

Exceptional waves: Parents of disabled children negotiating 30 years of Icelandic social policy

Social Policy and Social Capital: Parents and Exceptionality
1974–2007 by Dóra S. Bjarnason

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Social Policy and Social Capital: Parents and Exceptionality 1974–2007 focuses on the experiences of the parents of disabled children in Iceland. The emphasis is on, as the author puts it, the “waves” of municipal and state policy that underpin services concerning disabled children and their parents over the last 30 years, but issues of medicine, education, gender and the family, among others, also receive a fair share of attention. There is food for thought to be found within these pages for academics, educators and practitioners in a wide range of disciplines to be sure, but specialists within particular fields of study may not be satisfied. From the perspective of Icelandic disability studies, there are some curious omissions in the references cited. Those who focus on the development of Icelandic disability policy may find little that has not already been covered in the Icelandic language literature. Those working in education or social work in Iceland may have similar opinions. Given these factors, as well as its publication in Eng-

lish, it is not entirely clear who is the intended audience. Yet this is offset by the fact that there is some striking material within these pages that span a long and noted research career.

The 33-year span for a study that aims to analyse policy as well as present a social history is indeed ambitious. The timeframe that the work is placed within (1974–2007) seems to coincide with the author’s own research experience and personal engagement with disability issues. However, the author’s method of examining policy developments over these three decades is intriguing and in my opinion successful. This is done though a cohort model. The parents of children born in the period of 1974–1983 are referred to as the “Explorers” as they encountered a heavily medicalised environment in which the birth of a disabled child was perceived by practitioners as a ‘tragedy,’ and the services on offer tended towards exclusion and segregation. The author illustrates quite well that the gains in policy advances and service pro-

visions were made not as the result of the wisdom of policy makers, but due to the hard work and determination of parents and the emergent parent organisations. The “Pioneers” (whose children were born 1984–1990) benefited from some of the gains made by their predecessors, though services remained mired in older ways of thinking. The author builds the case that the parents of children born between 1991 and 2000 (the ‘Settlers’) experienced a shift in the issues from being viewed as a private and individualised matter between parents, doctors and educators to that of a wider policy concern debated at a more prominent level of public discourse and media visibility. Subsequently, the ‘Citizens’ (children born 2001–2007) have come to perceive services and supports as rights and entitlements as their due as citizens of a modern welfare state and the discourse has now become framed in the language of human rights predicated upon international agreements. The narratives that the author incorporates into the text vividly bring home the effects of policy shifts on a human level that are often lacking in policy studies. However, the choices of the specific temporal brackets used to denote these families (e.g. 1984–1990) are debatable. There were significant pieces of legislation issued in 1979, 1992 and 2008 that are relevant here and which could also serve to mark such boundaries. I could well imagine a scholar of policy or social history demanding to know more about the analytical choices underlying this framework.

The book is also organised around what

the author calls three ‘big ideas.’ The first is adapted from the sociologist Peter Berger in order to argue that disability moved from a “private problem” to a matter of public policy concern. In my interpretation of the text, the material actually illustrates that issues of disability were never a solely ‘private’ matter located within the home, as doctors, practitioners and state officials seemed to be intimately involved with all stages of the life process and in governing the lives and bodies of disabled children. However, toward the end of the book I found that I warmed to this framework as it related rather well to the ways in which policy and services are conceptualised and practiced. Older parents tended to defer to the knowledge and authority of specialists, whereas younger parents, through their lobbying and organisations, forced policy debates into the media and a higher level of social visibility. In that sense, I agree that issues of disability became more ‘public’ in contrast to the earlier and less visible struggles between parents and the medico-governmental authorities. I was initially concerned that the ‘explorer-pioneer-settler’ framework would suggest a linear evolution of policymaking and a simplistic story of ‘progress.’ But the author deftly illustrates that this is not so, and for every gain made there are forces at work which suggest that there is always an ongoing struggle against retrenchment and set-backs.

The second ‘big idea’ is the use of social capital with which to explore the differing outcomes of variously situated parents. Often associated with the work of

Pierre Bourdieu, one's location within the larger socio-economic order and the ability to make things happen and influence outcomes is argued to be contingent upon access to differing forms of social capital. However, barely a page is spent discussing the author's take on social capital until Chapter 7, which serves as the conclusion. The author's formulation of the notion of social capital appears to be influenced more by Robert Putnam than Bourdieu, but this is not much discussed. The third 'big idea' is the attention paid to fathers who, as the author argues, are often left out of studies on disability and parenting and ignored by doctors and service providers, who focus on the mothers. Yet I find it curious as to why fathers receive a dedicated chapter (Chapter 6). A key strength of the text, in fact, is its careful attention to gender and how the author skilfully compares and contrasts the voices and views of mothers and fathers throughout the book.

This brings me to the last and perhaps most serious point. There seems to have been limited editorial support for this book from the publisher. The text would have benefitted from the involvement of a stronger editorial team, considering the range of issues that need to be addressed from errors of spelling, grammar and punctuation to the order and organisation of the text. A brief perusal of some academic forums and internet postings suggest that the publisher (Nova Science Publishers) has been criticised for a number of

dubious practices, one of which is the lack of editorial support for their publications. A good editor would have also fine tuned the focus of this book for commercial purposes, as I remain unclear of the intended market. It does not appear to be intended to engage with local scholarship or policy debates, given that it is published in English via an American publisher. Its focus is also somehow both wide (disability policy, family, parenting, gender, education, services) yet at the same time restrictive (English text, Iceland, 1974–2007). However, there is a lot of engaging material here. I have already decided to use the section 'Stories of abortions' for my own teaching purposes. The decision to abort foetuses upon the detection of impairment is a rarely researched issue, yet the author is able to present the conflicting and anguished positions of mothers, fathers and even doctors on these issues to a degree that I have not encountered before. This is testament to the author's skill as a researcher and interviewer. That being said, I remain hesitant if I would put the book in its entirety on a course syllabus. And that is a shame, as a good deal of the material has the potential to make an important contribution, but which the attention of a good editor is needed to make shine.

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