

BOOK REVIEW

Parents with intellectual disabilities: past, present and futures, edited by Gwynnyth Llewellyn, Rannveig Traustadóttir, David McConnell and Hanna Björg Sigurjónsdóttir, Chichester, John Wiley & Sons, 2010, 290 pp., US\$32.19 (paperback), ISBN 978-0-4707-7294-2

The book takes a look at the accurate and increasingly discussed issues on parenting and family life of people with intellectual disability (referred from now on as ID). The starting point is the human rights approach to the issue reasoned with the international agreements of UN and EU according to which people with disabilities must be guaranteed the basic rights to live in the community and be part of community life – and that means also the right to start a family and have children. The book is welcomed and is an important address to the global trends on developing services for enabling, helping and supporting citizenship, self-determination and inclusion in community and society for all different people. The book makes visible the very common and ‘normal’ experiences, feelings and dreams of pregnancy, having and caring for the baby and living a family life of the parents with intellectual disabilities – mothers and fathers separately and together. Also the children’s experiences are valorized. The book also makes visible how vulnerable parents and their children are, mostly because of the unjust responses and controlling positions of other people, and powerful, often isolating and exclusive structures of institutional welfare practices around them. These are shown to be based on still very limited and stereotypical views of people with ID and their capabilities.

These practices can be seen as eugenic. Nowadays, eugenics takes more subtle and privatized modes than it did a few decades ago when people with ID were isolated in institutions and their love-life was more or less made impossible, with restrictions on relationships and even the relatively common practice of sterilization, especially to women. Deinstitutionalization of the caring practices has been a common trend lately and this has challenged society to deal with the question of sexual and reproduction rights of people with disabilities. But as it is emphasized in the book there still remain very powerful practices that make people’s lives only happen within the community but still in isolation, not being part of the community, and there definitely is a difference between these experiences of *living in* and *being part of* community. This difference is dealt with in various ways in all the articles of the book, analysing tensions between ideologies and everyday practices in helping and supporting people with ID. This makes visible many very important aspects of the meanings of differences, diversities and power relations in society.

The book is a result of over a decade of lasting co-operation and discussions in the international network of researchers studying these questions. Authors come from seven countries: Iceland, Denmark, Australia, the United Kingdom, Canada, Sweden and USA. The cultural differences in the services for people with disabilities

are not dealt with in the articles, which could have been covered to a greater extent. But this also emphasizes universalities that become visible when reading the stories – because very powerful stories are told in various articles valorizing different aspects of the everyday life of parents with intellectual disabilities. The articles are all based on empirical work – either reviewing others' research or dealing with the researchers' own empirical work, and the rich empiria is definitely one strength of the book. The epistemological stance of the book for the 'evidence-based good practices' is also demonstrated in the principle that most articles are ended with a section titled 'principles for practice'. In these sections, the authors offer guidelines for professionals and institutional help and support services which, considering the subject, can be seen as most appropriate in helping in transforming these quite new and ground-breaking ideas into clear guiding principles.

The first part of the book is titled *Family and Community Life* representing a collection of articles about personal stories and experiences of parents, their children, social networks and connections to community. The first article *Becoming a Mother – Becoming a Father* gives a view of the findings of Hanna Björg Sigurjónsdóttir's Icelandic study and Rachel Mayes's study in Sydney, Australia. Their starting point is to take a look at the gendered experiences of becoming parents with intellectual disabilities. One important aspect they raise is that a vast majority of the families had not planned the pregnancy. That makes the experiences of the pregnancy time for any family very different compared to when it is planned. But in the case of parents with ID it often means quite heavy negotiations with the parents' whole social network: facing doubts about their competence, maybe pressures for abortion or adoption or the threat of taking away custody of the child. Also the gender differences in the experiences of the expectant mothers and fathers are emphasized as often being neglected, with mothers given the status of the parent – which hides the fact that parenthood is culturally strongly gendered. This aspect does not feature as heavily in the rest of the articles – in many of them the focus is exclusively on mothers.

Gwynnyth Llewellyn and David McConnell write in their article about the childhood experiences of Australian pregnant women with ID who attended as clients in prenatal clinics in Sydney. They were interviewed two times during the pregnancy and once soon after the birth. The description of the method is precise and thorough and also introduces the parental bonding instrument (PBI) which researchers recommend as a useful tool to get into important discussions of the childhood experiences of mothers with ID. The authors emphasize that these experiences are important to be aware of when assessing the need for help and support with the family. For example, those parents who have spent their childhood in institutions or those living with their families in local community have very differing needs. Furthermore, when many women with ID addressed neglect or even abuse, these of course have many consequences in parenting their own children.

Icelandic researchers Sigurjónsdóttir and Traustadóttir write in the following article about the importance of the extended family, grandparents and siblings to any new parents but especially for the parents with ID. And when the people with ID, usually in Western welfare systems, live in manifold relations with services provided by the community, there are also manifold encounters with these instances. The article is based on longitudinal studies and work with people with ID – and on the personal experiences of the authors as mothers and grandmothers. It also offers to

the reader very interesting and valorizing stories about three different families and how they cope within these networks.

In the next article, Jytte Faureholm writes about the life experiences of the Danish children who have parents with ID. She has based her text on her longitudinal interview study with boys and girls who had one or both parents with ID. The article raises very important aspects about the issue and also shows how the experiences of the children in these families are very much the same as in any other family – children cannot choose their parents and to put it simply: they love and respect their parents and suffer if their parents suffer. But this can also be neglected and is capable of even ruining the child-parent relationship in case the parents cannot get appropriate support.

The article by Gwynnyth Llewellyn and Marie Gustavsson brings an Australian-Swedish perspective to understanding community in the lives of parents with ID. The authors' message is that experiencing family life within community offers plenty of opportunities for all parents including parents with ID to have simple connections and participation in community life in day care, school and hobbies of the children. To get support for the family participation in these simple connections would be very important to improve *living in* the community and translating it into *being part of* the community. However, in the article it is a bit controversial that the questions of societal systems providing care, help and support are not considered as a part of the community the parents are living in (or taking part in), but in the section Principles for Practice, the text takes for granted a certain kind of professional distance in the relationships between support workers and their clients mediated by the support plans and intervention programs. In the next article, Brigit Mirfin-Veitch continues with the issues on citizenship and community participation by showing two strikingly opposing stories that illustrate the practices of support producing inclusion in and exclusion from citizenship, self-determination and participation.

Traustadóttir and Sigurjónsdóttir finish the first part of the book by the article *Parenting and Resistance: Strategies in Dealing with Services and Professionals*. It raises the fact that parents with ID very often encounter hostile and powerful service system that takes them as incompetent and tries to question their ability to parenting children. Even though there are professionals who provide support and develop empowering strategies to help parents cope with the challenging tasks of caring for and bringing up their own child, there still remain very strong self-evident practices that threaten to take away the custody of the child from parents with ID. The strategies of parents to deal with this hostility are shown to be quite logical and appropriate modes of resistance and sometimes even show their competence and successfully challenge the self-evident expectations.

The second part of the book is titled *Human Services Enabling and Disabling Parents with Intellectual Disabilities*. In the first article about parenting education programs, Canadian expert research-practitioner Maurice Feldman's offers practical, evidence-based guidelines for guiding parents with intellectual disabilities for successful learning of the knowledge, skills and behaviours to ensure appropriate parenting. It also raises further questions and tasks for developing programs 'to increase parent confidence and competence in accessing the local community' to increase their social participation and decreasing social isolation.

The rest of the book also presents different practices and aspects of the support and help given to the parents with ID and analyses the big gap between the ideology of full citizenship, self-determination and participation, and the service-providing

practices. Sue McGaw and Sue Candy's article takes the notion of supported decision making as the focus of their UK-based study. Their article focuses on the hard decisions of the women making choices of whether to have a child or not and in negotiations with child protection authorities. They show, for example, the harsh fact that the forced sterilizations and abortions still happen too often to women with ID and their sexual behaviour is seen as a taboo that makes it difficult to get appropriate information for hard decisions in these issues.

Beth Tarleton takes a close look at the UK policy ideologies that explicates in principle the trust in the 'good enough' parenthood of people with disabilities. The principles formulate the rights of the parents to get help and support in this challenging task and even gives quite precise guidelines on what should be taken into account in these practices. She shows how, despite these beautiful guidelines, the risk of losing the custody of their children is always there for parents with ID due to the difficulties in getting help and even of being heard in the cases concerning their life decisions.

This big risk of losing the custody of the child and the complicated net within the processes of institutional child protection is discussed in the article of David McConnel and Hanna Björg Sigurjónsdóttir. The authors are very experienced researchers who base their article on their impressive longitudinal studies and an eloquent literature review on the field. This issue is also dealt with in the articles of Linda Ward and Beth Tarleton. Both articles highlight very typical experiences of parents with ID regarding the child protection process which are intimidating, disabling and depersonalizing, with the parents being left alone and unsupported, and that the procedures in the court and in their personal contexts being done to them, not with them, underrating and disregarding their own views. Ward and Tarleton write about the importance of practices and difficulties in having independent advocacy for parents with ID, especially as 'a final tool' in the child protection proceedings. The final tool means that it is far more important to develop adequate help and support in the everyday experiences of family life and parenting, but if the process is initiated with the help of child protection authorities it is very important that parents get an independent advocate who takes care to provide adequate information, help in literary work, and empower the parents to encounter the authorities.

Interesting and apparently workable tools that bridge the gap between rights and reality, and research and practice are introduced in the article written by Canadian researchers Marjorie Aunos, Laura Pacheco and Katherine Moxness. They have been developing and piloting strategy and initiatives to formulate standards of practice for parents with ID in Québec, Canada. These tools are also discussed in the article of McConnell and Llewellyn, based on their study of Australian parents with ID and the research program to identify supporting practices especially directed to the community participation of the mothers with ID.

As from the Finnish perspective, the discussion on this issue has not been very lively – not yet anyway. The independent living and participation in community life has been quite limited for people with ID in Finland. Lately, the deinstitutionalization process has been emphasized with national policies and programmes. Due to these policies and programmes, community-based residential services have been established, and especially young people with ID are in a very different position nowadays than they were just a few decades ago. I have written this review from two viewpoints. The first is that of a researcher; I am studying life histories and social

networks of individuals living in the residential services for people with ID in Finland asking if the citizenship, self-determination and participation actualize in their lives. The second is the mother's perspective; I am the mother of a 21-year-old daughter who has just moved out of home and started her independent life in the city. So the questions dealt within the book are very accurate and thought-provoking for me. The book has been an illuminative experience in many ways and I warmly recommend it to anyone.

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