

Hear our Voices!

Promoting and encouraging the participation of children with intellectual disabilities, Side-Event 'Our Journey from Exclusion to Inclusion', 26.9.2014

A project of Inclusion Europe, Eurochild, Cedar Foundation, QUIP, and Down Syndrome Foundation Madrid, in collaboration with Lumos and supported by the European Commission

Recommendations for consideration by the CRC and CRPD Committees in concluding observations and general comments

The "Hear Our Voices!" project started bridging the gap between children with and without disabilities, by training and teaching children with intellectual disabilities to participate in various matters which affect them directly. We worked with children living in small group homes, in large institutional settings, and in their families. We developed tools for individual and collective participation, through pilot activities with parents and professionals who want to make this right a reality in their daily work. We found effective tools and adjusted those to suit both our activities and the strengths and skills of our staff. We saw that one of the major motivations for children is fun and amusement. We learned how to convince children that they can make changes in their lives, can get involved in the process of decision-making, and how small decisions can lead to major changes and can prompt new ways of looking at their own lives.

Participation starts at home, in families, at school, in formal and informal education and in services - all places where children should be listened to, should be able to express their opinions and should feel free to assume their roles and responsibilities. Participation particularly allows children to express their views and to be heard in the context of preventing and reporting abuse. Participation also means to actively involve children with disabilities throughout the policy cycle, including in agenda-setting, planning, implementing and monitoring policies, as well as programmes and services that affect the lives of children with disabilities.

Therefore, to ensure **meaningful participation of children with disabilities**, it is essential

- to consider ensuring the participation of ALL children in ALL environments including those living in institutions or alternative care and to recognise the degree of participation of children with severe disabilities and/or complex needs and as an essential indicator for this.
- to make age-appropriate, accessible information available for children with disabilities, as a fundamental basis for equal participation, especially by using visual tools or audio and tactile aids.
- to use different communication methods (including Alternative and Augmentative Communication Devices), provide early communication advice and help to children and to their families, as well as support to ensure that children with severe disabilities and/or complex needs can meaningfully contribute, be heard and understood.
- to consult directly with children themselves and with their families, as well as with civil society organisations from both the child rights movement and the disability movement, including organisations that represent children with intellectual disabilities and their families in all relevant sectors.

We call upon the CRC Committee to **review the CRC General Comment n°9 on Children with Disabilities** in cooperation with the CRPD Committee, in the light of the shift in approach to disability as highlighted in the United Nations Convention on the Rights of Persons with Disabilities.

We call upon both Committees to explicitly require that State reports include evidence about the participation of children with disabilities and intellectual disabilities, particularly as provisions on the rights to participate for this group of children are either poor or simply non-existent. It is important that in the reporting process, the Committees provide **guidance for State Parties** on measures to develop policy and practice on participatory activities, specifically insisting on making these fully inclusive of children with physical, sensory, intellectual and

psychosocial disabilities, and to those living in institutional or alternative care settings. **Evidence and indicators for sufficient participation of all children** could include:

- Evidence that children with disabilities are provided with the necessary accessible information they may need, so that they can make informed decisions. Such information should be available in a range of alternative formats, as it forms a pre-requisite for participation¹.
- Evidence of consultation with disabled children at local level (by local authorities)² and existence of clear guidance on how to do so in order to involve children with different needs.
- Evidence of existing alternative formats of consultations, including easy-to-read, which should be available to children with different types of disabilities³.
- Published findings on opinions of children, including children with different types of disabilities, about their schools, their leisure facilities and activities, and about the mainstream and specialised services, available to them⁴, as well as an analysis and conclusions for further actions.
- Lists of appropriate programmes or affirmative action projects facilitating the participation of children with intellectual disabilities⁵.
- Evidence of disability awareness training of key staff working with children, but also on communication methods and support for self-advocacy to ensure that children are heard and understood⁶ regardless of their level of disability.
- Evidence from legislation and practice of the use of individual and collective participatory mechanisms (e.g.: use of Person Centred Planning method, children's council), in child care services, including in residential institutions, children's homes and other living facilities.
- Evidence from legislation and practice of the use of both individual and collective participatory mechanisms at schools (e.g.: use of Person Centred Planning method, Pupils' Council, participatory project involving children with and without disabilities)⁷.
- Curricula in both mainstream and special education that includes information about human rights and children's rights, including those of disabled people⁸.
- Evidence that available and accessible complaint mechanisms exist in places frequented by children with disabilities (such as children's hospitals, schools, child services, etc.), and that staff working in such services are trained in child participation and communicating with children with intellectual disabilities.

We also call upon both Committees to **encourage State Parties**

At all levels of action (national, regional, and local)

- to address child participation in a comprehensive manner to avoid falling into the gap between disability rights and children's rights policies. Children with disabilities should be fully integrated into existing child participation mechanisms and have specific mechanisms targeting them.
- to recognise the knowledge and the expertise of children with intellectual disabilities and their families in relation to their lives and their real needs.
- to provide support and financial assistance to projects and initiatives that aim to meaningfully consult children with disabilities, including children with intellectual disabilities, in matters of importance, using accessible, non-threatening and appropriate communication.

¹ Art. 7, 9, 21 CRPD, Art. 12 and 17 CRC

² Art. 4.3, 7, 33.3 CRPD, and Art. 12 CRC

³ Art. 7, 9, 21 CRPD, and Art. 12, 13 CRC.

⁴ Art. 7, 19, 23.3 CRPD, and Art. 18, 23, 29 CRC

⁵ Art. 4.3, 5.4, 7 CRPD and Art. 12, 23 CRC

⁶ Art. 4.1i), 7, 13, 24, 25 CRPD and Art. 12 CRC

⁷ Art. 7, 24 CRPD and Art. 12, 23 CRC.

⁸ Art. 8, 24 CRPD and Art. 29 CRC

- to make sure that children with intellectual disabilities and their families are involved and participate fully throughout the policy cycle, in designing, planning, implementing and evaluating policy changes and service provisions, in order to ensure a constructive and trusting relationship.
- to provide capacity-building and financial resources to organisations of children with disabilities and their families, to make sure that they will have the capacity to fully participate and contribute to all relevant policy changes.
- to provide a wide range of support and adjustments to ensure participation, such as age appropriate materials, sufficient time, appropriate venues and approaches, skilled facilitation, etc
- to develop adequate measures and adapted instruments for children with intellectual disabilities to express their views and to be heard in case of abuse.

At school level

- to ensure that both mainstream and special schools and their curricula provide opportunities for children to be heard, and equip children with the necessary skills such as decision-making, self-determination and knowledge of rights so that, with the proper support, they can participate fully in all aspects of their lives.

In child care services

- to provide individual care plans for every child attending a support service or in transition from institutional to community-based living;
- to creatively combine and use child centered approaches and communication systems to help children be heard and participate in the decision-making process.
- to ensure that children are actively involved in the planning and monitoring of services, and in measuring the quality of the services they use.
- to create meaningful everyday participatory mechanisms for children in child care services, including children homes and other living facilities.

With different stakeholders:

- to ensure that in all environments children are able to hold responsibility for their own lives and for what happens to them, in order for them to learn they also have the right to receive appropriate information and to speak their minds.
- to work with families of disabled children to reduce their fears about participation in inclusive settings. As parents play an important role in advocating for the rights of their children and for quality services, they need to be supported to become advocates, to actively listen to their children and to convey positive messages within the community
- to support and invest in training the staff of child protection authorities and incorporating child-centered methods into their work.

<http://www.childrights4all.eu/>

 <p>www.inclusion-europe.org</p> <p>Inclusion Europe</p>	 <p>www.eurochild.org</p> <p>eurochild 10 YEARS 2014</p>
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