

Our Words. Our Actions.

Making lives better for young people with intellectual disabilities



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Thanks to children and young people who participated in the Turning Words into Action project for the front cover illustration.

Easy Read version developed by CHANGE in 2013

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Protecting Children. Providing Solutions.



Foreword



The World Health Organization and 53 countries have signed a Declaration called 'Better Health Better Lives'. The Declaration has 10 promises governments have made that should make life better for children with intellectual disabilities.

The Declaration says it is important to listen to what children and young people want and need. Lumos has

been working with three countries – Bulgaria, the Czech Republic and Serbia - to make this happen. The European Commission supported Lumos to run a project called 'Turning Words into Action'.

Many of the children and young people who took part in this project have intellectual disabilities. The project helped them feel able to talk about what is important to them. It helped them understand their rights and the promises in the Declaration.

They talked about important things like health, education, equal rights and their dreams for the future.

They talked about how they could make things better for other children with intellectual disabilities.

Then they told politicians in their countries what their governments need to do to make things better for children with intellectual disabilities. This is to make sure they have the same chances in life as all other children.

This report has been written by the children and young people themselves. It is written in their words.

The report is for politicians, for parents and for people who look after children with intellectual disabilities. Politicians, parents and care workers can make big decisions that are important in the lives of children. I would like politicians and care workers around the world to really listen to what the young people are saying in this report. I hope they understand that children with intellectual disabilities must have a say in the things that affect them.

The report is also for children and young people with intellectual disabilities, to give them ideas about how they can get involved and make things change for the better. As one of the children said “Our voices can make a difference. We can break down barriers!”

If we all work together, we can make things better for all children with intellectual disabilities. We can make sure they don't have to live in institutions, but can live in their families and communities. We can make sure they can all go to school and have chances to follow their dreams.

Georgette Mulheir

Chief Executive Officer

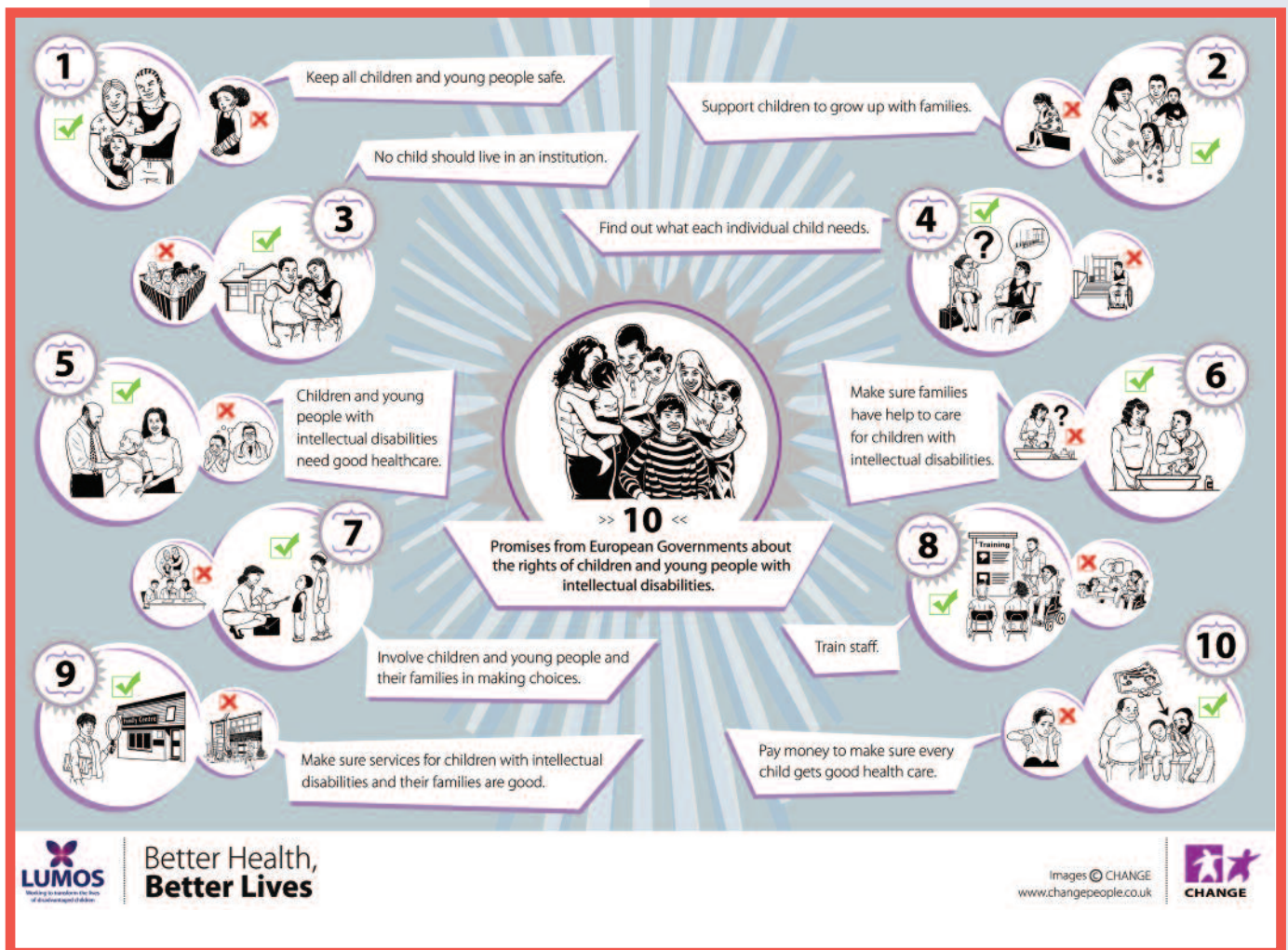
Lumos

Introduction



Children and young people with intellectual disabilities are often forgotten about. Their needs can be ignored by governments.

The World Health Organization Declaration, 'Better Health Better Lives' says what needs to happen to make lives better for children with intellectual disabilities.



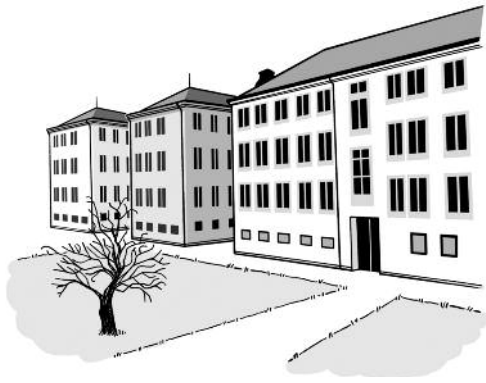


This is a report about the Turning Words Into Action project. This project wanted to make sure that governments listen to children and young people with intellectual disabilities.

Children and young people with disabilities should be part of the community. They should be listened to when institutions are being closed down.

The project happened in three countries: Bulgaria, the Czech Republic and Serbia.

A group of experts helped the project. They were called the Steering Group. Young people with disabilities and their families were also part of this group.



When the project started, people working with the project went to visit children and young people with disabilities. These people were called the project team.



They visited children and young people who lived in institutions. They also visited children and young people who lived at home.



The project team talked to the children and young people they met about the new child participation groups. The groups were started so that governments would listen to children and young people with intellectual disabilities.



One child participation group was started in Bulgaria, one in the Czech Republic and one in Serbia. Children and young people with intellectual disabilities were part of these groups.



Each child participation group had a local coordinator – Aneta, Zlatka and Aleksandar. The local coordinator made sure all the actions in the project happened.



The child participation groups had meetings. It was important to have fun at the meetings. It was also important that everyone could say what they wanted.

Children and young people learned lots of new things. Some children even took part in international meetings with politicians.

They told the politicians what was important in their lives. They talked about what they think should change. The politicians said that they learned a lot from the young people. They said they would try to make things better.





Shaun from the project team helped train the young people. Shaun has an intellectual disability. His job is teaching lots of people about how to make things better for children and adults with disabilities.



This helped the young people find out they could do a lot more in their lives than most people think. The young people were more confident.



The project had two big meetings with people from all three countries. Some young people from the groups were in these meetings. Everyone talked about what they had done to make life better for children with disabilities.



It was good that young people with disabilities from different countries could meet. They talked to each other about their experiences. They said they learned a lot.



One of the project team, Dan, drew pictures of the meetings so all the young people could understand and remember what had happened.



The young people marched with signs in Bulgaria. There were young people from all three countries there. They said that children and young people with intellectual disabilities have the same rights as everyone else. They should also have the same chances in life as everyone else.



At the end of the project the children and young people organised an event. They chose what kind of event they wanted and planned it. They were helped by the project teams.



In Bulgaria the children and young people organised an event called the 'Tour of Dreams'. They travelled from their home town to the capital city of Bulgaria, Sofia.



On the trip they met with other children and young people. They also met with politicians and the British Ambassador to Bulgaria. They talked about what their dreams are for the future. They also said what they were worried about.



The politicians promised they would try to change things for children and young people with intellectual disabilities.

The event was a big success. It was shown on television.



The children and young people in the Czech Republic organised a party for their local community. There were people with disabilities and people without disabilities. They had lots of fun together.

They got their favourite music band to play at the party. Some of the music band had intellectual disabilities and some of them did not. They had lots of fun playing music together. They realised they are all the same and love playing music.



The group made a poster. They also made crafts and cards with important messages. They shared these with people in their community.



The young people made a film of the party. You can see this film on Lumos's website:
www.wearelumos.org



In Serbia, children and young people brought two large cubes into a shopping centre. They painted messages to adults and their government on these cubes. Many children and their families came along and joined in.



The event helped people in the community understand what children and young people with disabilities can do.

This will help everyone understand each other better.

What the children and young people said

Here are some of the things the young people said to each other and to the politicians. There are also pictures by some of the children and young people.

When we got to know each other and agreed to work together we made our own rules. These rules helped us make sure that everyone could say what they wanted. Here are some of the rules we made:

1. Listen to each other when we speak.
2. Talk using easy words (no jargon).
3. We should all be friends.
4. We need to talk loud and clear.
5. We need to share our experiences.
6. We should have breaks.
7. We should have fun and dance.
8. Respect each other.
9. Have patience, slow things down and take your time.
10. Turn off mobiles or put on silent.



During our sessions we discussed different topics and issues.
We shared our dreams, these are some of them:

“I have dreams I would like to share. Any young person with disabilities has the right and need to have contact with so called ‘ordinary’ people. We are good for each other.”



“I would like to fly by plane.”

“...my dream is to work at a library, but that can't happen because I don't have an education.”

“I would like to participate at the Olympic games. I have been to Athens and I was riding a horse and I came first.”

“I would like to become a photographer because it is a very entertaining job.”

“I want to be a horsekeeper”



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



We talked about things that we like



“I like good company”

“I like it when I am welcomed”

“I would like to have a friend”

“I like drawing”

“I like games”

“I like having snacks and talks”

“I like having fun”

“I like that we discuss serious things here”

“I like making necklaces”

“I like singing and dancing”

“I like socialising with other kids”

“I like us learning new things from each other”



We talked about what we do not like or things that we find difficult:

“I like talking to people and I do not like it when they avoid me.”

“It was hard for me to be a part of the school process , I couldn't concentrate. I was lucky enough to have a good teacher. He taught me some maths and how to read and write.”

“If I had a chance to change something, I would change people's attitude to me. I wish they could see me as an equal person. I want everybody to have access to school, jobs and fun with no barriers. I wish people did not think that we are second class people.”

“Friendship is complicated because I am not always good with other people. It is difficult to meet new people. When people are different it can be hard to be open.”

We also had lots of fun by visiting local parks, playing games and just getting to know each other better while doing things we like.



We enjoyed learning about our rights and about the **Better Health Better Lives Declaration**.

We talked a lot about the promises in the Declaration. We talked about what each promise means to us in our lives. Here is what we said about the 10 promises:



1

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!”

“If someone bullies you, you have your parents to protect you.”

“If you do not have parents, you are in big trouble.”

“Nobody likes being bullied.”

“Ensure that all parents treat their children well!”

“If you are hurt, you want to hurt back.”



“When you’re with your family you feel safe and there are people you can rely on.”

“Everybody should have a family and live with their family.”

“I think helping families should be a priority. When a child is born with a problem, parents have to be informed. We should ensure specialists work with the child and know how to support the child and his family, helping the child all the time.”



3

Promise 3 - No child should live in an institution

“It is important to help children get ready to live outside an institution. It is important to talk about what will change in our lives.”

“Some people with learning disabilities suffer from inadequate treatment inside and outside of institutions.”

“It is better living in the community than living in an isolated and lonely environment.”

“We believe every child deserves to be happy with his or her family.”

“Close all institutions, a child’s place is in the family!”

“Not even one child deserves to be alone and to have an unhappy childhood.”

“Every child needs a kiss goodnight.”

“Father, mother and child together!”

“We want to be supported to live independently in our communities – not segregated in large residential institutions.”



4

Promise 4 - Find out what each individual child needs

“Teachers need training how to support children with special needs.”

“We are all different and we are ALL IMPORTANT!”

“Good school means that the teachers respect us, all people and schoolmates treat us nicely.”

“We need special ramps and assistants because the child with a disability cannot get into school on their own.”

“We should think about how to integrate a child with disability to normal schools.”

“It is a matter of pure luck how good your teacher will be.”

“The school should provide transport for its pupils with disabilities.”





“We need special toilets at school.”

“Young people with learning disabilities need better opportunities for employment.”

“Everything has to be accessible for people in wheelchairs.”

“We have equal rights and we insist on this.”

“Children with problems should have a chance to go to the cinema, theatre, parties; to have access to work when they are old enough.”

“Make schools more accessible and increase the funding available for the needs of disabled children.”

“We would like to go to normal school.”

“We want to be treated nicely.”

“I need timely, positive, accessible medical care!”

“It is important that we are healthy, we need good health care.”

“A good doctor is that one you can speak with normally and openly.”

“Good doctors should do their work as best they can. They should avoid mistakes and I can talk with them in a friendly way.”

“People with special needs should have consistent health care with good doctors.”

“It should be easy to communicate with doctors.”

“Children should be healthy and safe at school.”





“The doctor must not just be a good specialist but a good human being too.”

“I want to be healthy, to find a job and to have a family.”

“Doctors have to be careful about the decisions they are making, a good doctor is one that can reach the right decision.”

“We should have a right to choose our doctors. They have to be good and willing to cure us. Every doctor should be happy when they are able to help a person with a problem. The doctors should understand the suffering of each human. And when the doctors succeed in curing a person, they should be happy that they performed a good deed and that during their lives they had given everything to save human lives.”

6

Promise 6 - Make sure families have help to care for children with intellectual disabilities

“Parents should have the right to keep their jobs.”

“It is very difficult to get some financial support or social care services for families in my country.”

“Families need support. We are speaking about the families. And children should have the chance to go to school.”

“We should not give families money only, but also friendly support.”

“Some children don’t get good care from their birth parents, they could get better care from foster parents.”

“In my country, help is given to foster families, the same should be given to birth families.”

“We have a right to have a personal assistant.”

“Families should have more money for their child from the government.”



7

Promise 7 - Involve children and young people and their families in making choices

“The child’s voice is very important.”

“You can ask other people about our difficulties, but we can say best what we need.”

“We need you to ask us what we want.”

“Children and young people can make decisions for themselves and they can say what they need and what is the best for them.”

“It is very important if you ask me questions - How was it today? How is it going?”

“Self-advocates should speak more about the rights of children.”

“You can ask the mother or the father, but you will get the best answer from the child.”



“I told others to accept people with disabilities because we are all equal. I am pleased that I have been able to share my impressions so far. I hope that from my stories and from the words of other mothers we can achieve some positive results. New horizons should open up for young people with special needs. I hope that in the future we can have more of these meetings because they are very useful for all of us.”

“We want to be involved in decision making. We are writing down our thoughts about the 10 promises. I think it is important to have friends and I think all children should live in families.”

“Children’s voices can make the difference and bring down the barriers.”



8

Promise 8 - Train staff

“Those who assist me, please believe in me.”

“I would like to educate professionals who take care of children with disabilities. They should know more about us.”

“Specialists who work with children need specialised training to identify special needs.”

“Better trained teachers and greater contact between teachers and students.”

“I want to talk to doctors, I want to tell them how they can help us better.”



“Everybody wants to work – the problem is that employers don’t want to take people with learning disabilities on.”

“Governments should provide good quality of services for children.”

“I have graduated from the 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.”

“All of us have the right to keep on studying and then get a job and be like other people. We are not second class people, we are the same. We should have equal rights.”



10

Promise 10 - Pay money to make sure every child gets good health care

“I would like to tell the President: Make sure that children have got enough money.”

“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.”



“The project gave me a chance to solve difficult problems and to learn that people with disabilities have a right to our lives being fully valued by others. Thanks to the project I met children and young people and their mothers from another town. They fight to be heard and recognised that they exist.

“If I had a chance to change something, I would change people’s attitude to me. I wish they could see me as an equal person. I want everybody to have access to school, job, fun, no barriers. I wish more people would be good to us, and there were more trained specialists I could ask for support. I wish people would not think we are second class people. Thanks to the project, I realised that we - all young people and adults - can fight for our voices to be heard.”

“I have an idea. I will tell the director of the library to organise an academy for children with disabilities and for children without disabilities together. Where we could be together and do the same things. I would like to organize this academy.”

“I would like to travel around the world and visit lots of countries. I would like to help other people.”



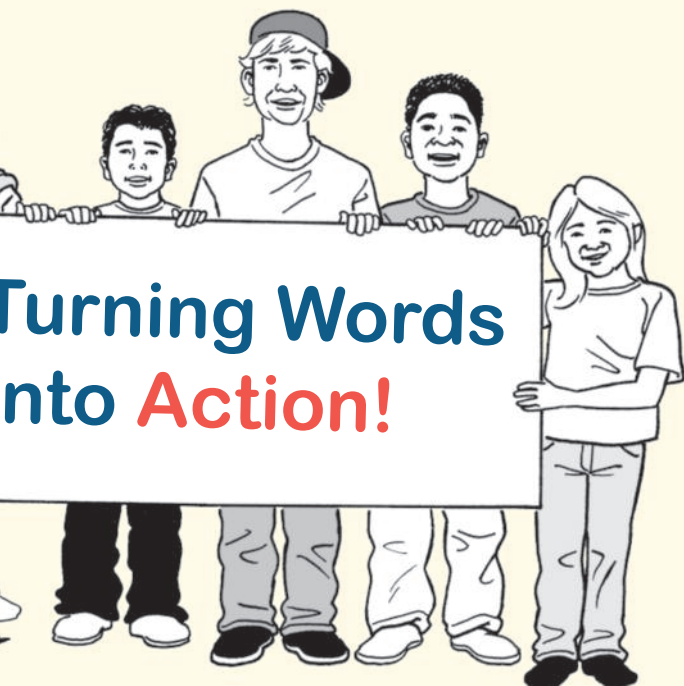
“This is an exciting project as it is the first time that children and young adults with learning disabilities have been given a proper chance, across Europe, to express their views.”

“I want to help make things better for children and young adults with learning disabilities. This project is all about making this happen.”

“I liked this initiative very much because we children, through talking, sharing and games, received lessons for life. We learned how to solve difficult things in our lives.”

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

“I want to keep going as a chair of the self-advocacy group, so I can help more children and young adults. I want to broaden this. I am the first woman with a disability from Serbia to climb a mountain which is 6700m high.”



The most important things we want to tell you



- The Better Health Better Lives Declaration is very useful and practical.
- Supporting children and young people with intellectual disabilities to be involved is very important. Including children and young people helped everyone to learn together.
- 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.
- 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.

- It is important for everyone to work together.
- 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.
- It takes time to support children to be involved and grow in confidence.
- More children without disabilities should be included and have a chance to work together with children with disabilities.



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The contents of this publication are the sole responsibility of Lumos and partners and can in no way be taken to reflect the views of the European Commission.

About Lumos and CHANGE...



Lumos works to help eight million children around the world who have been separated from their parents and put in institutions. Most are there because their parents are poor or because they have disabilities. Lumos works with the UN, European Union, national governments, institution staff, children and families. Lumos tries to make sure that all children can be brought up by their families and can join in the life of their communities and grow up to be happy, successful adults.



CHANGE is a leading UK human rights organisation led by disabled people. CHANGE employs people with learning disabilities to campaign, run projects, research issues, deliver training and co-produce easy read resources about issues that affect the lives of people with learning disabilities.

Word bank



Advocate - Someone who supports people to get their views heard. It can also mean standing up for someone's rights.



Community - The people and the area where you live.



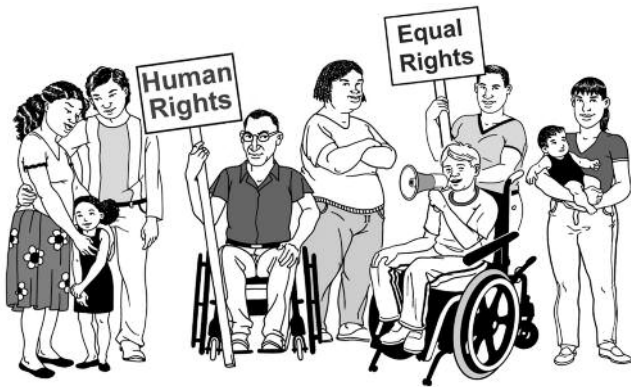
Declaration - A list of promises or agreements.



Education - Schools or ways of supporting people to learn.



Employment - Jobs and having paid work.



Equal Rights - Everyone has the same rights. Children and young people with intellectual disabilities have the same rights to be included as everyone else.



Expert - Somebody who knows a lot about something.



Government - A group of people who are chosen to make decisions for the country. Governments in Europe are chosen by people voting for them.



Institution - An institution is a very big care home. It can be for children or adults. The people who live in the institutions are looked after by care workers. They have been separated from their families, friends and communities.



Local Coordinator - A person who supports this project. They support children and young people to be involved and included.



Participation - Being involved or being included.



Politician - Someone who is chosen to run the country.



Project - People working together to make something better.



Steering Group - A group that helps people working on a project and gives good advice.



World Health Organization - An organisation that works across the world to make sure that everyone has access to good healthcare.

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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>

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