

BOOK REVIEW

Anne-Marie Callus and Ruth Farrugia, *The Disabled Child's Participation Rights*. London and New York: Routledge, ISBN: 978147242875 (hbk), ISBN: 9781315615509 (ebk), pp. 172

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The book under review advocates for participation in decision-making as a fundamental human right which cannot be denied to disabled children. Informed by the 1948 Universal Declaration of Human Rights, by conventions, such as the the 2006 Convention on the Rights of Persons with Disabilities, and by a vast repertoire of research literature, including relevant court cases, such as those heard before the European Court of Human Rights, the book makes a forceful case for disabled children's rights in general and for their participation rights in health, education, home life and relationships, highlighting ways in which these rights are validated, valorised and celebrated, as well as analysing barriers that block access to and enjoyment of such rights.

Callus and Farrugia build their argument for the disabled child's participation rights on the fundamental right to life. Termination of life beyond the legal limit and up to the end of pregnancy is permissible in, for example, Austria and Denmark, if foetus is diagnosed with severe disability. I share the authors' view that such laws are clearly discriminatory and are based on a very negative view of the value of a disabled child's life - the disabled child as a burden to family and society (sic). Also, and here I am again in agreement with Callus and Farrugia, the authors claim that such laws weaken the ethical basis of subsequent laws meant to safeguard the rights of the living disabled child and the provisions that stem from such laws. In addition, such laws tend to fuel eugenic sentiments, as illustrated by the reaction of the gynaecologist-obstetrician and researcher in medical ethics from Aarhus University, mentioned in the book, who reacted very positively to a Danish newspaper report titled 'Plans to Make Denmark a

Down Syndrome Free Society by 2030', describing the 'plans' as a 'fantastic achievement' (sic).

Analysing European Court of Human Rights (ECHR) cases relevant to the subject, Callus and Farrugia affirm that the cards are stacked in favour of the selective termination of life. Quoting two ECHR decisions, one Polish and another French in origin, the authors illustrate how parents' rights are often privileged over the disabled child's right to life, compromising, in the authors' own words, the children's right to participation before they are born.

In a postpartum scenario, Callus and Farugia dedicate four chapters to discussing participation rights of disabled children in 'Health', 'Education', 'Home Life' and 'Relationships'. In all four chapters, advocacy is based on legal foundations, drawing consistently, but not exclusively, from the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities.

In Chapter 2, the Child's right to participate in decisions regarding his/her 'Health' are discussed against a backdrop where simple to very complex medical decisions are often taken by parents or guardians on behalf of the disabled child. While making a strong ethical case for participation rights in this area, the authors adopt a pragmatic approach to participation by allowing for mediation by significant adults in situations characterised by, for example, severe disability. Mediation, however, requires an adult environment which is well informed with regard to the child's participation rights and which is willing and skilled enough to be able to understand the child's wishes and to communicate such wishes to other adults in difficult circumstances.

In 'Education', the area dealt with in Chapter 3, Callus and Farrugia advocate for the actualisation of participation rights through a universal-design approach to education. This approach recognises the individual needs of each child within an educational milieu that promotes full inclusion. Individualised Educational Programmes (IEPs) which are truly child-focused guarantee individual participation rights through the child's engagement with his/her own needs, at both the conceptual and pedagogical phases of the educational provision. Universal-design approaches which are genuinely child-centered include support services, such as therapy, as part of the educational programme, promoting child participation as a means to address his/her holistic needs.

In the chapter on 'Home Life', the authors lament the lack of research on participation rights of disabled children within their family while highlighting the difficulties that children with disabilities face in acquiring different degrees of independence within home or in out-of-home contexts.

Such contexts are generally marked by over-protectiveness and by regular exclusion of the child from decision-making, leading to chronic dependence. In Chapter 4, Callus and Farugia advocate for the democratisation of the disabled child's home life, the debureaucratisation of institutional living and the promotion of communitarian ways of life. In my view, this and other chapters within the book would have benefited from a critique of hierarchical and asymmetrical relations of power that are becoming increasingly hegemonic. Millions around the world are being schooled into cultures of silence and marginalised by technologies of power that are in no mood to dialogue or to put human life at the centre. Internationally, the silencing of the disabled child's voice is symptomatic of such power relations. In addition, the intersection of disability with, for example, social class, ethnicity, and gender would have added another layer of complexity to the authors' analysis, since roadblocks to participation are often correlated with economic, social and cultural capital.

'Relationships' is the last major area explored in the book. As rightly indicated by Callus and Farrugia, this area is the least regulated by legislation out of the four areas considered in this volume. Relationships develop informally and are difficult to regulate through formal means such as legislation. Nonetheless, this is an important area of exploration since it provides the emotional nourishment for children with disabilities, not only to survive but also to live with dignity as full and active citizens. The process of socialisation, friendships as well as sexual relationships for older children are some of the themes analysed within Chapter 5.

The concluding chapter brings together the themes and issues discussed in Chapters 2-5, revisiting the scope for participation in disabled children's lives, highlighting the centrality of professional development and awareness-raising among parents and care-givers and emphasising the importance of disabled children's active participation in research and policy-making. The bottom line of such a process is a society with a shared understanding of what participation rights are, an education process that maximises participation and agency, and an enabling environment that promotes participation on the disabled child's own terms.