

## **Input to the Committee on the Rights of the Child**

Uloba – Independent Living Norge SA is grateful for the opportunity to provide input to the Committee on the Rights of the Child on children's rights and alternative care. Uloba is a non-profit organisation run by and for disabled people. Our work is dedicated to the promotion of full equality, participation in society and freedom of self-expression for disabled people. Our goal is a diverse and inclusive society, where there is room for everyone and everyone is of equal value. Our work is based on the Independent Living ideology and disabled people's fundamental human rights.

### **The situation of disabled children and young people**

There are approximately 93 million disabled children in the world; and half of them do not attend school.<sup>1</sup> We know that disabled children and young people generally face stigma and obstacles that prevent them from fully participating in society. Disabled children and young people are often invisible and hidden away by their families, kept apart from society. This may not be evident in national statistics however, and thus they remain 'unseen' by decision-makers, service providers and society as a whole. We know that their rights are violated in numerous ways. They often do not receive sufficient and comprehensive information, help and support from their municipality or help from specialist services, and often receive co-located services and segregated housing arrangements. More serious violations also take place: up to 68 per cent of disabled girls and 30 per cent of disabled boys across the world are sexually abused before their 18th birthday.<sup>2</sup>

Society tends to want to 'fix' disabled children rather than change attitudes towards them. The focus is on medical responses to correcting 'defects' rather than on generating broader support to help children achieve their potential. Stigma and the obstacles created by society often lead to disabled children and young people being institutionalised. Across the world, disabled children are almost 17 times more likely to live in an institution than other children.<sup>3</sup> This creates an extra vulnerability that non-disabled children and young people do not have to deal with. It is therefore important that legal safeguards are in place to protect disabled children and young people. During 2020, decisions were made regarding respite care in an institution for 2,118 children under the age of 18 in Norway.<sup>4</sup> This paints a picture of disabled children and young people being seen as a burden for their families and society. We believe that irrespective of functional ability, children have the right to achieve their full potential, and be included in society.

### **Human rights of disabled people**

Although the UN Universal Declaration of Human Rights applies to everyone, we know that many disabled people are unable to enjoy these rights. The UN therefore adopted a separate Convention on the Rights of Persons with Disabilities (CRPD) in 2006. The CRPD has been pushed through by disabled people, to ensure that we are full citizens with the same rights and obligations as other citizens. In other words, the CRPD sets out requirements for how countries must ensure that disabled people

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<sup>1</sup> [Children With Disabilities | UNICEF USA](#)

<sup>2</sup> [Children with disabilities | UNICEF Europe and Central Asia](#)

<sup>3</sup> [Children with disabilities | UNICEF Europe and Central Asia](#)

<sup>4</sup> [Health and care services \(IPLOS\) in KPR \(municipal patient and user registry\) - Directorate of Health](#)

can enjoy their human rights. The convention states that disabled people shall have power and control of their own lives, with the same opportunities as everyone else to make their own decisions. Uloba's political work has the same point of departure as the CRPD, which is based on the social model and the Independent Living ideology.

Norway ratified CRPD in 2013. Despite this, the convention has not been incorporated into the Norwegian Human Rights Act, as has been the case for the conventions on the rights of women and of the child. In autumn 2020, representatives of the Socialist Left Party submitted a proposal to the Norwegian parliament, the Storting, on incorporating the CRPD into the Human Rights Act. A slim majority voted against the proposal on 9 March 2021, but several parties are backing incorporating the UN Convention on the Rights of Persons with Disabilities in their parliamentary election platforms. There will therefore be a large majority at the Storting for incorporating the CRPD into the Human Rights Act after the 2021 election.

The CRPD is very important for disabled people, as it clarifies the parties' obligations and the principles concerned. We would like to highlight three important human rights principles that apply to disabled children and young people. They are: 1) the principle of the best interests of the child 2) the child's right to care and protection, and 3) the right to family life. The CRPD and the Convention on the Rights of the Child elaborate on, among other things, how these principles are to be understood and how they must be based on non-discrimination. It is important for Uloba that the rights of disabled children and young people are recognised and respected.

### **The principle of the best interests of the child**

The principle that the best interests of the child should govern decision makers entails that the interests of children and young people are highlighted and emphasised when decisions of importance to the child are made. For disabled children and young people to be able to express their views, it is important that they receive information adapted to their needs, and support to express their views irrespective of functional level. This is essential to meet Article 12 of the UN Convention on the Rights of the Child: The child's right to express their views, and Article 12 of the CRPD: Equal recognition before the law. The UN CRPD Committee highlights decision support as a useful tool for facilitating disabled people's self-determination and co-determination. Decision support means making information available, e.g. interpreting what information means and that information is placed in an understandable context.

There are currently no decision support services in Norway. Those in need of such support are often placed under guardianship. Persons under guardianship are denied the right to decide over their own lives. If a person is also registered as 'not competent to consent', they are regarded as being unable to have a view about their own lives. This violates human rights, and particularly affects disabled people. Uloba is therefore in the process of developing a decision support board model (*Beslutningsstøtteråd*), based on micro boards developed by Vela Canada over the course of 30 years.

We believe that this will be a good model for addressing the needs and interests of disabled children and young people. A decision support board will comprise a

number of people who know the child, which will make it easier to safeguard the best interests of the child principle.

### **The child's right to care and protection**

A common consideration with respect to disabled children and young people is to build on resources already there for the child. This is important in order to be able to implement measures that are well adapted to the child or young person's needs. The measures that are implemented should preferably be in the home and not in an institution.

One important tool, which is not granted nearly enough, is the citizen-controlled personal assistance scheme (BPA). Uloba developed BPA in Norway, and we are the main facilitator of BPA in Norway. According to the Independent Living ideology, the CRPD and intentions clearly stated by the Government and the Storting the object of BPA is to contribute to equality for all. BPA shall enable disabled people to live free, active, varied and equal lives in all areas of society, and it is an important tool for securing disabled people's right to an independent life and to be part of the community, cf. Article 19 of the CRPD.

In 2020, 553 children under the age of 18 were granted BPA.<sup>55</sup> BPA creates more predictability and continuity for the family and child. This is because it is the parents who decide who to appoint, what the assistant is going to do, and when and where the assistance is to be provided. Overall, this is the least invasive option in a child's life. Children need and have the right to participate in their day-to-day lives and recreational activities on a par with everyone else. BPA gives children independence. As a service, BPA can follow the child in their transition from child to adolescent, and from adolescent to adult. With BPA, children and young people can gradually gain more responsibility for their own lives, which equips them to be better prepared for adulthood.

On 20<sup>th</sup> September 2019, the Government appointed a BPA committee to review and recommend improvements to the citizen-controlled personal assistance scheme in Norway. The committee shall submit its report in the form of a Norwegian official report, by 15 December 2021. The committee shall consider how BPA can help to secure equality, equal opportunities irrespective of place of residence and participation in the community for disabled people, good working conditions for the assistants and ensure that the scheme is sustainable. The scheme is to be defined as an equality tool, and not as a health scheme. The committee shall look at how BPA can be organised to ensure participation in work, education and recreation.

Today, children's assistance needs are met by means of many different services, such as home help, personal support contact, sport support contact, home nursing, residential care facilities for children, respite institutions etc. Traditional health and care services have not been developed for children, but for older people. This creates obstacles for schooling, because these services do not take into account the pupil's need for practical assistance in connection with homework, being part of the class

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<sup>55</sup> [Health and care services \(IPLOS\) in KPR \(municipal patient and user registry\) - Directorate of Health](#)

environment in their spare time, recreational activities, being part of the family etc. Nor are children allowed to take their assistants to school and have to make do with the assistants appointed by the school. This creates a great deal of uncertainty and unpredictability for children.

### **The right to family life**

Disabled children and young people often experience institutional care. This could be in a respite institution, residential care facility for children, municipal respite care centre, co-located housing, nursing home or extended after-school programme. This is because it is believed that disabled children and young people need health and welfare services which cannot be provided in a family, family home, respite family etc. This is a stark contrast to the way non-disabled children and young people are treated, and violates both Article 9 of the Convention on the Rights of the Child and Article 23 of the CRPD: [...] State Parties shall ensure that children with disabilities have equal rights with respect to family life. [...] States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families. [...] In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents<sup>6</sup>.

The same requirements are not made of 'residential care facilities for children' as of other institutions for children. Location requirements apply to child welfare institutions in relation to school/kindergarten, recreational activities, public transport and adequate outdoor play areas. Such requirements do not apply to residential care facilities for children. The regulations that apply to residential care facilities for children are the same as for other nursing and care services institutions, and have been devised for the elderly, not for children and young people's need for development, play and self-expression.

Uloba has received feedback from several parents who have been reported to the Child Welfare Service when they have applied for or complained about the services they have been allocated. Some children and disabled parents need different services, including BPA, to be able to live equal lives. Conflicts between the patient allocation office and parents often concern which services are in the best interests of the child and family. The municipalities often argue that respite in an institution is better than BPA, and place less emphasis on the child's right to family life. We fear that the Child Welfare Service can use Section 5-1 b) in these conflicts to justify a care order. This provision states that parents must ensure that disabled children's special needs for treatment and training are met. Our investigations have shown that a number of disabled parents' attempts to acquire BPA hours in connection with parental duties have culminated in municipalities sending notes of concern to the Child Welfare Service. Numerous parents of disabled children have reported the same thing.

Uloba finds that BPA for children makes family life easier, reduces stress and increases the life quality of the child, siblings and parents. Parents find that young people can be more independent and social with BPA than without it. Norwegian surveys have also shown that parents can focus more on their jobs, cope better with their day-to-day lives and experience more flexibility when a child is allocated BPA.

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<sup>6</sup> [Article 23 – Respect for home and the family | United Nations Enable](#)

When a child has BPA, one of the parents generally acts as scheme supervisor, which means that the parents can adapt the assistance scheme to the child's needs.