		
Steering Group Meetings	2	200.00	1	455.77 €	Room hire on 26/03/13-TWIA planning meeting £78 Invoice from Saint Luke's Centre & £312 for Serbia Preparatory Meeting	Recorded on SAGE Feb/ March 2013
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