

Misconception: The Experience of Pregnancy for Women with Intellectual Disabilities

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ABSTRACT *The experience of pregnancy and motherhood, from a woman's point of view, has only been considered worthy of research in recent decades. In this time, a small number of studies have examined the experiences of mothers with intellectual disabilities. No study to date has focussed on the lived experiences of pregnancy for women with intellectual disabilities. This paper reports findings from a phenomenological study into becoming a mother for women with intellectual disabilities. We focus on the stories of three Australian women with intellectual disabilities about their experiences of being pregnant. Three key themes of the pregnancy experience for these women are illuminated. First, through experiencing their pregnant bodies the women began to understand themselves as mothers. Secondly, the women actively made decisions regarding how their baby would be cared for. Thirdly, the women involved trusted others in these important decisions. This paper gives voice to a group of marginalized women whose views about being pregnant have traditionally been silenced and/or ignored.*

Women with intellectual disabilities are commonly considered unfit to parent or likely to produce offspring with disabilities (McCarthy 1999) and have subsequently been afforded even less control over their own bodies than their non-disabled peers. Their reproductive capacity is commonly constructed as a burden requiring suppression or elimination, rather than a normal part of womanhood. Historically, routine segregation, enforced contraception and sterilization were measures used to prevent these women from having children in many Western countries (Bass 1963, Hillier, Johnson & Harrison 2002, Pfeiffer 1994). Although involuntary sterilization has now been “officially” abolished in many countries (Blackford 1993, Brady & Grover 1997, Walmsley 2000), unlawful sterilization procedures are still being performed in places such as Australia (The National Children's and Youth Law Centre and Defence for Children International (Australia) 2005). Furthermore, many women with

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disabilities continue to face pressure from family and professionals to have abortions (Booth & Booth 1992, 1995, Llewellyn & McConnell 2005, Pixa-Kettner 1998). In short, negative attitudes about women with intellectual disabilities having children are still evident in the community and in professional practice and continue to have a significant impact on their freedom to choose to undertake adult female roles (Brown 1996, Edgerton 1999). Despite this, few disability researchers, and even fewer feminist researchers, have studied the implications of pregnancy for women with disabilities.

The little research there is on the pregnancies of women with disabilities has tended to focus on the reactions of others to the pregnancy rather than the experiences of the pregnant women themselves. Such studies indicate that the reactions of people close to these women when they announce their pregnancies are almost exclusively negative (Booth & Booth 1994, 1995, Llewellyn & Brigden 1995). Rather than an event to be celebrated, for this group of women pregnancy is frequently treated by others as a mistake never to be repeated (Booth & Booth 1995). For instance, Llewellyn (1994) reported that the announcement of pregnancy was often met with disbelief or dismay, signalling to mothers-to-be the suspicions of others regarding their capacity to care adequately for the child.

A more significant body of literature has examined parenting by adults with intellectual disabilities and, within this, several studies have privileged the voices of parents themselves (e.g. Booth & Booth 1995, Llewellyn & McConnell 2005, Taylor 2000). Despite the majority of participants in these studies being women they are consistently referred to as “parents”, whereas studies of parenting in the broader community are more likely to use the gendered term “mother” (e.g. Crouch & Manderson 1993, Wearing 1984). Thus, within this degendered literature the gendered experiences of women with intellectual disabilities as women and as mothers are effectively silenced.

Feminist scholars have stressed that listening to the stories of women with intellectual disabilities is a crucial first step in the process of challenging existing stereotypes and revealing gaps in our understandings of their lives (Traustadóttir & Johnson 2000). Yet, to date, researchers have failed to acknowledge and explore the gendered experience of pregnancy for women with intellectual disabilities from their own point of view. This paper begins to redress this significant gap in the disability studies literature.

Methods

The findings presented here come from a phenomenological study that aimed to uncover the meaning of becoming a mother for women with intellectual disabilities. In broad terms, phenomenology concerns itself with phenomena, which can be understood via an examination of lived experience (van Manen 1990). In this study, the lived, embodied experiences of pregnancy were explored by conducting multiple in-depth, semi-structured interviews with women with disabilities while they were pregnant, in order to understand the phenomenon of becoming a mother. This paper focuses on three key themes of women’s pregnancy experience, highlighted through the stories of three women.

Of the total 17 women who participated in the study, the majority (12) were recruited during their first antenatal clinic appointment at two large public hospitals in an Australian city. Information outlining the nature and purpose of the study was distributed to all women attending their first antenatal appointment at the target hospitals. A project team member was available in the clinic to explain the project and answer any questions. Consenting participants completed a brief questionnaire, and gave permission for the researchers to examine their hospital records following their baby's birth.

The questionnaire established whether women (i) had received exceptional help at school (such as assistance from a remedial education teacher) due to a special learning need; and/or (ii) had attended a special school specifically designed for children with special learning needs; and/or (iii) had received in the past or currently received a disability pension related to a cognitive limitation and/or (iv) consider themselves to have learning difficulties or to be a slow learner and/or (v) had others describe them as a slow learner. For the purposes of this study these criteria were considered indicative of a special learning need. Women who answered affirmatively to any question were invited to participate in interviews about their pregnancy experience. An additional four women were recruited via professional support organizations, and the remaining woman was recruited via word of mouth through a colleague. The same criteria were used by professional support agencies to identify potential participants.

Participants completed the Kaufman Brief Intelligence Test (Kaufman & Kaufman 1990), which indicated each had an IQ score of less than 80. Given that the questionnaire identified women with special learning needs, which are not limited to intellectual disability, this test was used in order to capture the experiences of women thought to be in the mild and moderate ranges for intellectual disability, as well as women often considered to have "borderline" intellectual disability or mild cognitive limitations (Tymchuk, Lakin, & Luckasson 2001).

The women ranged in age from 18 to 37 years. Five women were having their first child, five their second, and two their third child. Four women were having their fourth child and one woman was having her fifth. All 17 women were, or planned to be, full-time mothers once their babies were born. Two women had been employed when they became pregnant and continued to work during their pregnancies for varying lengths of time: one as a factory worker and the other as a supermarket cashier. Thirteen women were in long-term relationships, and four either were not in a relationship or their relationship had ended when the pregnancy was discovered. Fifteen women were from an Anglo-Australian background, one had emigrated from South America as a child with her family and one was from an Aboriginal background, although she had lived her whole life with a white Australian family. All the women lived in the outer suburbs of a large Australian city.

Semi-structured interviews were conducted by the first author at a time and place convenient for the women. In each case this was the woman's home. Semi-structured interviews allow a focus on specific aspects of a topic, for example, emotional reactions to discovering a pregnancy, but acknowledge that each

conversation is unique and questions are matched to what participants are willing to share (Rubin & Rubin 2005). The number of interviews conducted with each woman ranged from one to seven, with an average of two. Interviews were generally relaxed and conversational in nature and were conducted without any preconceptions about the ability of each woman to communicate her experiences. As each interview progressed, the interviewer's communication style was adapted only if necessary, for example, by simplifying the language used. In general the women did not find it difficult to talk about their experiences of pregnancy. Interviews were transcribed verbatim for analysis.

Analysis of interview material first involved constructing a description of each expectant mother's experience of pregnancy. The descriptions, derived from the transcripts of all interviews with each woman, constituted her "pregnancy story". These descriptions were different from each other, as each was revealed within the woman's life context. Second, following a process described by van Manen (1990), essential themes were identified through a process of inspecting each description. This involved (i) attending to the text as a whole (including whole descriptions); (ii) re-reading smaller sections of text; and (iii) a detailed examination of the text sentence by sentence within the descriptions. What was sought was not only that which was common to each woman's experience, but that which characterized the pregnancy experience.

Recognition of "the physical signs" as essential to the experience of pregnancy provides a clear example of the processes involved in determining an essential theme. The theme was evident in every description; that is, each woman described how she had experienced the physical signs of being pregnant, albeit each experience was different. Furthermore, this was considered a fundamental characteristic of the experience, that is, without the expectant mother's recognition of the physical signs of her pregnant body, the pregnancy experience would be fundamentally altered.

This paper takes the pregnancy stories of three women with intellectual disabilities in order to examine three themes evident in their stories. Each theme was considered fundamental to the pregnancy experience for women with intellectual disabilities.

Results

The following three women's stories of pregnancy were selected, not as being representative of the whole sample, but because their experiences are diverse. Nevertheless, despite this diversity of experience these three women share several elements in common with all 17 of the participants in this study. All names reported in this paper are pseudonyms to protect the anonymity of participants and their families.

Marian

Marian and Joseph have been living together since Marian was thrown out of her parents' house at the age of 16 years. Though they have two children together, Marian describes Joseph as her friend. Their eldest, Zoe, was born

when Marian was 19. Zoe was not planned, and Marian's relationship with Joseph was somewhat ambiguous. "I thought I was too young to have a baby at the time. I was a baby myself, so I wasn't really fit enough to be a mother at that age."

Marian's experience is not unlike that of many women with intellectual disabilities (Booth & Booth 1994, Llewellyn & McConnell 2005). Some of those close to her have told her that she is not capable of caring for her child, and that she should not be having children. After Zoe's birth Marian's aunts came to help her look after her new daughter. This quickly turned sour. Her family accused Joseph of sexually assaulting Zoe. Marian said her family made up this lie as a pretext to take the child away from her. The case went to court and Zoe went into care with Marian's aunt. Marian was distraught and fought for several years to have her daughter restored to her care, but was told her child was settled in her new family and should not be moved. During the court case Marian found that she was pregnant with a second baby.

At the time I was pregnant with Jacinta. It just happened. I wasn't very happy about it, but I didn't tell nobody 'til I was six months. I knew I was pregnant but I didn't tell anybody. I just wanted to keep it inside because I really wanted my other daughter back. I finally had to get it off my chest that I was pregnant and tell the court because my aunt told me that the magistrate said I can't have any more children, so that's the threat I had to put up with. The magistrate didn't even say that. Mum's sister is a liar. The court didn't finish until 1999. Jacinta was born in 1997. I started bringing her into court and the magistrate said to me that ... I've changed, I'm a good mother and they were very happy. Zoe wasn't given back to me though because she's been in my aunt and uncle's care for ... a long time.

When Marian confirmed she was pregnant for a third time she was shocked. She had previously been to the doctor and was told she had had a miscarriage. After another trip to the doctor an ultrasound confirmed a well-advanced pregnancy. Marian was distressed and requested an abortion. As her pregnancy had advanced to almost six months an abortion was out of the question. Her feeling of distress was so intense she began harming herself in an effort to induce a spontaneous abortion. "When I went to the ultrasound I didn't have a look at the screen".

Marian had several reasons not to want another baby. Firstly, she feared her family's intervention. Whenever Marian was pregnant she suffered verbal abuse from her family.

I was ashamed of myself because I guess with people in your head and it brings you back to thinking about the way my family carries on. They carry on in a stupid way and think that I'm uncope-able, [incapable] which I'm not uncope-able. I always have a lot of trouble when I'm pregnant. They want the best for the child, not the best for what I think. They reckon that the child should have more better care than what I can give. My family on my mum's side make me really upset and all that. I get abused every time when I get pregnant. I think they want me to suffer for the rest of my life.

Secondly, she feared Joseph's reaction. Marian was unsure who the father of this baby was and was afraid Joseph would be physically violent. Although she did not reveal to Joseph her uncertainty about the paternity, Marian did

tell him that she was pregnant and that she planned to give the baby up for adoption. He revealed that he had suspected she was pregnant, and was thrilled about it.

He told me, “Don’t give it up for adoption, we made it, so we can look after it together now”. It made me feel more happier than what I was. It shocked me. But I’ve decided to keep it now; I’m going to show my family up.

Despite Marian’s initial reaction to the pregnancy as a disaster, towards the end, she described with tenderness the baby she was expecting. “Oh dear, I call him [her baby] ‘Darling’ now. . . I say to myself, ‘I can’t wait to hold him.’”

Marian summed up her experience across three pregnancies and her experience of being a mother to two children with these words:

My family hounding me about how I can’t look after a baby and I know that I can. I am good with Jacinta . . . Because I had one bad experience in my life with my first daughter [Zoe] I think I can cope. I think I have made a big achievement with Jacinta and now is my opportunity to have another big achievement, to see if I can really do it. I reckon, to me, I can do it. I’m out to show up my mother’s side of the family because they reckon I’m stupid, I shouldn’t be having kids because I got a little bit of disability, and they say that because I have a little bit of a disability that’s how my kids are going to be like. They reckon I shouldn’t be having kids; the kids should be going to a new home so they can get better looking after. . . I get so upset and cranky. I’m out of my head. I’m a good mother. . . . Every time I get pregnant I go through a difficult time. It’s just how people react in front of me, they like to annoy me. I sit down and all of a sudden my mother’s on the phone, just every day of the week she goes on with the same crap about how I shouldn’t be having children. Every time when I get pregnant I go through stress. It’s very hard, and very stressful. Even if she is my mother. But the mother shouldn’t be carrying on like that. She lies and she manipulates. I don’t really care about my mother. I think I’ve got a lot of hate against her. What she did, and what she put me through – I might as well spit it out and tell the truth.

Brianna

Brianna lives with her husband, David, and three boys aged nine, four and two years. The youngest boy is David’s son. Brianna’s other sons are from previous relationships. Like Marian, Brianna has endured significant opposition to her pregnancies, particularly from her mother, who has little faith in her abilities as an independent woman:

My mother never thought I could do anything. She’d never let me do things in the kitchen when I was growing up. I was never allowed to have my own money, she used to keep it and control what I could spend it on. My sisters always had their own money. They were allowed to do things. She made all my decisions for me. I was never in control of my own life. I was the one she saw as stupid and dumb. She never thought I’d be able to look after myself, or look after my children.

When Brianna first got pregnant her mother told her to have an abortion. Brianna, the eldest of three sisters, argued that her mother didn’t know how to look after a baby either when she was born. “You don’t know how to be a mother before you are one. I didn’t know, no one taught me. My mother certainly didn’t.”

Brianna's anger at her mother and the external circumstances surrounding her pregnancies contrast sharply with the way she describes her baby inside her.

When I first got pregnant with Thomas I thought, "I've got something growing in my stomach and it feels beautiful, it feels beautiful that you've got something growing in your stomach. No woman knows what's going on in their tummy until they actually fall pregnant." You get that feeling and you say, "I'm pregnant." And it starts growing and it's wonderful when you have your man put his hand there and feel that first kick. It's a lovely feeling that you've got a human being growing inside you. It's just wonderful.

Before Thomas was born Brianna's mother threatened to phone an adoption agency because Brianna refused to have an abortion. Brianna realized this was an empty threat, as she would have to sign her baby over, which she also refused to do. Following Thomas' birth her relationship with the baby's father broke down. Brianna left and moved into a flat on her own with her young son.

Within two days of me being there the welfare were on the doorstep wanting to know if everything was all right and if I was looking after Thomas properly. I'm sure my mother phoned them to come around. A couple of months later it was the same again. For five years I looked after Thomas on my own. He was my companion, we did everything together. People said, "Oh Brianna can't cope with a baby. How will she manage?" But then they started telling me what a wonderful job I'd done with him when they saw me with him.

Brianna described becoming a mother as wonderful. There's a lot of responsibility involved, and that responsibility has changed her attitudes and perspective. She said she is "still the same girl I was before I fell pregnant with Thomas, but my life has changed." Brianna wanted to be a mum. She wanted to be a better mum to her children than her mother was to her. Her mother, she says, doesn't understand that Brianna does not cope with her children alone, that she and her husband care for their children together.

Brianna's fourth pregnancy was unplanned. Indeed, she and her husband had been using contraception, thus the news was unwelcome initially: "I don't really want to be pregnant." Do I want this baby? "Not really; not now . . . but yes." Her husband's reaction was similar, "Oh no, not another one, I don't want another one now. . . . Well what will be, will be. We just have to manage." Brianna and David had financial constraints to consider before planning a fourth child. Also, because their youngest child was recently diagnosed with autism, there was also the question of whether they could manage another child if she/ he too had a disability:

I'm going to ask for a test. . . . it's like a menopause test like, to see if the baby's going to be all right, if the baby's got a Down syndrome or if the baby's got a fault. It's a special test they can take while you are pregnant and they see if the baby's retarded or whatever, yeah. So, if it has me and David have talked about it and we're going to get rid of it, you know I'm going to have an abortion. But if it hasn't we're going to go straight through with it.

Reflecting on her pregnancy with her fourth child, having made the decision to continue she said:

Becoming a mother is special: you get to hold this little baby in your arms, you get to hold it for the rest of your life. Each child is special. My body changing makes me feel . . . that there's a baby in there, a real live baby, it makes me feel happy. It's a good feeling being pregnant. It doesn't matter how many children you have, when you feel the baby move inside you, you realize there is a real live human being in there, how could anyone kill that human being in your tummy? My pregnancies were all different. Each one is exciting, each one is special.

Esther

Esther is in her late thirties and lives in a new, government housing townhouse with her nine-year-old son, Stephen. Her mother and sister live nearby and she sees them regularly. Esther, who became pregnant after being repeatedly raped, is the only mother in this study who decided to give her baby up for adoption. She believed she was not her rapist's only victim. When she discovered she was pregnant she broke down and revealed to her family a long history of abuse. Stephen has the same father as the baby she was carrying. Since no relationship existed between Esther and this man, her family had always wondered who Stephen's father was. She did not tell her family because the perpetrator had threatened her if she did. Both pregnancies were just as devastating to her family as they were to Esther.

I was cranky about being pregnant, all this I have to go through now. I was angry at [Terry]. He do it all the time. He told me, "Don't tell no one." I thought I can trust him and he said, "Don't tell your mum, don't tell your friend all this." He's in big trouble. He knows he's in big trouble. I had to tell someone sooner or later. . .

Esther's family grieved with her when her second pregnancy was discovered. For Esther the news only got worse when she found it was too late to have an abortion, despite her requests. The pregnancy was too far advanced. "Oh my God, here we go again."

Esther's embodied experience of pregnancy has at times transcended the great distress caused by being sexually abused, falling pregnant to her abuser and then having to reveal the abuse first to her family and then to the police.

It's a baby girl. We just find out last Monday it's a girl. I feel better, I just want to know it is a girl, I just wanted to know. . . I'm going to give her a name, but I keep it to meself. This pregnancy is different to Stephen. Oh my God, I can feel it [the baby] wriggling around.

The pregnancy did not only impact Esther's life, but her son Stephen's as well. She was aware of how the changes might affect him.

When I'm sitting here with Stephen all the time I feel the baby move. He said, "I don't want to feel the baby any more mum." . . . He just wants me all the time, just wants me to play with him. I do play with him, but he says, "You can't sit on the floor properly mum." I told him, "Stephen, when this is done mate, I can get on with my life, get on with you."

Esther believed that if she was the baby's caretaking mother, Stephen would be taken away from her. She did not say why she thought this was the case.

Stephen knows I'm not going to bring the baby home. He knows I'm going to keep him. We told him straight away, we're going to bring the baby up for adoption. He's just happy I'm keeping him. He knows he's not going, "Mate, you're staying with your mother", I said, "I promise you mate".

Esther, who was fostered days after her birth, lived with the one foster family her whole life, and referred to her foster mother as "mum". Foster care gave Esther a loving, stable home but she knew from watching and living with other foster children that her experience of family life was the exception rather than the rule. While Esther feels foster care is not a good option for her baby, ultimately her choice was not to keep the baby: "Once this baby is born I can get on with my life, get on with my life with Stephen properly. I don't want to be pregnant again, you see?" Her family supports her decision to have the baby adopted.

Discussion

Three key themes are evident in the stories of the 17 women who participated in this study, despite the diversity of their personal situations. The first is that, even for those women for whom discovering they were pregnant was devastating, there was tenderness and even joy at the physical presence of the baby as they experienced their bodies growing and changing to accommodate a developing foetus. Perhaps more significantly, they experienced the baby as a part of, and yet other to, themselves. Such descriptions of the experiences of women with intellectual disabilities are not currently found in the literature. It has been assumed that they do not experience, or desire to experience, the same things as other women (Brown 1996). Yet the stories of the women presented here suggest that they experienced their pregnant bodies in much the same way as other women represented in the general literature on women's experiences of pregnancy and becoming a mother (Van der Zalm 2000, Young 1984). The women's stories tell of their bodies doing what women's bodies are designed to do in pregnancy, and of their responses to their changing bodies as they began to understand themselves as mother of the child they carried. Thus, the stories of Esther, Marian and Brianna demonstrate that it is inaccurate to consider them as degendered beings (Asch & Fine 1988, Johnson 1998, Kumaniecka-Wisniewska 2003, Traustadóttir 1997). They are women and have experiences "peculiar to women" (Bergum 1989, p.53).

Secondly, the women actively made decisions regarding whether the pregnancy would continue or not, how the baby would be cared for and who would provide care. For Marian, Brianna and Esther the decision to have a baby was not one they made prior to discovering their pregnancy. For Esther and Marian the decision to have the baby or not was effectively out of their control because they did not have the option to terminate the pregnancy. Legal mandate made abortion impossible. This did not mean, however, that these women were not actively engaged in decisions regarding their unborn babies.

Women with intellectual disabilities have been constructed as passive, dependent, incapable, and in need of support (Brown 1996). Brianna and

Marian explicitly describe the effect of such stereotypes in their lives. Both encountered significant opposition to their childbearing and to the decisions they made about their unborn babies. These women acted against their critics. Esther's experience was different, perhaps due in part to the circumstances under which her child was conceived, but it was Esther, and not her family, who felt she would not cope with another child. All three women challenge the stereotype of passivity and dependence, suggesting instead that as pregnant women and expectant mothers, they are intimately and actively engaged in decisions regarding the life of their unborn children.

Thirdly, these decisions were not made in isolation from those closest to them such as a partner and family, those who supported their authority as a mother of the baby they carried and those whose lives would be affected by the birth of the baby. In short, the women did not make decisions independently, but consulted with people with whom they have had long-standing, trusting relationships. Researchers studying the support networks of mothers with intellectual disabilities have recently taken as their theoretical starting point that "mothering is best understood as a deeply embedded social occupation" (Llewellyn & McConnell 2004:188). Carrying out the mothering role therefore is viewed as influenced by those who can provide support for the mother (Booth & Booth 2000, Llewellyn & McConnell 2004). The women's stories indicate an appreciation for the social nature of mothering work: they expect they will need support and seek out people around them to provide that support. Each woman identified at least one person who supported her decision-making regarding the child she carried. For Brianna it was her husband, for Marian her partner and support worker, for Esther her mother and a close family friend. Prior to this study researchers had not considered the function of women's social networks, or significant support relationships leading up to the birth of a baby. These findings therefore extend the empirical work on support networks by suggesting that women with intellectual disabilities seek support in decision-making for a baby, prior to its birth.

Conclusion

When women with intellectual disabilities are recognized as women, their experiences of gendered phenomena can be better understood. Understanding the experiences of pregnant women with intellectual disabilities highlights their desires and needs, from their point of view. Such knowledge could be used to inform the provision of support services for these women. Two examples are offered. First, doctors, midwives and other health professionals routinely in contact with expectant mothers may need to be especially vigilant against projecting pejorative beliefs about the decisions women with intellectual disabilities make for and about their babies. They should also be aware of the presence and potentially negative consequences of such attitudes on the mother as she prepares for her baby's arrival. These attitudes are apparent in the women's stories and the women are painfully aware of them.

The short-term nature of many disability support services may be unhelpful for providing women with support to make significant decisions for and about their unborn babies. The women clearly indicated that these decisions were made within the context of longstanding relationships, built on trust. Support services for pregnant women with intellectual disabilities may need to be tailored to allow the longer term involvement of support workers with expectant mothers with intellectual disabilities. Support workers should also be sensitive to, and respectful of, decisions made in the context of a woman's intimate relationships.

The experience of pregnancy is only one example of gendered experience in the lives of women with intellectual disabilities. As scholars interested in issues of gender and disability, it is perhaps time we began to explore others, such as the experience of being a mother or daughter or woman. When women with intellectual disabilities are given space to talk about their lives, they challenge what we believe we "know" about them. It is time we listen to them.

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