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The possibility of choice: women with intellectual disabilities talk about having children

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Until very recently, the choice to be or not to be a mother was essentially unavailable to most women, even today, the possibility of choice remains everywhere in jeopardy. This elemental loss of control over her body affects every woman's right to shape the imagery and insights of her own being. (Rich 1979a: 196)

As feminist researchers who have been working with women with intellectual disabilities, we found Adrienne Rich's quotation to be particularly poignant and ironic in relation to our recent work. Rich argues that a dominant traditional discourse in our societies has positioned women unquestioningly as mothers. Indeed she argues that 'a woman's status as child bearer has been the test of her womanhood' (Rich 1979b: 261). Women with disabilities have in the past been excluded from this societal expectation and their womanhood has been a problematic issue for those around them (Asch and Fine 1992; Johnson 1998a). This has been particularly the case for women with intellectual disabilities who were constituted by the eugenics movement early this century as a threat to the very structure of society because of their child bearing capacity (Brantlinger 1995; Rose 1979; Scheerenberger 1983).

Consequently, many women with intellectual disabilities were subject to sterilisation, constant surveillance and institutionalisation (Johnson 1998a; Potts and Fido 1991; Trent 1994) to prevent them from becoming mothers. For women with intellectual disabilities, then, the dominant discourse historically has situated them as women who are unfit to have children or to be mothers. This issue raised questions for us about the lives of women with intellectual disabilities now: What effect has the explicit exclusion from child bearing and mothering had on the way women with intellectual disabilities see themselves? How far does this historical view of women with intellectual disabilities as 'non child bearers and non mothers' still impact on their lives?
As a feminist, Rich challenges the traditional discourse equating womanhood and motherhood. She advocates a position that will free motherhood and child bearing from traditional societal expectations. Indeed in our lifetimes we have seen how the availability of contraception, changes to the economic and social structures and the rise of feminism have led to increased choices about how women live their lives. The traditional view of motherhood has been challenged.

Women now choose not to have children at all, to have them outside traditional family structures and to have them at particular times in their lives. As Rich notes, such choices are not made without a struggle. In this chapter we argue that for women with intellectual disabilities the challenge to the prevailing discourse and their struggle have had a different form. Feminism, deinstitutionalisation and the impact of self advocacy and rights discourses on the lives of people with intellectual disabilities have challenged some of the old stereotypes, including the view that women with intellectual disabilities cannot and should not be mothers or bear children (Johnson 1999b; Walmsley and Downer 1997). The contested nature of these issues is shown in the number of research studies carried out over the past fifteen years about people with intellectual disabilities and parenting (Andron and Tymchuk 1987; Booth and Booth 1994, 1998; Feldman 1986; 1994; Keltner, Wise and Taylor 1999; Llewellyn 1993, 1994; Pixa-Kettner 1999). Much of this research appears to have been directed at proving the capability of people with intellectual disabilities to be satisfactory parents. Some of it has sought to explore how such people themselves see these issues (Booth and Booth 1994; Llewellyn 1995). However while the research covers many aspects of parenting, we found that it did not really explore how women came to decisions about whether or not they would have children. This raised questions for us in our own research: How do women with intellectual disability make decisions about having children? What factors affect these decisions? What effects has the new rights discourse had for women in relation to having children?

The importance of women’s choices and voices

Rich argues strongly for the importance of choice as an issue for women for it is by choice that women can become empowered and take control of their bodies and their lives. For women with intellectual disabilities however, choice remains a difficult issue particularly in relation to child bearing and parenting. In spite of evidence that some women with intellectual disabilities have always taken on caring roles, there remains a view that they are ‘child like and dependent’ (Walmsley 2000). In
relation to their sexual lives there is evidence that they often feel they have limited choices about whether or not to engage in sex (McCarthy 1999) or in the development of relationships. The questions that these issues raise for us are: What, if any, choices do women with intellectual disabilities have in deciding whether or not to have children? What do they see as the issues that affect this decision-making?

We have found little discussion of our questions in the literature, particularly from the perspective of women themselves. Some women, not labelled as having disabilities, have written about the complex motivations that may lead to their decisions about whether or not to have a child (Dowrick and Grundberg 1980; Oakley 1980). And more recently women with physical disabilities have explored their experiences of life, including parenthood (Browne, Connors and Stern 1985; Keith 1994; Morris 1991; Wates and Jade 1999). But women with intellectual disabilities are only peripherally included in these works. For example, a collection of stories told by couples with intellectual disabilities discusses only superficially their views about child bearing (Melberg Schwier 1994). However, the recently published stories of two women with intellectual disabilities provide a more detailed account of their decision-making about having children.

It [sterilisation] was made a joint decision and that decision was made by me and my husband. I had the tubal ligation in 1983 and soon after I had that I felt this tremendous . . . I still can’t describe it even today. I had a great big burden off my shoulders. And I still think, looking back today, I still made the right decision. That’s allowed me to do the things I’ve been doing since then. It’s freed me up and I haven’t been tied down or anything like that. (Millear 2000: 245)

Millear’s decision was informed by her knowledge of the law and her rights and by a desire to live a life without children. In contrast Janice Slattery (2000), writes movingly of a decision not to have a much wanted child. She describes the decision made in consultation with professionals, family and her husband as difficult and painful.

It was a very hard decision for us. And we came to the decision that we didn’t want to put our child at risk of being teased at school like I was. I was teased about my balance and that and my speech and we didn’t want our child to have that. And also we didn’t want to put my health at risk because of my age. And if we did have a child with a disability I would have difficulty raising it. Like I wouldn’t know what to do. I wouldn’t know how to get him speech therapy or where to go to school and that. (Slattery 2000: 99)

For Slattery the issues had to do with her painful experiences of being ‘disabled’, her concerns about her ability to care for a child (perhaps with disabilities) and her age. These two women chose not to have
children, one with a sense of relief and the other with great sadness. For both of them the decision was a momentous one, taken after a lot of thought and consultation. It was a decision in which they were active participants. How do other women with intellectual disabilities make this decision? How do they feel about the decisions they have made or been forced to make?

**Women talking about having children: in Iceland and Australia**

This chapter explores how some women with intellectual disabilities view the issue of child bearing in our two countries, Iceland and Australia, and seeks to explore the questions raised for us by Adrienne Rich's statement. The chapter is based on separate studies which we have undertaken with women with intellectual disabilities in Iceland and Australia over the past few years.¹

**The Icelandic study**

The research with Icelandic women with intellectual disabilities started in 1994 with a small project, focusing on a woman with an intellectual disability who was a leader in the Icelandic self-advocacy movement. During interviews with this woman, whom we have named Stella, we learned that it was not her leadership career that she was most interested in talking about. Instead, her major concern was with motherhood, the recent abortion her family had forced her to have, her fight against sterilisation and her strong desire to have a child. When we started a larger study of women with intellectual disabilities in 1996, we placed a strong emphasis on motherhood and family life (Sigurjónsdóttir and Traustadóttir 2000; Traustadóttir and Sigurjónsdóttir 1998). Over a period of three years we have spent time with about thirty women with intellectual disabilities. Ten of the women are mothers. They comprise a diverse group and their living situations varied. The oldest woman was 83 years old and the youngest was 25 years of age. The wide age range in the group of mothers helped us understand how changing ideas, attitudes, policies and services over the years have influenced the possibility of motherhood for women with intellectual disabilities. Many of the twenty women who did not have children had been sterilised, some of them had a strong desire to have children and some did not want to become mothers.

The research was conducted using ethnographic methods (Hammersley and Atkinson 1994; Taylor and Bogdan 1998). We have spent a
long time with each of the women and taken part in their daily lives and talked to them about their interests, including motherhood and family life. We wanted to gain in-depth knowledge of their lives and attempt to understand things from their perspective. We have kept in touch with most of the women over a period of a few months and up to three years. We still keep in touch with Stella, who participated in our initial study in 1994.

The Australian study

Thirteen women have contributed their life histories, with a particular focus on sexuality and relationships as part of a two-year study titled *Living Safer Sexual Lives* (Johnson, Hillier and Harrison 1999). The women ranged in age from their early twenties to their late fifties. Some had spent part of their lives in institutions and others had lived all their lives in the wider community. Women researchers spent a minimum of three occasions with each person in a free flowing discussion, which ranged across life choices and experiences. The stories were taped, then written up and returned to the contributors for change and corrections. The resulting stories are powerful and cover a wide range of issues that the women are concerned about in their lives. Eleven women expressed some view about child bearing or motherhood in their interviews and for some this issue was a central and important part of their lives. The women differed in their views of the issues and also in the degree to which they believed that they had some control over the decision-making.

Our work with the women in these studies suggests that their experiences are very similar across our two societies and that they raise important issues for us as women, and in our work with people with disabilities. In this chapter we draw on the stories to explore the diversity of women’s experiences and to examine how they are affected by the changing discourses about women and intellectual disability. The women’s names are changed to protect their confidentiality.

Women with intellectual disabilities talk about having children

The women who participated in our studies conveyed a wide range of issues in relation to discussions about having children. Here, we explore two major themes that directly address our questions: the challenges to the legitimacy of their desire for a child; and the variety of factors that influenced a woman’s decision about having children.
The challenges to desire

None of the women who had been involved in decisions about having children, or the desire to have them, had found the processes easy or simple. They were trapped between two opposing discourses: one which focused on their own perceived desire and right to bear a child and to be a mother, and the other which has excluded them from the possibility of motherhood. Some women had internalised the societal discourse and did not see child bearing as a possibility for them.

Helga Jónsdóttir, has a large collection of children’s photographs she has taken over the years. She treasures these pictures and goes through the albums frequently. Most of the pictures are of her sibling’s children when they were babies, some are children of staff she encountered in service programs, and some of the pictures are of young children she has met in parks and playgrounds. ‘I love children’, Helga’s face lights up when she talks about children. But she has internalised society’s views about her possibilities to have a child of her own and believes it would be inappropriate for her to become a mother.

Other women, however, struggled against the societal restrictions. Often they were unsuccessful. Elaine, now 44, reflects back on an ongoing struggle to attain marriage and parenthood, a struggle which she lost.

I would have liked children. I’m getting too old. I would have liked to have a child. I said to mum. I said, ‘Janet’s [sister] married and got children. Bill’s [brother] got a girl pregnant and didn’t marry her now and Simon [brother] he’s got three and he’s married’. And I said, ‘What about me?’ I said, ‘how do you think I feel mum? I feel horrible mum’. I said, ‘You and dad don’t even give me a chance’. You know. And I got really pissed off with mum and dad at one stage you know. I said, ‘One of these days I’m going to run away from home. And get meself pregnant and then you might have something to moan about. Mum said, ‘Over my dead body young lady’. She said, ‘I’ve been through that, I don’t want to bring any more up’. Mum and dad treated me like a little child. When I got older they changed a little bit.

Elaine believed that if she had got pregnant she would have been forced by her family to have an abortion. She comments:

I didn’t want to bring a baby into the world and not have her. And you know when I had sex with James I went to the doctors because mum thought I might have got meself pregnant and I said, ‘What about if I did?’ I said, ‘What would you do?’ She said, ‘I wouldn’t own you’. I said, ‘Yeah I thought so’. I said, ‘your own daughter’. I said, ‘You wouldn’t own her’. I said, ‘You’re not my mother’. And then mum went home bawling her eyes out. ‘Cause mum was hurt.

Elaine mourns her lost opportunities as both wife and mother:
Well in me I think back and I have a little cry now and then you know that I wasn’t married and had children. I would have liked it. I am an auntie. Anyway that’s the way it was. It didn’t turn out. What can you do? Mum and dad wasn’t that hard on me. Only about getting married. I couldn’t have children. Mum thought if I had a baby it would have been like me. Mum was scared if I got pregnant and had a baby it would have polio too. That’s what mum was thinking in her mind. And dad was thinking too. I thought mum was a little bit hard on me. You know mum and dad the way they brought me up. It was different the way they raised me and the way they raised Bill and Janet and Simon. They can do a lot more things than me.

Her account of her parent’s anxieties about her possible decision to have a child contains not only a rejection of her as a woman and a mother unable to care for her baby or to be a wife but also a rejection of her as a daughter in that her parents did not want another child like her. This was a repeated theme in the stories that the women told us. Further, Elaine felt strongly that she was treated differently to her brothers and sisters in relation to marriage and children. This sense of being differentiated from siblings was common among the women. Molly described how her parents supported her sister when she became pregnant at 18, but also describes how when she was 23 and became pregnant they insisted that she have an abortion.

Parental reactions to the possibility of their daughter having a child seemed to reflect the view that they should not be mothers because they would not be able to cope, because the child might be disabled or because they might be required to become primary care givers. But for the women in our studies these reactions were seen as oppressive, life constraining and agonising.

Sometimes family intervention went beyond verbal discouragement. For example, when Elaine became involved with someone in a long term sexual relationship her mother suggested sterilisation.

And then mum said, ‘What about having your tubes cut and tied?’ Mum wanted me to have it done. The doctor said, ‘you want to make your mum happy?’ And I said, ‘Yes. Of course. I love me mother’. ’Cause you’ve only got one mum. And I said, ‘Yes I want to make mum happy’. ‘Well what about it?’ I didn’t really have a choice. But there was nothing I could do about it. ’Cause I only had me tubes cut and tried to make me mum happy.

The power of societal or family pressure against women with intellectual disabilities becoming mothers can be extremely strong in spite of legislation which aims to protect them against discrimination on the basis of disability and which restricts sterilisation. A woman’s love for her parents, manipulation, her distress or coercion can lead women to agree to either sterilisation as in the case of Elaine, or abortion in Stella’s case.
From childhood on, Stella had watched friends undergo sterilisation and was relieved that this had not happened to her. When she was in her 20s, however, she learned that her family was strongly opposed to her having a child. She was in a long-term relationship with a man and they were planning to establish a home together. Stella's family was afraid she would become pregnant. She was on the pill but they wanted her to be sterilised. Stella had not realised her family was so strongly against her having a child but this did not stop her from wanting to become a mother. She became pregnant.

No one congratulated her or was happy for her. Everyone reacted negatively. Her family put an enormous pressure on her to have an abortion. In particular, her oldest sister insisted that she have an abortion and be sterilised at the same time. 'She forced me to have the abortion', Stella recalls. The sister threatened that Stella would be locked up in an institution if she didn't have the abortion. The fear of being institutionalised made Stella go with her sister to a social worker where she signed a paper that she would undergo both procedures. Stella was devastated and felt desperate. She could not bear the thought of never being able to have a child. Without her sister's knowledge Stella went back to the social worker later that same day and told her that she would have to go through with the abortion because of her sister, but she did not want to be sterilised. She had the abortion the next day.

Both of these women were strong self-advocates and plainly both struggled against their family's opposition. Yet both found it difficult to stand out against the pressure from family members.

Women making decisions about having children

There is a tendency among workers and families to see women with intellectual disabilities as passive and non-participative in decision-making. Certainly some of the women in the studies appeared to have little say in what happened to them. But many of the women thought seriously about their possible choices in relation to children. The reasons they gave for decisions they had taken about this issue were varied and often demonstrated powerful internal struggles between competing desires and needs. They also often demonstrated care and concern for others, particularly towards those with whom they were involved in relationships and for their possible children. Their responses were consistent with Gilligan's view that for women 'the moral imperative . . . is an injunction to care, a responsibility to discern and alleviate the 'real and recognisable trouble' of this world'. (Gilligan 1993: 100). While the 'womanhood' of these women may have been challenged by societal proscriptions they demonstrated that they were speaking with women's voices in their decision-making.
For example, Ruth has recently left an abusive relationship with a man with whom she became pregnant.

I had a termination last year. I wanted to have the child but because my fiancé was too intellectually disabled and because of his temper I just didn’t go through with it. I just couldn’t let him bring up a child knowing that he could hurt it. That was a decision I made because he was too pig headed. He wanted a baby and that was it. That was final. Too bad what I wanted. He wanted it so bad luck what I wanted. He wanted the baby and he couldn’t see my point of view. He couldn’t see why I couldn’t bring it up. I was still living at home and I didn’t want my mum to help me even though she would have. She’s already brought up four kids.

They were really the main reasons [for the abortion]. It worried me a lot. I didn’t want to bring up a child in that environment. I could have a child in the future if I wanted to. It is possible that the baby would end up with the same thing [as me] but other than that there’s no reason not to have a child.

I should have waited you know but at the time I guess I wanted a baby really because I wanted to prove to myself that I can care about a child better than what my father did when he left me. I wanted to prove to my child that I can do that. I could stay with the situation. I also wanted a kid because I love children. I wanted a child because I wanted someone to love me I guess, ‘cos at the time I was feeling that nobody wanted me. I was in the relationship with George and it was not going as well as I would have liked but I still wanted a child.

Ruth has given a great deal of thought to her decision to have an abortion. Concerns about her unborn child’s safety, a violent partner and the possible extra work for her mother are issues weighed against her desire to have someone who will love her and whom she can love.

Other women commented that their health made it difficult or impossible for them to have children or that they felt they couldn’t manage to care for a child.

So Alicia, who is married to Rob, comments:

I can’t have kids . . . because my ovaries stopped growing. I found out by my doctors. Because I’ve got diabetes . . . really small hands and feet. It didn’t worry me at all really. I mind my nieces and nephews lots of times. I wouldn’t like a child. It’s too much hassle. I can’t cope with the little ones, I can’t chase after them. Babysitting my nieces and nephews is enough. I like them and all that but they are really hard to look after. It’s hard enough just being myself. I couldn’t look after another person, especially a baby. Rob understands.

While Alicia cannot physically have children, it is clear that this is an issue that has been discussed in some detail between her and her partner.

Women who decided to go ahead with having a child, often in spite of family or societal opposition, often also showed a high degree of planning and decision-making.
Halldóra and her partner Kristján had been living together for some time. They had often talked about having a child ‘but it was not on the agenda to have children right away’, said Halldóra. They wanted to wait and see how well they could take care of themselves before they had a child. Halldóra was also afraid her epilepsy would make it difficult or impossible for her to have a child. Although her epilepsy was mostly under control she still had occasional fits. She also worried that her medication might harm the fetus. ‘Because of this’, Halldóra said, ‘we were sometimes saying we might need to adopt a child’. She was using the birth-control pill when she unexpectedly became pregnant. She was three and a half months into the pregnancy when realised she was expecting a child.

This unplanned and unexpected pregnancy created mixed feelings. On the one hand, Halldóra and Kristján were happy and wanted to have the child. On the other hand, they worried about Halldóra’s health. Halldóra consulted her family doctor and he told her there was no need for concern because there was nothing physically which hindered her in carrying and having the child, and the medication would not affect the fetus. Halldóra and Kristján thought about an abortion, ‘But it was always “no”. We could not destroy this life that had already began’. Halldóra decided to have the child.

For Halldóra and her partner, having a child was a serious undertaking. They had established safeguards to ensure that they could care for a child as well as themselves and had also carefully considered Halldóra’s health. Confronted with her unexpected pregnancy, they weighed up the choices before deciding on the way which seemed best to them. What more can we ask of any prospective parents?

**Conclusion**

We have found this a difficult chapter to write. In part this is because the women’s stories have an integrity and wholeness, which loses much of its power when they are fragmented and analysed. But there is a power too in the aggregated voices, which can be heard through the chapter. For many women with intellectual disabilities decision making about having a child is a serious and central issue in their lives. None of the women with whom we spoke had been through this process without struggle and pain. The issue for us in this chapter has not been whether or not the women who spoke to us would be ‘good mothers’. Rather, it has been the way in which they have been constituted by society and by their families, and how this has impacted on decision-making for them.

We would have to conclude that the traditional discourse which prohibited women with intellectual disabilities from having children still remains dominant and that some of the reasons women give for their
child-bearing decisions reflect an internalisation of this discourse. While other women may struggle to broaden definitions of motherhood and family, the women with intellectual disabilities with whom we spoke, are struggling to take a first step towards fulfilling their desire for children.

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