

BOOK REVIEW

Women with intellectual disabilities. Finding a place in the world

Rannveig Traustadóttir and Kelley Johnson (eds)
Jessica Kingsley Publishers, 2000

There has for some time been an increasing concern, not least among disabled researchers, about the way non-disabled researchers tend to have preconceived ideas about the everyday lives of women and men with different kinds of impairments. This line of critique is aimed at the tendency among non-disabled researchers to conduct research *about* disabled people instead of *with* them; i.e. as active participants in the study. Those responsible for the idea behind this anthology appear to have taken seriously this line of critique and have in a real sense included the voices of those disabled people focused on; i.e. women with learning difficulties. This aspect is one of this book's strong points.

The study

One expressed aim of this book is "... to fill a gap in the disability literature which has failed to take account of the needs and voices of women with intellectual disabilities. It makes a strong case for the importance of considering these women and their worlds as important in disability writing and action" (page 15). The editors also wish to extend the dialogue between non-disabled feminists and disabled women by including in this book the voices of women with learning difficulties. An expressed wish is to *increase the power of women with learning difficulties and make visible the strengths and abilities of this heterogeneous group.*

This book spans over a number of issues such as family life, work, friendship, abuse, sexuality, motherhood and community life generally. There are four main parts; i.e. "Finding a place in families", "Finding a place in relationships", "Finding a place in work" and "Finding a place in communities". The authors, many of whom are political activists, of the different chapters come from eight different countries; i.e. Czech Republic, Australia, Slovakia, New Zealand, Norway, Iceland, the UK and the US. Different countries and cultures are included, as an understanding of cultural diversity is viewed as a neglected area generally and as important to take into account. Some of the chapters are personal stories written by women with learning difficulties alone, some have worked together with another woman or as a member of a group. There are also stories written by friends, family members, as well as feminist writers. Each chapter begins with a short easily understood English version of the topic discussed in order to enable some women with learning difficulties easier access to the book. The kind of research referred to in this book falls within the ethnographic or qualitative tradition.

Enticing stories

The different personal accounts by the disabled contributors are informative and enticing. They expose realities of which we have little knowledge (of this personal kind), and which seldom are publicised. Women's experiences have traditionally been of little interest and their stories thus remain to a large extent untold. This applies particularly to women with learning difficulties. These untold stories mean that there is a great deal of knowledge which is lacking with regard to past and present living conditions for disabled women.

The different life stories told reveal the complexity of issues such as trust, friendship, love, jealousy and sisterhood. It is easy to portray an over-romanticised picture of issues such as these. This book does not fall into this trap. There are a great number of insightful and educational accounts which I would like to cite, but due to limited space I have to be selective.

One such account is the one by an American woman, Pat Felt, who has spent 30 years in institutional living, which has made it hard for her to trust people. Her story demonstrates the important part which trust plays in our lives and that it is built on reciprocity (page 223):

In my past, there haven't been very many people that I trusted. A few, but not very many. In my family, I trusted a few people. But the way I was

raised made it hard for me to trust. I didn't feel some of them trusted me. The family talked for you; it wasn't you talking for yourself. They made lots of decisions for me without asking. The biggest one was sending me to the institution. Also in the institutions I was in, I only trusted a very few people. It's hard to trust people who act like they don't trust you. There were a few who I could trust, but not very many.

Included in an account by Amanda Milliar from Australia, who frankly refers to being jealous of her non-disabled brothers and sisters for being able to do things which she cannot do, is a telling metaphorical definition of jealousy, which I cannot resist citing (page 241):

... But the real jealousy comes from deep down; it's been building up like a brick wall. And all of that jealousy is in all of those bricks and gradually seeps out ...

The social meaning of womanhood and disability

The women's stories tell us something of the society in which they live. They mirror the prevailing understanding of gender and disability, or rather what it can mean being a woman, as well as disabled.

This book does not, which is a common approach, treat women with learning difficulties exclusively as disabled and as asexual users of various services, but as *women*; i.e. as having a gender identity. This means that the women share with us, the readers, also experiences which mirror the way womanhood is understood. This makes the stories multifaceted, and informative about the social meaning of gender, as well as of disability.

Some of the stories show that the conception of how a disabled woman should be entails being "good"; i.e. behaving in a way approved of by others (e.g. staff). Verna, a woman from Australia, asks her sister (whose existence she has been unaware of for 67 years when living in an institution) the following, when returning to her community residential unit after she has been to her sister's place for a weekend visit (page 50):

I've been good today, haven't I? Will you tell them I have been good for you?

In the same chapter, a nurse refers to the occasions when Verna is upset as her having "her tantrums".

The kind of language the women themselves use and which is used when speaking about women with learning difficulties mirrors prevailing social attitudes towards women and disability. "Being good" and "having tantrums" is a terminology which we usually link to the behaviour of children. Here we can see it applied to an adult woman which indicates a disciplinarian approach to women with learning difficulties.

A different tone

There is one chapter in this book which differs from the others in that it has a different tone. The chapter is written by Michelle McCarthy who deals with interesting and neglected areas with regard to disabled women's lives; i.e. sexuality and abuse. The chapter offers some statistical data about the incidence and prevalence of sexual abuse among women and men with learning difficulties.

In this chapter there is an instructional tone and a normative approach, particularly with regard to masturbation and the non-accepting views on same-sex relationships, which some women with learning difficulties are claimed to have. This particular tone and approach can probably be explained by the fact that the author is a social worker (as well as a researcher), who works with providing sex education and sexual health information for women with learning difficulties. McCarthy makes an important point in that it is of value that myths about derogatory effects of masturbation, which can serve as an obstacle to pleasurable experiences and cause women who masturbate to feel guilty, are dispelled. It is, however, the manner in which McCarthy promotes masturbation (which appears to be more common among non-disabled women) and uses herself as a role-model, which I question (page 136) :

...What is different, however, is that even after support and encouragement from me (i.e. telling the women that I think masturbation is a normal, positive activity that most women, including myself, do at some point(s) or throughout their lives), still only about one-third of the women with intellectual disabilities have said that they do masturbate or have done so. This is quite different from other research evidence with non-disabled women where much higher proportions say they masturbate...

This can be understood as a well-meaning effort to enhance satisfactory sexual experiences for the women. It can also, however, be understood as a means to "normalise" and correct the everyday (sexual) lives and attitudes of women with learning difficulties. This coincides badly with one of the referred to aims of this book; i.e. to promote the empowerment of women with learning difficulties. If that which is implied; i.e. that women with learning difficulties (after having been informed that masturbation is "a normal, positive activity") may masturbate less than non-disabled women, is correct, why does this constitute a problem? And, for whom? It is worth noting that women with learning difficulties have also in earlier times been seen as having the wrong approach and behaviour with regard to sexual issues (as a means of exercising control over them).

My point is here that the tone and approach in this chapter demonstrate the fragile line between information and instruction/correction. In so called sexually liberated times, normative definitions of the "right" and "natural" approach to sexual issues and behaviour risk being no less judgemental than those of earlier more sexually restrictive times. Surely, self-determination is not about having "the right" view on masturbation and same-sex relationships, but feeling free to have, and express, one's own views (even when these can be defined as "out of date")?

Authors of their own lives

As having been stated, one of this book's strong points is that the women with learning difficulties involved are not generally merely discussed or briefly cited, but "authors of their own lives". This is a role not always ascribed disabled women (nor men) in research, nor within the social services generally. This approach does not require (as this book shows) the ability among these women to write, nor for that matter, speak, in a common manner, but rather the ability (of others) to listen.

Several of the accounts by the disabled women offer a possibility for self-reflection for us non-disabled readers. One such account is the one expressed by Nancy Ward, one of the contributors to this book. She states (page 177):

...People with disabilities often get used as tokens, just to make people without disabilities look good or feel like they are doing a good thing...

While I agree with the claim made in the book that this is a "women's book"; i.e. a product of the work of women which deals with women's everyday lives, I nevertheless recommend this book to all those, irrespective of gender affiliation,

interested in learning (and teaching) about social values and norms relating to normality, marginalisation and empowerment.

The combination in this book of personal experiences of women with learning difficulties and members of their families in the form of life stories, and accounts of current research on the topics discussed is of great value. So called "disability issues" risk either being discussed exclusively on a theoretical level, in the sense of making disabled people invisible and their own voices unheard, or exclusively on an empirical level which lacks problematisation and analysis. This book succeeds in combining personal accounts and experiences with a theorising of gender and disability in such a way that it deepens our understanding of the complexity of the issues in question.

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