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**Commentary**

**Children with learning disabilities and their participation in judicial procedures – What can disability advocacy offer?**

Children with learning disabilities, autism or long-term mental health problems face multiple obstacles in the justice system. This is especially concerning given that these groups of children are those who are the most vulnerable to , for example, having their right to education or their right to family life violated (World Health Organization, 2011). Today, still over two million children live in institutions around the world (Save the Children, 2014), and many hundreds of thousands of them live in residential institutions in Europe (Eurochild, 2016b, Mansell et al., 2007). Children with disabilities are more likely to be placed in institutions than their non-disabled peers (Save the Children, 2014). Furthermore, children with disabilities or mental health problems are also admitted to psychiatric hospitals where they are subjected to involuntary psychiatric treatment that may also breach international human rights law (Minkowitz, 2007).

As noted by Horowicz, many children are placed in long-term care without any court procedures that evaluate the reasons for placement and assess the child’s best interest. Even when such procedures apply many questions remain: who makes such decisions and on what grounds? Is the child’s best interest looked at and evaluated by independent experts or advocates? Are appropriate safeguards in place? Is the child informed, asked and listened to? This commentary will consider how disability advocacy and advocates’ regular lobbying tools – human rights laws – put these questions into context.

It is clear that legislation should be carefully tailored around children’s special needs, especially when judicial systems make decisions about their lives. However, children with learning disabilities are systematically side-lined in justice systems, getting very little or no protection and safeguarding during legal procedures that contribute to their admission to institutional care (Mental Disability Advocacy Center, 2015). Their cases are usually discussed without their involvement, only calling on experts’ and carers’ opinions. Such limitations are not necessarily due to lack of will amongst carers or the judiciary. The problem is rooted in at least two contexts: lack of appropriate legal measures, and lack of targeted advocacy.

Other problems may also play an important role. For example, stigma and the absence of relevant, disability-specific knowledge in the judiciary may make it seem appropriate for a judge to rely only on partial information provided by carers or medical professionals when placing a child into an institution.

**Gaps in legal standards for children with learning disabilities**

Today’s legal systems in most countries incorporate elements of international human rights treaties that include principles regarding children with learning disabilities. Human rights legislation is endorsed by almost all civil society organisations active in the disability field. This includes the European Convention on Human Rights, the United Nations Convention on the Rights of the Child (CRC) (UN General Assembly, 1989), and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN General Assembly, 2007) the latter two setting international human rights standards relevant to disability policies. States Parties to these two conventions must bring their national laws in compliance with them, meaning that both UN treaties are potential drivers for legislative changes that impact the lives of disabled people including children with learning disabilities.

Human rights conventions, of course, are only influential when implemented. By definition, human rights are universal, which means laws should recognise children as bearers of rights regardless of the form or severity of their disabilities. Implementation of this principle is hindered in practice almost everywhere. Children with learning disabilities are seldom seen as persons whose best interests must be carefully safeguarded during court procedures despite the fact that both the CRC and the CRPD have made it mandatory for States Parties to adopt measures that follow the ‘best interest of the child’ – a requirement that has proven to be rather vague in the absence of specific measures.

Principles provided by the UN do not give clear guidelines for countries that wish to work on the problem. Indeed, the vagueness of legal protection with regards to children with learning disabilities is often startling. For example, General Comment No. 1 of the CRPD, looking at legal capacity, states: “*to comply with article 12 [of the CRPD], States parties must examine their laws to ensure that the will and preferences of children with disabilities are respected on an equal basis with other children*” (Committee on the Rights of Persons with Disabilities, 2014). It is questionable how such requirement can facilitate meaningful legal changes in countries where appropriate protection of all children is not in place.

In fact, due to their specific needs, children with learning disabilities need more protection than their non-disabled peers, and this is admitted in Article 7 of the CRPD: “*States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, […] and to be provided with disability and age-appropriate assistance to realize that right*.” The CRPD gives no further details as to how exactly this should be realised. This provision is mandatory for all states that have ratified the Convention although, to date, there is no international impact assessment available to evaluate the extent to which countries have implemented any such progressive measures.

Data does exist, however, showing that children with learning disabilities are denied the basic rights provided in the CRPD even in countries that have long ratified the Convention. A recent report has found that even national human rights monitoring bodies working to observe human rights violations paid no or minimal attention to disabled children’s situation in ten Eastern and Central European countries (Mental Disability Advocacy Center, 2015). The situation is further exacerbated by the lack of statistical data on how many children with disabilities participate in judicial procedures and what judgments they receive. Data on children with learning disabilities in the justice system usually comes from individual cases, oral history and some targeted qualitative research with judges, social workers, carers or children. Even this kind of data is scarce. It appears that, in many countries, there is no consideration given to or assessment made of the specific needs of children with learning disabilities entering the justice system (Mental Disability Advocacy Center, 2015).

Another obstacle to the implementation of human rights law is that legal texts themselves are rather abstract and open to different interpretations. Policy-makers may use this as an opportunity to ‘bend’ the meaning or intention of international law. For example, a study on the extra-judicial dimensions of the CRPD showed that contested translations and socially embedded interpretations made it difficult to implement the principles intended to guide the Convention (Mladenov, 2013). Furthermore, translations of the CRPD into languages like German, Hungarian or Bulgarian have been debated by Disabled People’s Organisations (DPOs) (Virtanen, 2008, Mladenov, 2013), making it very difficult to realise or even initiate meaningful changes in policy. Finally, the implementation and monitoring of human rights laws are contingent on extra-legal, for example political or economic factors that UN Conventions have very little influence on (Stein, 2007).

In the absence of legally enforceable and clear practical guidelines, hindered by distorted interpretations, it is not surprising that the two major UN Conventions seem to have made little impact on how children with learning disabilities participate in court procedures. However, there may be another underlying reason for this situation: the existing ambiguity within advocacy organisations representing disabled people, including children with learning disabilities.

**Gaps in advocacy for children with learning disabilities**

DPOs have long been drivers for progressive legal and policy changes (García-Iriarte et al., 2015; Barnes et al., 2003). Their participation in policy-making has contributed to profound changes since the 1970s such as deinstitutionalisation programmes, discrimination legislation, increased accessibility and inclusive education. The CRPD has also made an impact. For example, as a result of disability advocacy building on requirements enshrined in Article 12 of the CRPD on legal capacity, some European countries have been implementing progressive changes in their guardianship laws (Kozma and Petri, 2012). It might be expected that DPOs should play a leading role in changing law about disabled children’s participation in legal procedures. The question is: who advocates for children? What DPOs should represent children with learning disabilities?

The CRPD itself is quite clear about DPOs’ pivotal role when it states in Article 4(3): “*In the development and implementation of legislation and policies to implement the present Convention, […] States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations*” (UN General Assembly, 2007). It is, however, open to interpretation how this representation can be fulfilled and assessed, since children have limited legal capacity to represent themselves. Such broad recommendations are repeated elsewhere, for example in General Comment No.1 on the CRPD (Committee on the Rights of Persons with Disabilities, 2014). Readers seeking the right interpretation of the CRPD may rightly ask: who are the representative organisations of children with learning disabilities?

The answer sheds light on one of the long-standing ambiguities of contemporary disability advocacy, because children with learning disabilities or autism are represented both by organisations controlled by parents and professionals and by other DPOs representing all disabled people, controlled by disabled people themselves. These are two, often distinctly different parties. Taking the example of a group of disabled children living in a group home in one European country, it is unclear who represents them in the advocacy fora: (a) the national or local organisation of families of people with intellectual disabilities, controlled by parents and professionals, or (b) the national or local Independent Living organisation, established and led by people with disabilities?

Another issue is *indirect* representation. For example, the European Disability Forum (EDF), the leading organisation of persons with disabilities in Europe, states in the Founding Statutes Article 1 that EDF is composed of “*European Non-Governmental Organisations of/for disabled people representing disabled people, and parents (as such term is defined by each member organisation) of disabled people* ***who are unable to represent themselves*** […].” The latter reference to the inability to self-representation is of crucial importance here because it also reflects the views of traditional law where disabled people in general are viewed as passive recipients of care rather than active citizens who can speak for themselves when allowed and supported to do so.

But children with disabilities are also represented through DPOs controlled by disabled people, for example self-advocacy organisations that speak for a broader group of children or adults living with learning disabilities. Independent Living organisations usually emphasise that children should not be placed into institutions at an early age but should be given the opportunity to stay with their families or find foster families (European Network on Independent Living, 2014). On the other hand, it is usually parents who make the decision to place their child in a residential institution. The child’s best interest as represented by the parent’s decision stands, therefore, in stark contrast with adult disability activists’ opinion that no children should be admitted to institutions. Further contradictions are revealed by self-advocates with learning disabilities who state parental opinion sometimes differs from their own wishes, limiting their rights to make choices about crucial aspects of their lives (Goodley, 2000). It is also known that some parent groups may oppose deinstitutionalisation programmes, for example because they see residential care as the best option for their children (Barnes, 2014; Simpson, 2008; Dunn, 1993). In the absence of substantial data and targeted research we can only assume there may be differences between the advocacy work of parent-led organisations and self-advocacy organisations. Experience certainly shows that parent-led organisations successfully cooperate on many issues with self-advocacy groups (where the latter are present at all), but it is unclear how policy-makers or courts can deal with differing opinions when such cooperation is lacking.

It is also worth remembering that the political slogan of ‘nothing about us without us’, emphasised by the CRPD, had previously been stressed by the CRC as well, asserting that self-representation is not reserved only for adults (United Nations, 1989). The CRC encourages societies to see children as bearers of rights rather than subjects of care. In the context of disability advocacy, the question is what measures could and should be taken in order to have disabled children’s voices heard within parent-led or adult-led organisations. It is right that children must be carefully assessed and listened to in court procedures. It is equally important that advocacy organisations work *with* children and not only, on their behalf, with their parents.

**Evolving practices in children’s advocacy**

Practices to involve children in advocacy, decision-making or even human rights monitoring are not unknown within the broader human rights movement. For example, UNICEF has issued a handbook to promote children’s advocacy work with sections dedicated to good practices, setting up minimum standards for consulting children and explaining differences between real and false consultation (UNICEF, 2010).

One international advocacy organisation (founded and led by legal experts) recommends that, in line with the CRC and the CRPD, children should be asked to express their views and preferences during legal procedures, using all possible ways of communication such as drawing and painting, body language, facial expressions etc., and that such provision should be in place for children of all ages (Mental Disability Advocacy Center, 2015). Furthermore, a General Comment of the responsible UN Committee recommends “*it is not necessary that the child has comprehensive knowledge of all aspects of the matter affecting her or him, but that she or he has sufficient understanding to be capable of appropriately forming her or his own views on the matter”* (United Nations Committee on the Rights of the Child, 2009, para. 21.). This latter recommendation means that we should not see full understanding of laws as a prerequisite when assessing a child’s preferences – rather, we should provide children with accessible information that allows them to express their opinion. Good examples are available e.g., Queen’s University in Belfast has run a child-friendly survey to hear children’s voices on how the government should spend its money (Eurochild, 2015). The European network of children’s organisations, Eurochild, runs a dedicated webpage for participatory advocacy featuring best international practices (Eurochild, 2016a) where many similar examples can be found.

Other cases show that disability organisations are also starting to work with children with learning disabilities, empowering them to speak up for themselves. For example, a Hungarian human rights watchdog organisation successfully cooperates with parent-led advocacy organisations and schools for children with severe and multiple disabilities, providing special classes and visual materials for children to understand their legal rights (Hungarian Civil Liberties Union, 2016). Such examples show that active citizenship can and should be achieved for everyone and empowerment should start in early childhood.

Good practices and innovative recommendations alone are not enough to make substantial changes in policies. However, their availability can give inspiration to policy-makers and DPOs to use them. The road from exclusion to tokenistic involvement to full participation is certainly very long. Investing time, expertise and other resources into children’s advocacy and self-advocacy groups seems crucially important because, if we can learn one thing from the history of disability advocacy, it is that progressive changes require pressure and lobbying of decision-makers by the people most affected, disabled people themselves. Children with learning disabilities are those who should benefit from safeguarded judicial procedures and they are those who can make a change. DPOs should start working more with them and not only with others representing them.

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