

Research with Icelandic families and children with disabilities: About walking on eggshells and the relevance of social capital

Social Policy and Social Capital: Parents and Exceptionality 1974–2007

by Dóra S. Bjarnason

Geert van Hove

Ghent University

A lot of books have been written in the last decennium about families and the way they survive with their children with disabilities. However, this is a really different book.

Dr Bjarnason succeeds in giving us insights into the lives of fathers and mothers while using a historical mirror. The families we learn to know are situated with their stories within a period of 30 years. Such a time line opens opportunities to understand how fast communities and their social security and systems have developed and how we get used to certain achievements (appendix 1 is very helpful to come to this insight). It is necessary to honour pioneers who were “fighting” for their rights in an era when human rights were not yet integrated into the care system discourses.

The author shows that “nothing about us without us” can become more than

a slogan. By using family stories as the central “*pièce de résistance*” for her book Dr Bjarnason shows that she fully understands how inductive research can be realized. The families are more than an illustration for the points of view of the author. Their experiences and expertise get an equivalent weight in the confrontation with theoretical frameworks.

Dr Bjarnason gives an extra impulse to her book by using the theoretical framework of “social capital”. Authors such as Bourdieu, Coleman and Putnam brought this concept into the social sciences. A lot of colleagues in the field of special education – especially those who got trapped in a medical discourse – do not make use of this very dynamic and even almost provocative concept. In this book, the author introduces this concept to give us insights into – in parallel with the sad moments – the resilience and resistance of families

with children with disabilities. Some of them manage to build bridges to the community. Some of them can get away from the margins and create fascinating stories. Within this part of her work the author shows how theoretical frameworks and concepts can guide us to a deeper level of understanding. With this part of her work Bjarnason shows how inductive and deductive work can be combined in a productive way.

The author gives us also a nice lesson in the things we should keep in mind while organizing qualitative research. In Appendix 2 and throughout the whole book she shows that research about this topic can't be called research if we are not guided by the highest ethical standards. The author uses the metaphor: 'walking on eggshells' to discuss her multiple positions. Being a mother, being a mother of a son with a label, being an Icelandic citizen, being a researcher, being an advocate, Bjarnason manages to teach us about the possible pitfalls and benefits of these different perspectives. It has to be said she manages to bring in her experiences without romanticizing them. Appendix 2 should become one of the basic texts in courses about qualitative research.

One of the creative elements in this book can be found in the deconstruction of the

concept of family while Bjarnason points to the very specific position of fathers. We know that a lot of "family research" is based on mother's perspectives. We know that a lot of researchers report about the difficulties they are confronted with in contacting fathers (they are absent, working...). The author is confronted with the same 'problems' but manages - through a kind of healthy stubbornness - to organize a lot of meetings with fathers. This opens up possibilities to get insights into family dynamics, positions and roles. In conclusion, we also want to motivate colleagues to read the book because this book is written within and about the Icelandic context. Although one would think that social networks in such a small country are close and harmonious, and one would think about slogans like "it needs a village to raise a child", parents of children with disabilities in Iceland are bringing stories about feeling lonely, about rejection and isolation. This research result shows how important strategies of active support for families are, and how central the topic of social capital should be, starting from early support and intervention programmes.

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