

# WHEN THE WIND BLOWS

*An ethnographic study of one woman's learning difficulties and  
her experience of having a baby*



WOMEN'S HEALTH  
GOULBURN NORTH EAST



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*An ethnographic study of one woman's learning difficulties and  
her experience of having a baby*

Rock-a-bye baby

On the tree top

When the wind blows

The cradle will rock...

~Excerpt from 'Rock-A-Bye Baby'  
Traditional English Lullaby

Women's Health Goulburn North East (WHGNE) was established in July 2000. Previously known as NEWomen, Women's Health Goulburn North East is the government funded, specialist women's health service for the Goulburn Valley and north-east Victoria.

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Artwork by Sally Nansen.

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## *Introduction*

A newborn baby lay in a humidi-crib in the next room and the young mother sat proudly on her bed. She wore an unbecoming blue and white hospital gown and next to her was a man who was slightly drunk. The man was the young woman's father. He had been celebrating the birth of his granddaughter since the day before and his emotions flowed happily, praising his daughter enthusiastically as she smiled and laughed and blushed. It was an intimate family setting. Young mother and grandfather, baby just nearby; a bunch of flowers colouring the bleak white walls of the hospital room, and the smell of grog in the grandfather's hair and clothes. Hope hovered determinedly, like a bird high up on a great wind.

This report details the story of a young woman with learning difficulties and her experience of having a baby. In a context where debate continues to rage around the choice of women with intellectual disability or learning difficulties to conceive, give birth and raise their children, this report offers insight into a woman's relationship with the system of support offered through the health, disability, education and welfare fields. It suggests that where informal supports are severely lacking in a woman's life during her experience of having a baby, the role of the 'system' increases to meet this need, and as such bears particular responsibilities in the type of support that it offers.

When the system fails to recognise this responsibility, problematic patterns of relating to women with intellectual disability and learning difficulties remain unquestioned. Like the deep grooves in a worn track, services and workers continue to travel down a predictable path of practice without realizing how they may be creating or reinforcing learnt helplessness in women that ultimately undermines their attempt to parent.

This report offers an alternative approach to supporting women with intellectual disability or learning difficulties. It focuses on a woman's particular learning needs around advocating for herself and her baby, making complex choices, and being given the appropriate guidance and mentorship to explore the rights and responsibilities of being an empowered adult, woman and mother.

Sadly, the tide of public opinion continues to turn heavily against women with intellectual disability or learning difficulties becoming parents. Those 'against' the efforts of such women to have a baby point energetically to the high rates of child removal for this demographic group. It seems important, therefore, that the story of the young woman in this report is read and reflected upon by those who have power to influence public opinion, and particularly by those working within the system of support offered in the health, disability, education and welfare fields. When the wind blows wildly, a woman must have access to *appropriate* support if she and her baby are to remain strong and steady in its blast.

## *Literature Review*

"Historically women with disabilities have been regarded as incapable of being adequate parents" (Sykes, D, 2003, p.39). Contemporary attitudes continue to wrestle with the experience of parenting for women with intellectual disability or learning difficulties. As

such Sykes' statement highlights three points that also touch on current debates in the research field.

### *The notion of 'adequate parenting'*

The phrase 'adequate parenting' is problematic. According to Llewellyn "(there is a) lack of valid and reliable measures with which to judge parenting" (Llewellyn, 1997, p. 243). Booth and Booth suggest that the concept of parental adequacy is not clearly defined and that parents are largely assessed against "implicit middle class standards" (Booth and Booth, 1993, p.461). Cann and Mildon agree with these claims, stating that there is a "lack of a generally agreed definition of what adequate or 'good enough' parenting actually is" (Cann and Mildon, 2003, p.74).

Despite this, the notion of 'adequate parenting' is largely supported by a thrust of punitive evidence of child protection cases involving parents with intellectual disabilities or learning difficulties that have had their children removed. According to Sheerin "the almost systematic removal of children from parental custody has been a characteristic of parenting by learning disabled persons for many years" (Sheerin, F, 1998, pp.129-30).

In 2002 McConnell et al put figures of child removal from parents with intellectual disability or learning difficulties in the range of 40%-60% worldwide (McConnell et al, 2002, cited in Tarleton et al, 2006, p.vi). More recent figures from Tarleton et al claim that parents with intellectual disability or learning difficulties are 15-50 times more likely than other parents in the community to have their children removed from them and placed in care (Tarleton et al, 2006, p.7).

It is important not to arrive at a simplistic conclusion regarding these figures. "It is easy to conclude," write Llewellyn and McConnell, "that high rates of notification and child removal indicate inevitable parenting failure. Reviews of court proceedings...suggest a different conclusion...Parents with intellectual disability (are) subject to prejudicial treatment from child protection agencies and courts" (Llewellyn and McConnell, 1998b, p.2). In another paper McConnell et al state the prevailing negative attitude clearly: "Child protection authorities and courts frequently presume that parenting failure or child neglect are inevitable and irremediable" (McConnell et al, 2002 cited in Tarleton et al, 2006, p.1).

### *The notion of being 'incapable' of parenting*

This prevailing negative attitude towards both women and men with intellectual disabilities and learning difficulties is central to their experience of parenting, and begins well before the child protection and court system is involved. Of this prevailing attitude, Whitman and Accardo write, "with regard to parenting failure the question would seem to be not whether, but when" (Whitman and Accardo, 1994 cited in Llewellyn, 1997, p.243).

According to Tarleton et al, "the views and experiences of parents with learning difficulties themselves have only recently begun to be heard, and responded to, in the literature and elsewhere" (Tarleton et al, 2006, p.7). In the same paper the collective voices from a 'Gathering Day' of British parents with learning difficulties who had lost their children into



care were summed up simply as “these parents felt they had not been given a chance” (Tarleton et al, 2006, p.4).

The presumption that parents with intellectual disability or learning difficulties cannot ‘learn’ how to parent is ridiculed by a weight of research. According to Llewellyn and McConnell, “recent studies demonstrate that parents with intellectual disability can acquire and generalise parenting skills and ‘unlearn’ negative behaviours” (Llewellyn and McConnell, 1998b, p.5).

### *The notion of being a ‘woman with a disability’*

The literature explores the overemphasis of the factor of disability in a woman’s life. According to Johnson et al, “intellectual ability is only one aspect of a woman’s being, and physical, sexual and emotional ability need to be considered” (Johnson et al, 2001 cited in Burns, K, 2002, p.9). Burns writes, “we (the broader community, families and service providers) relate to women with an intellectual disability first, and perhaps only, through her disability. We fail to relate to her as a woman” (Burns, 2002, p.9).

The social model of disability explores the environmental context that people with disabilities dwell within, including the reality of oppression, discrimination and exclusion and suggests that this is what disables them. According to Burgen, “mothers with disability experience much discrimination that focuses on their impairment and what is assumed they cannot do rather than on what they have been able to learn and achieve” (Burgen, 2007, p.8).

However, in addition to this, the literature also reminds the research community of the balanced approach needed in the disability debate. Those women who are free from the overt (though not necessarily the covert) label of ‘disability’ by not fitting into the strict IQ eligibility criteria for intellectual disability, but who present with learning difficulties, are also vulnerable in their experience of parenting.

This is particularly so when parenting support is offered too late for the parent to keep her child. According to Tarleton et al “[there needs to be] appropriate eligibility criteria for assessments for services...many parents with learning difficulties do not currently reach the thresholds for community care services or support. They only show up on a service’s ‘radar’ if their children are seen as ...being at risk” (Tarleton et al, 2006, p. xi). Booth and Booth draw both arguments together succinctly: “There is no clear relationship between parental competency and intelligence...Parenting behaviour rather than IQ should be the criterion by which parental competence is assessed” (Booth and Booth, 1993, p.462).

### *Belinda’s story in the context of the system*

As Sykes’ opening quote illustrates, there are both historical and contemporary debates around the experience of women with intellectual disabilities or learning difficulties having a baby. Into this troubled context strides Belinda, a young woman with learning difficulties and the research participant for this research report. Her own story gives meaning to the literature and debates mentioned above, while also adding a unique perspective for an

audience of workers and professionals in the system of support offered in the disability, health, welfare and education fields.

For this reason it is also useful to do a brief search of the literature around the relationship a parent with intellectual disability or learning difficulties might have with the system. One key to understanding this relationship is to consider that “parents must be viewed in their family and community context, not simply as individuals ‘standing alone’” (Llewellyn and McConnell, 1998b, p.9).

Importantly, the literature reveals close parallels in the family and community (social) context of parents with intellectual disability or learning difficulties with that of parents in the general population who may come to the attention of child protection services. That is, families who are considered ‘at risk’. Drawing from a range of research Booth and Booth list the factors of inadequate income, unemployment, poor vocational skills, a disadvantaged childhood, an insufficiency of social supports and a lack of ordinary living experiences as just some of the shared characteristics (Booth and Booth, 1993, p.463).

Sykes adds the factors of substandard housing, depression, poor self esteem and high stress levels. He asserts that these factors will have a “greater impact on the capacity to parent than disability (Sykes, 2003, p.44). Llewellyn and McConnell agree: “Social isolation, poverty and other socio-economic constraints may undermine parental ability” (Llewellyn and McConnell, 1998b, p.9).

Because of a parent’s vulnerable social context their relationship to the system may need to include support from a variety of fields, beyond simply the disability field. Booth and Booth suggest to do otherwise is a mistake of “false attribution” (Booth and Booth, 1993, p.462). Llewellyn and McConnell explain this phrase as where “parents’ difficulties are attributed to their disability, when in fact (they) derive more from poverty, poor housing, social isolation, harassment and the lack of appropriate adequate support services” (Llewellyn and McConnell, 1998b, p.3).

While on the one hand it is important to move away from such an “intense focus on a [parent’s] learning disability or learning needs” (Llewellyn, 2003, p.8) and to focus more on the social context of parents in order to support the financial, practical and emotional needs there, it would be unwise to completely ignore the impact of disability in a parent’s experience. Of particular importance to this research report is the interplay of social context, disability and what Burgen describes as “learnt helplessness” (Burgen, 2007, p.12) in the relationship between parents with intellectual disability or learning difficulties and the system of support offered in the disability, health, welfare and education fields.

It is difficult to locate in the literature if the elements of social context, disability and learnt helplessness independently intersect with a parents’ relationship to the system, or whether the relationship consists of a confusing and interdependent blend of all three. In favour of an interdependent approach, Llewellyn discusses the “disabling barriers” (Llewellyn, 2003, p.15) that marginalise people with disabilities to a social context fraught with disempowerment, mistreatment, low self esteem and poverty, which then gives rise to the need for system support.

Of interest to this research report is whether system support itself can sometimes be a ‘disabling barrier’, and perhaps responsible for ‘dis-abling’ a woman with intellectual disabilities or learning difficulties beyond simply her individual impairment, with the result

that learnt helplessness is either created or reinforced in her experience of having a baby. Ironically, with learnt helplessness comes an added reliance on system support and a social context of poverty and marginalisation. In such a cycle, parenting efforts are drastically undermined, and sometimes children are removed. To some extent, therefore, this research report observes the 'system' as a subject to the research process, with Belinda bravely drawing apart the curtains of her experience of having a baby, and allowing the professional and research community entrance.

## *Methodology*

This report is the result of an analysis of secondary data (transcribed interviews and field notes) gathered during a former research project. While the name of this research project cannot be divulged for confidentiality reasons, it was apparent that the original data collected would be useful to engage a reading community of researchers, professionals and workers in deepening insights around system practice and its impact upon the parenting experiences of women with intellectual disability or learning difficulties. With this conviction in mind, ethics approval was sought and gained from the NHMRC (National Health and Medical Research Council) and the report, *When the Wind Blows*, began to form.

Because of the confidentiality deemed necessary to protect Belinda (the research participant from the former project), all identifiable data has been removed from her story, and indeed the name 'Belinda' is a pseudonym, as are all the names in this report. However, a short description of the design of the former research project does not compromise confidentiality and is useful to discussion.

### *Design of the former research project*

The original research included seven months of data collection, conducted from March 2006 until September 2006, using ethnography as the research strategy; a practice that "places researchers in the midst of whatever it is they study" (Berg, 1989, p.52). Belinda was the woman chosen for this research project as there was already an established relationship between herself and the research organisation. Belinda's pregnancy was viewed as an opportunity to follow a woman with learning difficulties in her experience of having a baby.

An advisory body including two former employees of the WIN clinic was established. The WIN clinic is a clinic for women with individual needs connected to the Royal Women's Hospital in Melbourne, and supports the pregnancy and birth experiences of women with intellectual disability or learning difficulties. After Belinda gave her consent, the ethnographic process began in the fifth month of her pregnancy.

Ethnography follows a qualitative research approach where there is an "aim to capture the richness and complexity of lived experience" (Alston and Bowles, 1998, p.207). During the seven months, Belinda's life was learnt about as it was literally witnessed and played out before the watching eyes of the researcher. Every Tuesday, Belinda drew the researcher into her experience of pregnancy, birth and early parenting, herself leading the way

through her schedule of antenatal clinic appointments, shopping trips, and family visits, as well as into the deeper and less travelled paths of buried hopes, loneliness and personal reflection.

Using ethnography promised and achieved the establishment of a relationship between Belinda and the researcher in which Belinda's own knowledge and experiences were measured as vastly more important than any professional experiences or qualifications of the researcher. Referring to Daniels, McCarthy states, "it is common for ethnographers to adopt the role of 'acceptable incompetent' so that the research subjects have to show and explain things to the researcher" (Daniels, 1967 cited in McCarthy, 1999, p.81). The fact that the researcher has never herself given birth nor had much professional experience with the maternity field enabled this process to be authentic.

Using ethnography also gave opportunity to an inherent feminist approach to research in which common threads of shared gender and humanity between Belinda and the researcher were acknowledged rather than ignored. This came about largely from spending such large chunks of Tuesdays together, in which, even with the existence of the ever-rolling tape recorder, dialogue eased away from the more structured approach of research questions into a familiar co-relating between two women.

In a similar strain, Johnson writes of her own ethnographic research project with institutionalised women with intellectual disabilities. She remarks, "Discussions which I held with the women...were informal and involved a dialogue which ranged widely across their lives and mine. There was a strong emphasis on story telling and narrative. Such an approach is inherent in feminist approaches to research" (Johnson, 1998, p.13).

The dialogues and field notes throughout the Findings section of this report are the result of this approach. Interestingly Belinda's self-disclosure increased as the months went by. In this way McCarthy similarly points out the importance of developing 'rapport' or relationship between the ethnographer and a research participant/subject. She writes, "If the subjects do not like and/or at least respect the researcher, s/he will not be allowed 'in'" (McCarthy, 1999, p.81).

Importantly, because of the research project's ethnographic style, where the researcher was generally unable to intervene or allow her own social drivers to 'rescue' to take over (with the exception of the welfare of Belinda's dog as can be read about in the Findings section), it was observed that Belinda began to tentatively explore an increased sense of her own autonomy, personal responsibility and empowerment.

As a result, where learnt helplessness with services and workers was in all other areas the 'norm' in Belinda's life, she instead began to take ownership and some leadership in the practical process of the research project, including initiating some of the themes in the discussions between herself and the researcher.

Data gleaned from the discussions in this way was significant in content and depth. It seems likely that having someone listen faithfully to her over a lengthy period of time; someone who, though not acting openly on her behalf, showed a deep interest in her life, was a catalyst for an increased sense of personal worth and self-belief, which is the beginning of empowerment.

## *When the Wind Blows: Secondary data analysis*

When ethics approval was sought and Belinda's consent (as well as the consent of other people who had also participated in recorded dialogues) was gained for the writing of this report, the secondary data to be analysed consisted of hundreds of pages of transcribed interviews, and a smaller collection of personal field notes written by the researcher. Data analysis followed a coding approach, drawing from what Alston and Bowles describe as *Invivo* codes that represented local meanings (both to Belinda and her local culture) and *Constructed* codes, relying more on the researcher's own meanings that she placed on events and words (Alston and Bowles, 1998, p.212). These codes were sorted as themes or core categories, which were then stripped down further to focus only on the data that was directly related to Belinda's relationship with the system.

A literature review was performed concurrently with this process, with special emphasis upon the relationship that the system has with women with intellectual disability or learning difficulties in their experience of having a baby. This further informed the researcher in her selection of constructed codes.

No qualitative research computer software packages were used for this analysis, and sorting and coding was achieved through copying and pasting the transcriptions and field notes into a Word table, with the chosen core categories written alongside.

## *The Findings*

The seven month period of observing and inquiring into Belinda's experience of having a baby revealed many points that are of relevance to the system of professional support offered through the health, disability, education and welfare fields. The story that emerged spoke plainly of a woman whose life, choices, hopes and disappointments constantly intersected with, were cradled by, and sometimes were even generated through the real and living entity known as the 'system'. Because of this, it is useful to briefly outline Belinda's relationship to the system before attempting to explore what impact it had on her experience of having a baby.

### *Belinda's relationship to the system*

Belinda showed me a list of people she wanted to call when the baby was born. "Yeah, well, coz they will want to know" she said, with happy confidence. Scattered in amongst the names of friends and relatives (affectionately termed 'cuz Adam' or 'cuz' Bev) were the names of workers from the welfare, housing and health fields. It intrigued me to see them there. "Are you planning to call the workers too?" I asked. "Well...yeah", she answered slowly, seeming a little confused by my question, "...Because they really want to know too. Everyone is really excited about the baby".

From *Field notes*

Over the seven months of the research it was observed that Belinda received support from or was in some sort of a relationship with workers, services and programs from a variety of 'system' fields. A normal day prior to the birth of her baby might include house hunting

with rural housing, a catch up with a youth worker, a check up with the antenatal clinic or a visit to Centrelink. Belinda's life circumstances threw her across many workers' paths. It was not unusual for her mobile phone to ring and for it to be a service or worker confirming an appointment.

These relationships often had a historical basis. Her connection with rural housing, for example, had existed for a few years before the research project. And special long-term support during her education years was a memory that Belinda spoke about sometimes, although she chose not to view it as disability support.

~What was school like for you?

~Yeah, pretty good, yep, I had special classes, not all the time, maybe once a week for some things.

~What were they for?

~Um, just helping me, like if I didn't know anything, like they were just helping me do projects and stuff like, if I didn't know it, know what it meant or anything, they'd just give me a hand, so it was like an extra hand.

*From The Dialogues*

Later, when her baby was born premature and with disabilities, the amount of services involved in her life increased. They criss-crossed over various service fields, largely referred by workers and programs she was already involved in. Sometimes Belinda could not rightly say what the services existed for, or even which organisation the workers came from. Nevertheless, she seemed to move eagerly through her schedule of appointments as if it were something like a social calendar. Certainly Belinda's desire to include workers in her list of people to call when the baby was born seems to suggest that the workers, at least initially, were considered by her to be friends.

Some of Belinda's own words below illustrate the types of relationships she had with the system during her experience of having a baby and are sorted into the diverse mix of service fields that they represent.

### Youth Work

~I go to (a youth welfare organisation) and I see social workers there and then talk to them (about) what's going on and what situation I'm in.

~I was just a little bit, you know, confused (about finding out I was pregnant), and didn't know what to do...and the youth workers said "Well, it's really your choice"...

### Antenatal Care

~One of the midwives or whoever I see today, um, they're gonna just check me over and probably talk about the blood tests that I had done.

### Housing

~Because of what happened with my mum, I had to move out. I had nowhere to go. Other people don't have (pause) um parents going to Court and going to wherever... (Social workers) participate in with my appointment at Rural Housing...so they sit with me in my appointment at Rural Housing and they jot down (pause) stuff that um Julie says, coz that's what's at rural housing...Julie.

~Oh, I've been on the listing (for public housing) for ages...four years

~Even though I only am living in this unit, I'm still going to find Private Rentals...cause its only emergency accommodation...emergency housing.

## Mental Health

~I come (to an antenatal counselling service) for my depression and anxiety...because that plays an important part while you're pregnant if you're stressed and that...so that's why I come here and see (the worker).

## Disability

~I'm just gonna have someone sit in there (at Vic Roads for my L's test) with me today...I don't know why they've said... oh well maybe because I've been so many times and I haven't passed or, yeah I don't know, because they said they were gonna get someone in there and to sit in there with me.

## Food Support

~Saint Vinnies said they're gonna help me (with the baby) and if you need (a) hand with anything, they said, just, they said, let them know...Well I go there, well I don't go there all the time, but, um, to get a food voucher, to help out with food and stuff.

## Legal System

~I haven't seen (my mum)...since she went in (to jail).

## Income Support

~I'm just trying to work out my Centrelink payment...So I've been talking to Wendy, she's a social worker from, (pause) antenatal clinic or something...so umm she said that, she was gonna get a hold of them, and see what's going on with my payment.

## Maternal After Care and Family Admission Facilities

~(Workers) come in once a week and help you settle your baby and...umm well they want me to go down to (a settling clinic for parents and baby), down in Melbourne, for a week.... just to have a settle in and just to manage with them.

## Maternal and Child Health

~Umm I'm not sure (how I'm going to get to long distance appointments for the baby without a car) but umm, but we're gonna work something out with umm, some of the services that come here. Coz all sorts of services are coming here.

## Health

~(The ultrasound) was covered by Medicare...You can only have one. Medicare only cover so much.

~I'm always going to the Hospital for something.

*From The Dialogues*

Belinda's experience of having a baby was deeply linked to her relationship with workers and services. This relationship was also significant to the social context of her local culture. Belinda's family and friends had workers and services weaved as a similar pattern of support and crisis intervention into their own lives. During the seven months of the research, many of her family and friends struggled with poverty, alcoholism, jail terms, disability, homelessness, domestic violence, lack of transport and mental illness. Often these struggles impacted on Belinda directly.

Belinda was on her own when she had her baby. She had asked her Aunty and sister to come to the birth, but in the end neither could make it. "They all know now", she said. A family friend dropped her off at the hospital but he didn't come in. Belinda spoke about the physical pain as she was climbing the hospital stairs. I queried further, searching for any disappointment she might feel about having been alone with only hospital staff when she had her baby. She looked at me with a characteristic shrug of her shoulders, and a short laugh.

The problem of housing continues. Since her mum went to jail, Belinda doesn't like to be on her own in her house, and will try to squat at other's homes if she can. Choices of where to spend the night are sometimes determined by the activities of the householders. Though frequently staying with a family friend, she has decided to stay with his next-door neighbour instead for a time. "My family friend's been on the piss", she said. "He was up all night, all morning, singing, my Dad was there...I'm glad I didn't stay there because (she laughed) I wouldn't have got no sleep".

*From Field notes*

Both in her life prior to and during the research period Belinda experienced fewer informal supports because of the complicated issues that members of her family and friends were personally wrestling with. For the entire scope of her pregnancy Belinda was on her own. The father of her baby was initially unwilling to recognise the unborn child as his, and Belinda bravely prepared herself to become a single mother. This is an important element in her experience. According to Burgen, "sole mothers with intellectual disability are at a further disadvantage because of assumptions about their disability and their greater need for system supports if they do not have adequate informal supports" (Burgen, 2007, p.10).

It seems likely that these were the reasons why the chief role of support for Belinda fell directly upon the shoulders of the system. This could also be why, in her mind, it is possible that she considered workers to be her friends.

Sykes refers to a study by Feldman et al (2002) where mothers with an intellectual disability were asked to list the variety of supports they receive. While family and friends were mentioned, the results showed that the most frequent support provided was that offered by workers (Sykes, 2003, p.48). All relationships carry the potential for both good and harm for those involved. Because of this, it is inevitable that Belinda's relationship to the system might include positive and negative results. Some of these results are explored in the following pages.



## *The interplay of Belinda's learning difficulties, social context, and learnt helplessness*

Belinda's choice of language is significant in explaining how she views her position with workers or services. When she mentioned that the naturopath told her to start taking multivitamins, I asked her, "How come?" She replied, "Well, I don't know, he just said, 'Just take these'". She looked slightly annoyed by my question. Similarly when the workers at Vic Roads organised someone to sit with her through a fourth attempt of her L Plates test, I asked, "How come?" It seemed likely that it was to have someone to help guide her through the questions, but instead she answered, "Oh, I don't know, they just said that...I'm just going on what *they* said."

It is interesting to balance this language with observations of her physical dynamics with workers. Belinda will walk casually into an appointment, jeans swishing, and wait, for however amount of time, resting and uncomplaining on a chair. She practices friendly easy relating and is the perfect model of compliance. In the antenatal clinic appointments the doctor asks her, "Do you have any questions?" and she gives a short laugh and says, "Nup".

*From Field notes*

The phrase, "I'm just going on what *they* said", was uttered frequently by Belinda throughout the research period. Her relationship with workers and services was repeatedly expressed as what appeared to be a willing relinquishment of self-determination or agency. Belinda's journey through pregnancy, birth and early parenting largely consisted of what other people were telling her to do.

As the research progressed and the baby was born, Belinda's reliance on workers increased. She believed herself (quite fairly) to be a 'learner' as a new mother and understandably needed to 'learn the ropes' before she felt confident with her new baby. However, although Belinda was obviously tender and very loving towards her baby, hospital staff began to become concerned. "She doesn't show a lot of initiative with her baby," said one doctor.

Belinda's practice as a new mother was limited in the beginning. The circumstances of the birth meant that the premature baby spent her first month in a humidi-crib in the hospital nursery. Here frightening emergency procedures occurred as the baby turned blue with a sequence of fits, and a diagnosis of disabilities was pronounced. Belinda spoke about her role in this way:

~There's not really much for me to do in there, you know, they gotta do it all, coz they know what they're doing.

*From The Dialogues*

When the baby girl's health had stabilised, but she had to stay in the hospital for a few weeks more, Belinda's services were called on but her role remained quite small, and she generally relinquished a large portion of the day to day care of her baby to the hospital staff. The following dialogue reflects this:

~I've been going there (to the hospital) like once a day, for a couple of hours and stuff, just to hold her and to feed her and that. I am doing the bottle-feeding only when I'm there but if I'm not there, well they do it.

~Are you sleeping during the night, or do you go in and feed her?  
~No, I (pause), I do whatever during the day and then I sleep (laughs).

From *The Dialogues*

As circumstances in her life became increasingly difficult, Belinda seemed to withdraw further into the seemingly comforting blanket of external support, decision-making and crisis intervention offered by the system. Inevitably, there were sometimes holes in this support - ragged gaps where a service couldn't quite meet her needs due to their funding limitations, or because a worker failed to identify a pressing need. Even during these times Belinda clung to her trust in and reliance on the system. She seemed suspended in a vague certainty that help would always come.

Belinda came in today clutching documents for Rural Housing. Her own place in public housing has finally come up and she has to move from emergency housing immediately. (Shocking timing on the system's part - with the baby due to come home from hospital just when Belinda has been told to move house). She spoke a few times about the big job ahead of her; moving, packing, finding boxes, carrying boxes on the bus etc., before she can bring her baby home. She walked out much as she walked in - feet dragging, reluctant to face the next step.

Belinda reminisced that when she last moved, a worker had bought his own car and trailer and moved her things for her. It reminded me of the hospital; the nurses feeding Belinda's baby at all hours of the night, and often during the day, too. One time when I asked Belinda how she had spent her day, her answer included a brief visit to the hospital to see her baby, and then home again to watch DVDs for the rest of the day.

From *Field notes*

Burgen warns, "few professionals have been trained to work with people with intellectual disability and may misinterpret situations" (Burgen, 2007, p.7). The above observations, field notes and dialogues are examples of material that may be misinterpreted to assume that Belinda was not committed to caring for her baby. In order to seek out what was really going on for Belinda during the research period it is necessary to embrace an interplay of factors.

For example, it is important to consider the psychological impact of Belinda's learning difficulties upon her ability to be confident and self-directive with her baby. Llewellyn writes, "segregation and frequent school failure may have left individual parents with low self esteem and poorly developed social interaction skills...it is therefore possible ...that the life history of a parent with intellectual disability contributes strongly to reliance on others...to guide parenting endeavours" (Llewellyn, 1997, p.253).

Belinda's social context also needs to be taken into account. Some of the more obvious points here include the previously mentioned single parenting, transient living, poverty, a severe shortage of informal supports, restricted family example, and lack of transport. These are complex issues for anyone. However, for Belinda, there were also the high stress levels involved with an unwell baby; a natural floundering confidence as a new mother; later relationship turmoil with the father of her baby; recurring bouts of depression; the growing threat of child removal; and the interplay of Belinda's fewer cognitive skills to navigate her way through all these challenges. It is really no wonder that she 'withdrew' at times, relinquishing both her agency and to some extent her baby to the open arms of what she believed was a supportive system.

Burns includes the comment of a professional who noted that, “women with intellectual disability comply for people to like them, to be seen to do the right thing” (Burns, 2002, p.29). Interestingly, Belinda’s compliance and lack of personal agency or initiative was not always negatively received by services. For example, her own description of childbirth describes the authoritative role that the professionals played, to which she submitted without argument:

~They made me take off my clothes and put on one of their gowns. There was blood on my undies so they told me to open my legs, so I did and they could see the baby’s head. I did what they told me to do. They told me to push so I did! They told me to breathe...it was hard...so much pain...

From *The Dialogues*

As a model patient, doing what “they told me to do”, Belinda tapped into what Thomas describes as the professional maxim that ‘we are the experts and know what is in your best interests’. She writes, “perhaps in reproductive contexts, where maternity services often construct women as patients to be cared for by expert others, disabled women receive a double dose of dependency creation” (Thomas, 1998, p.277). Another professional has observed, “women (with intellectual disability) are taught to trust adults and do as they are told without question” (Burns, 2002, p.29).

In this way it seems particularly unfair that Belinda’s passivity or lack of personal agency in other interactions with her baby and services was viewed negatively, without due understanding among these services of how they may have been promoting the professional maxim and the risk that this had of undermining Belinda’s confidence. Dixon writes of pregnancy and parenthood as a tentative time for women with intellectual disability or learning difficulties. She says, “many of these women easily realise their own weaknesses and how different they are from others, and will be relying on every avenue of support to bolster their confidence” (Dixon, 1996, p.9). It is therefore important that the mode of support offered by the system is appropriate and helpful. Put another way, Booth and Booth point out, “support may be either ‘competence promoting’ or ‘competence inhibiting’” (Booth and Booth, 1993, p.466).

Where support is ‘competence inhibiting’, learnt helplessness is the result. Burgen describes the nature of learnt helplessness for mothers with intellectual disability or learning difficulties in the following words: “(T)he women had *learnt* to be acquiescent or not try. This learned behaviour in the women presented as lack of initiative, ability or caring when they seemed to hesitate to respond to their newborn and it can be very difficult to remedy” (Burgen, 2007, p.12 *Italics added*).

Andron and Tymchuk have observed the socialisation of people with intellectual disability to become dependent, with little opportunity to make decisions and experience the consequence of their actions (Andron and Tymchuk, 1987, cited in Llewellyn, 1997, p.254). Llewellyn and McConnell agree with this observation: “Little may have been expected of children, youth and young adults with intellectual disability. The irony is that having been socialised to be dependent, as parents they are penalised for their dependency” (Llewellyn and McConnell, 1998a, p.35).

It seems likely that many of Belinda’s experiences in having a baby were drawn at least partly from the nature of learnt helplessness in her life, having been socialised through an interplay of her learning difficulties and her social context to become dependent on others. This was at the detriment of her self-esteem, confidence, advocacy skills, ability to make

choices, and to fully explore her rights and responsibilities as an empowered adult, woman and mother.

The role of the system in this way needs to be considered. As Belinda's main avenue of support, it seems likely that much of her socialisation in learnt helplessness was gained through her relationship with the system. Burgen suggests that services generally do not recognise the learning needs of women with intellectual disability or learning difficulties. "(The women) become reliant on support rather than developing knowledge and skills" (Burgen, 2007, p.10).

The following examples were observed in Belinda's life and seem to indicate where it would have been useful for services and workers to explore deeper the particular learning needs that the examples represent in order to assist Belinda in counteracting the negative influence of learnt helplessness in her life. From the research it seemed the system often failed to do this, and was itself at times an unfortunate stone in the road for Belinda to stumble over and fall.

### *Advocating for herself and for her baby*

We were chatting with a female hospital staff member in the maternity ward. I stood next to Belinda and we both faced the staff member. Together we explained a little about the research project. "It's about me having a baby," said Belinda to the staff member and then she faltered, looking to me for help. The staff member glanced at Belinda's swelling stomach and nodded, smiling pleasantly at her. I said, "We want to write down Belinda's story so that we can learn how to support women with learning difficulties with their babies." The staff member's face dropped.

She turned her body abruptly away from Belinda, turning towards me. "Oh" She said to me, rather dramatically. Then, (again speaking to me and not to Belinda) "Do you know about *this* service?" She rushed to a flyer stand and bought back some information about a program that offered support to new mothers with learning difficulties. Then she leant forward even closer to me. "But you must get her enrolled *now*" she said earnestly, "There is a *waiting list*". In confusion and embarrassment I took the flyer. Belinda still stood placidly next to me. By taking the flyer on Belinda's behalf I had participated in an act of disempowerment. As we left the ward I glanced at Belinda but she didn't say a word.

*From Field notes*

Belinda didn't advocate for herself when this disempowering situation occurred. The event happened when considerable work had already been achieved in building an equalising relationship, open communication and mutual respect between the researcher and Belinda. This is significant because it seems to suggest that Belinda's choice to not self advocate surfaced even within a 'safe' relationship, where it would be expected to be a lot easier to say if something had upset her.

Belinda's relationship with the system to represent and assist her provided workers and services with a power that she rarely questioned openly. It seems likely that the skill of self advocacy, or advocacy on behalf of others, was not yet learnt by Belinda. In the research this was also apparent when the need to advocate on her baby's behalf occurred.

~ How are you finding the staff, like the nurses in the hospital nursery?

~Some of them, most of them I should say, are good, but on weekends you can get really bitchy ones...Like one of them tipped milk all over her face, all over her.  
~What happened?  
~ Oh she, (pause) oh she wiped it up and everything and then she done, you know she was complaining a bit, coz (my baby) was a bit agitative and stuff, complaining about it.  
~What did you do?  
~ I didn't really do anything, but she was pregnant herself, I'm thinking, you know, she should know a bit better, like...

From *The Dialogues*

Belinda seemed to lack an empowered and assertive view of her rights as a mother when among people from whom she and her baby were receiving some sort of service or support. When the need to advocate on behalf of her baby arose, Belinda was silent. Though she felt indignant she did not vocalise these feelings to the nurse.

It wasn't until later that an attempt at advocacy was observed. After the birth of her baby, Belinda and the baby's father enjoyed a brief resurrection of their relationship. During this time a worker falsely accused the baby's father of physically abusing both the baby and Belinda, and in a rare act of disagreement with the system Belinda stoutly declared the worker to be 'wrong'.

~I know what domestic violence is. I know what it is because we learnt it in (a sexual health program for women with learning difficulties). And he (the baby's father) didn't do that!

From *The Dialogues*

Through this situation Belinda's understanding of workers as her 'friends' received a shock. Belinda's relationship with the system now included a rather threatening punitive and penalizing element. The worker's accusation heralded in child protection services and, as a result of heightened judgemental scrutiny of her learning difficulties and vulnerable social context, Belinda was suddenly confronted with the real possibility of having her baby removed from her care.

It is unclear in the research if Belinda felt betrayed by the worker. However, a situation had been observed about a month prior to the accusation that seemed to suggest a growing uneasiness in Belinda towards the system.

Belinda decided we would sit in the hospital foyer, a large sweeping airy space downstairs from the Nursery. "We can talk here", she said. She seemed reluctant for the nursery staff to see the tape recorder.

She told me about some friends who had their babies taken away by DHS. I watched her face. It was the first time Belinda had mentioned the practice of child removal and she seemed confused and bewildered. "Why do you think DHS might take babies away?" I asked. "I don't know", she answered and looked at me uncertainly. "Do your friends say why their babies were taken away?" I asked. Again she seemed unsure and shook her head, biting her lip. I said again gently, "Hmm, I'm just wondering...why would babies be taken?" Belinda was also thinking hard. "Mmm...I don't know," she said falteringly. "I'm not sure".

A nurse appeared just then on the staircase, and smiled and waved at Belinda. Belinda returned the gesture immediately, a short laugh shaking the confusion and fear instantly from her face.

From *Field notes*

The research suggested that Belinda had very little or no experience in advocating either for herself or for her baby. Relying so much on the system to look after her made her vulnerable and ill equipped to deal with the darker side of worker judgement and system abuse.

As the field notes above illustrate, even when actions on the part of the system confused or disturbed her, a friendly staff member or worker could quickly reinstate her trust. While it was encouraging to hear Belinda openly declare a worker to be 'wrong', it appeared to be an isolated incident. No more attempts at advocacy were observed in the course of the research.

When a woman feels powerless to voice her concerns about system practice, or to represent herself and her baby in cases of disagreement with the system, there is the risk that she will withdraw from whatever support the system is offering. Untrained in self-advocacy the woman will flounder, both needing support but fearing the consequences that further relationship with the system may bring. Llewellyn and McConnell refer to the number of parents who have "spoken of living under constant scrutiny and their fear that 'the welfare' might take their children away" (Llewellyn and McConnell, 1998a, p.33). Burgen writes similarly of many women who were "reluctant to become involved with any service, often eventually stating their fear of Protective Services becoming involved" (Burgen, 2007, p.6).

Though Belinda was unable to comprehend the reasons why a baby might be taken away from its mother, she - like all people - was able to scent danger and run from the threat that was approaching her. Later when she and her baby left the hospital Belinda was referred to various support services because it had been recognised by the hospital staff that she was going to need some extra help in her new role as a mother.

- ~ They want me to go down to (a maternal after care and family admission facilities) down in Melbourne, for a week... just to have a settle in and just to help me manage with my baby
- ~ Do you think you'll take up that offer?
- ~ Well they've got me booked; they already got me booked in for the 30th of July.
- ~ It sounds like there's a bit of hesitation in your voice. Tell me what's going on.
- ~ Oh well a few people have told me about that place, and they've been there before, and they said, "Oh don't go there, DHS will get involved". I don't know, they just said, "Oh if you go down there umm, they'll take your child off you" and that's coming from different people.
- ~ And did those people have their babies taken away from them?
- ~ Well, (pause) Jessica was one that told me about that place...and she doesn't have hers with her.
- ~ She's had her baby taken away?
- ~ Yeah. They just warned me, about that place for some reason, I don't know why, but every time I mentioned that name, or mentioned that place, they're like "No, don't go there".

*From The Dialogues*

Belinda never did spend a week at the facility mentioned above. In the end it was a relapse into depression that prevented her going, though it seems likely her fears were a contributory factor. It also seems likely that withdrawal from system support in this way was couched in her belief that she was powerless if the system decided to remove her baby from her. Having real learning needs around the skill of self-advocacy and yet never having been taught these skills, Belinda's belief is quite rational.

Ultimately, withdrawal from system support became one of the factors that frustrated her struggles in parenting further; and was quickly pounced upon by the child protection system. A legal case against Belinda to have her baby removed from her care began shortly after the end of the research period and continues during the writing of this report.

### *Making Choices – the story of Cuddles*

Cuddles is long and lean. His nose wets the ground under Belinda's gate, sniffing hopefully for companionship. She has a big bowl of water for him in the tiny back yard and an old doona in the shed. Sometimes when her family friend brings his car around they take Cuddles to the river for a run.

From *Field notes*

Belinda had some very good independent living skills. She could cook basic meals for herself, kept close attention to her physical beauty and hygiene, paid her bills, and had an Award saver account. ("It's payday tomorrow" she'd say of her Centrelink payment, swaggering a little with pride.) Rawlings et al discuss a woman similar to Belinda for whom, "living independently, everyday experiences at making choices ensured that their range and frequency was extensive. Choices about basic aspects of daily routine were made without difficulty" (Rawlings et al, 1995, pp.141-142).

However, inevitably Belinda's experience of having a baby threw her into occasions where much more complex choices had to be made. One example that stands out from the research in this way focuses not on her baby exactly, but on her dog, Cuddles.

When the research first began, Belinda was living independently in emergency housing provided by Rural Housing after her mother went to jail. Belinda had floated homeless and transient, squatting at the places of friends and family, until the system caught her in its arms and settled her and her dog, Cuddles, temporarily in the emergency unit.

Because the baby was born four weeks early, Belinda had not had time to arrange for someone to care for Cuddles while she was in hospital. Then in the bliss of attention raining down on her after the birth, she forgot about her dog.

~ Who is looking after Cuddles while you're in hospital?

~ Oh...I don't know.

From *The Dialogues*

Attempts by Belinda to arrange for someone to feed Cuddles while she stayed in the hospital were frustrated. Her father and the family friend who had a car celebrated the birth of the baby with joyful drinking that lasted a few days, rendering them incapable of driving to her house. Though they wanted to help, they found they couldn't.

Although somebody eventually offered to feed Cuddles, the situation illustrated to everybody, including Belinda, the need for her to make a choice about whether she was going to keep the dog or not. In the meantime she wavered between the options, indecisive and unsure.

~ Well people want me to get rid of him but I don't know what to do...I was thinking last night, yeah I should 'cause, (pause) you know... (pause)

- ~ How come you think people want you to get rid of him?
- ~ Because I'm more focussed on (my baby) now, and I've left Cuddles out of the picture, and he's left there and, (pause) bored in the backyard and umm, (pause) he sort of feels probably left out, (pause) so (laughs) (pause)
- ~ What is this choice like for you?
- ~ Oh (laughs) (pause) it's hard.

*From The Dialogues*

A little over a month after the baby was born Belinda was offered permanent public housing and when her possessions and her baby were moved to the new home Cuddles remained behind in the old yard. Paralysed yet again with the complexity of the choice before her, Belinda did nothing for days, and the dog began to starve.

- ~ Cuddles is still stuck at (the old) house.
- ~ Is he getting any food?
- ~ I don't know.

*From The Dialogues*

Belinda decided to give Cuddles to the RSPCA today. That is, nearly beside myself with anxiety for the dog, I blew the non-interventionist research role, and offered to help her call the RSPCA. Prior to my offer she had told me that she wanted to call the RSPCA, but that she was waiting to use her sister's mobile because she didn't have credit on her own mobile to make calls. She wasn't sure when she was going to see her sister.

As soon as I offered to help she looked immensely relieved. "Yeah", she said, "Coz it'll be better for him coz he'll be cold and hungry and they're gonna feed him there, and make sure he's not freezing."

Interestingly, judgement of Belinda's struggle to make a decision about Cuddles has fallen quickly upon her. An RSPCA professional, aware of the newborn baby and failing to grasp the complexity of the situation, grunted rather ruthlessly, "Well, it doesn't bode well for the baby".

*From Field notes*

Rawlings et al suggest it is normal for women with intellectual disability or learning difficulties to rely on support to make and carry through complex choices. They write, "because many people with intellectual disability have not had opportunities and experiences to make choices, they may need support to guide them and to help them find out about available options" (Rawlings et al, 1995, p.142).

When the system is offering this support, it is important that workers are aware of the fine line they walk. On the one hand they need to empower a woman to make her own choices, thereby negating the learnt helplessness which people with disabilities have been socialised into. As Rawlings et al write, "is the support person providing enough information for the person to function as independently as possible?" (Rawlings et al, 1995, p.146). On the other hand, workers must be realistic about an individual's practice at making complex choices and "not create limits" through failing to offer to help (Rawlings et al, 1995, p.142).

It is interesting to consider how the system itself contributes to the lack of opportunity for choice-making in a woman's life, and therefore affirms learnt helplessness. For example, Belinda experienced a dizzying run of workers flashing through her life in many chops and changes over the seven months. She was given no choices in this situation, though the workers were meant to be her support people. The following dialogue took place when the



hospital wanted Belinda to bring a worker with her to a meeting with a paediatrician to discuss the baby's health. It reflects the absurdity of the situation.

- ~I had my youth worker there with me.
- ~ Was that Joanne, or another worker?
- ~ Well I was seeing David, and then I got changed to Joanne, and now I'm not seeing Joanne anymore, I'm seeing Rose... she said, like, Joanne's doing something else, or things have changed around, so I'm seeing Rose now so...coz the doctor or one of the doctors or midwives said to me yesterday to bring in a worker, and I said "Yeah" so I bought in Rose. And then I had Mel; she's another social worker.
- ~ Was she there today too?
- ~ Yeah.
- ~ And where's Mel from?
- ~ Umm from some program or something
- ~ What's it like switching workers all the time?
- ~ Oh it's just (laughs) yeah...
- ~ What's it like?
- ~ Oh, well it's sort of confusing and, (pause) just frustrating and stuff, (pause) because then I've got to get to know Rose now, which I already got to know Joanne (laughs)...and David!

*From The Dialogues*

The lack of choice in professional support was also repeated in the hospital system, along with the same inconsistencies and rapid changes in service. Yet with her characteristic shrug Belinda submitted to what she didn't like.

- ~ Is this the first talk you've had with (the paediatrician) since the tests were done on your baby?
- ~ No coz there's been three paediatricians that I've met so far, (laughs) and they all seem to change and...
- ~What's it like to have to always meet new paediatricians?
- ~Oh (pause) I'd rather stick with the one but it's not my decision so...

*From The Dialogues*

Tarleton et al assert, "families respond well to services which provide consistency and continuity in terms of staff support and resources" (Tarleton et al, 2006, p.7). They also believe that parents themselves are the best people to judge what they need from support services. If Belinda had been encouraged by services to vocalise what her preferred choice of support might be, it is likely that her answer would touch on her understanding of workers as her friends, and a somewhat buried hope that these friends 'stick around'. Sykes writes: "Often people with disabilities are socially isolated...this can be further reinforced where a trusted worker moves on continuing this history of rejection" (Sykes, 2003, p.48).

According to Llewellyn, it is a "lack of recognition of personal autonomy" (Llewellyn, 1997, pp. 253- 254) that determines both the number of different workers involved in a parent's life as well as the inconsistencies in that support. Like all people, Belinda's personal autonomy was linked to the practice of making choices, and having a sense of control over her life. While her personal autonomy was disregarded by the system, she could never learn how to make complex choices. Nor could she, as an adult and a mother, be able to experience the consequences of her choices, which is an important learning need in itself.

## *Child or Adult? ~ The threat of social solation*

Belinda walked along the back walls of Big W, seeking out the toy she had in mind. It was something like a singing frog, pumping out an electronic contemporary song. She clutched the toy affectionately and turned to me with enthusiasm. "I've got him on my mobile phone too - see?" She played me his song on her phone while the frog also sung away boisterously in her hands. Belinda gazed at him, transfixed.

"Who are you buying this for?" I ventured. She looked confused, still staring at the frog. "Well...", she paused, "For the baby" and then, with a slight defensiveness in her voice, "But, you know, it will take a long time before the baby can play with him..."

He was an expensive toy but he was her first choice before the much-needed nappies, maternity pads, bottles and baby creams (the reason we were shopping in the first place). Later in the baby product aisles, she looked bewildered (as indeed was I) at the vast walls of choice. Eventually her arms carried a hesitant selection of baby products to the Lay By, her new toy frog sticking its head out at us from under her elbow.

From *Field notes*

Burns writes of a mythology surrounding women with intellectual disability or learning difficulties that states they are "eternally childlike" (Burns, 2002, p.6-7). It is not the intention of this research report to support such mythology by including the incident of the toy frog mentioned above. Nonetheless, the incident describes an important element in Belinda's experience of having a baby.

"When a woman is seen to be eternally childlike," writes Burns, "she is denied access and pathways to adult roles and rights" (Burns, 2002, pp. 6-7). This would suggest that some of Belinda's behaviour and values during the research period was at least in part another consequence of being socialised into the learnt helplessness of a child.

On a shoestring income, Belinda's budgeting decision to buy an expensive toy for herself before the necessary practical items of pregnancy and birth could be a consequence of being denied guidance in the adult role of financial management. As it was, her budgeting was generally very good. Nevertheless, the example is useful in alerting workers and services to the importance of considering a woman's learning needs in this way so that she might fully explore what it is to be an adult with both rights and responsibilities.

To restrict someone's emotional and psychological development based on a mythology that is both untrue and disrespectful is a dreadful thing. However it doesn't necessarily follow that Belinda's *behaviour* was dreadful. In fact, the research observed some truly beautiful moments of Belinda responding to her baby and to her world that seemed to be tied up in a refreshing simplicity and innocence.

Unfortunately, when these moments occurred, Belinda's world was not always kind in its response to *her*, and this, linked to her unawareness of her right to be given respect as an adult, seems to have led to some experiences of rejection and exclusion. One consequence of being perceived by others as 'childlike' was that Belinda was denied access to the adult right of mutual support in parenting. The following was observed while Belinda waited for an antenatal clinic appointment in a roomful of pregnant women.

The other women had eyed Belinda companionably when she sat down. Shy smiles came from them towards her but I noticed Belinda did not see this. "My goodness, I've never seen so many pregnant women before", I chuckled. Belinda only answered with a polite 'Mmm', and she seemed to look over and above the women's heads.

A woman's name was called. She sighed nosily, popped her two feet far out in front of herself and rocked her heavy belly up. She looked at the other women and with an air of importance said, "I'm 34 weeks'. The others nodded; one or two massaging their own bumps sympathetically. "I remember with my first", one said, "my ankles were so swollen I couldn't walk".

The women began to talk more easily among themselves. "How many weeks are you?" When Belinda was asked the question she answered clearly but failed to offer any additional information or to return the question. Undaunted, one of the women took another step towards her, "What's your pregnancy been like?"

"Yep, good", Belinda said, and gave a short laugh. She fell silent once more. I saw the women eyeing her curiously and then perhaps bored with their attempts retreated back into 'baby' conversation among themselves.

Another pregnant woman with two young children arrived. Loudly, she settled herself down on a bench and her children flopped on the floor with some toys. She was a strong, large woman and she filled the space of the waiting room as she easily elbowed her way into the conversation of the other women. Her confidence and command in communicating clearly impressed them, and she took the lead in their discussion.

"So who here is having their first?" She looked at each woman deliberately, but Belinda did not see this. She was watching the children on the floor instead. A wide smile brightened on her face as the children played with their toys. An occasional little chuckle snuck out of her mouth, sharing their fun, and the children looked up at her. They seemed surprised and pleased at her enjoyment. Then I noticed some of the women surveying her - lips pursed together and eyes narrowing on her happy chuckles. I nudged Belinda and said softly, "You're having your first, Belinda".

She looked at me, still smiling and said "Yeah", but it was vague and distracted and she seemed to eagerly return her gaze to the children.

The large woman's eyes lingered on Belinda. But then it was as if the other women threw conversational arms around her and quickly drew her away. Did I really see their circle tighten, suspicious faces looking back briefly at Belinda, their quick judgments leaving her outside in the cold?

I looked at Belinda. She had the joyful childlikeness I'd seen on her face in a pet store. In between talking together about such serious topics as unplanned pregnancies, homelessness, drugs, men, and family, we'd walked past a pet store where some kittens were for sale. She broke into rapturous laughter, and began to play with them. I was struck with this. In our talk together she'd been polite and patient, but with the kittens she was free.

*From Field notes*

Goodman states, "One makes contact with other parents only because of long waits at the antenatal clinics when one can swap notes" (Goodman, year unknown, p.6). However, as the above field notes document, Belinda's experience in the waiting room of the antenatal clinic did not promise instant connection. Llewellyn, McConnell, Cant and Westbrook write of a parent's social skills deficits that may inhibit acceptance by others, thereby

exacerbating the social isolation typical of people with intellectual disability (Llewellyn, McConnell, Cant and Westbrook, 1999, p.10).

Referring to Madsen, Booth and Booth agree: "Public prejudice and discrimination serve to deter or exclude people from using mainstream services such as family planning clinics, antenatal classes, adult education, (and) voluntary group for single parents" (Madsen, 1979 cited in Booth and Booth, 1993, p.466). In this way women with intellectual disability or learning difficulties are denied the mutual support so important in their experience of parenting.

Llewellyn reminds the professional and research community of a paper published by Harold Skeels and Harold Dye in 1939 (Llewellyn, 2003, pp.10-11). In a study too large to relate here in full, the object of the research was to discover if stimulation could encourage intellectual ability in young children. The findings of this early research overwhelmingly proved that it does.

What has been largely forgotten is that the children in this study (who were parentless) were deliberately transferred to an institute where women with intellectual disabilities were living in community together. Here the women took a "great deal of interest in the children, playing with them, making clothes for them, spending their small allowances on special gifts for them" (Llewellyn, 2003, p.11). It was women with intellectual disabilities who successfully provided the stimulation necessary to develop the children's own intellectual abilities.

Llewellyn suggests that these findings highlight the role of social context in a woman's experience of parenting (Llewellyn, 2003, p.11). Of particular interest to this section of the report is the factor of community, mutual support and co-parenting that existed between the women. Llewellyn asks the question, "Is it that caring for and stimulating children is much easier when women can learn together, share the parenting, and have opportunities to watch and learn from others?" (Llewellyn, 2003, p.11).

Though the women in the study ranged in age from eighteen to fifty years, they apparently had mental ages from five to twelve years and as a result may have had behaviour and values that were sometimes perceived as 'childlike'. Their success in parenting the children suggests it is certainly not true to say that a woman who may be viewed as 'childlike' cannot parent. Yet the barriers are raised, as being excluded from networks of pregnant women and mothers - because of being perceived as 'childlike' or 'different' - may undermine parenting.

Importantly, it was observed that Belinda herself chose not to respond to the offer of social networks and mutual support arranged for her by the system. In fact, she ignored all opportunities for formal connection with other pregnant women and mothers through the system's maternity support networks, such as antenatal classes and later a young mother's group. Though, in the case of the antenatal classes, the cost of \$50.00 influenced her choice, it nevertheless seems likely that she would not have participated anyway. The following words from one of her family members illustrate this.

~I said to her, I think that you should go and have classes, go to classes where they explain things, and Belinda said, "No I don't want to, I know everything", and it has been very much along the same lines all the way through.

From *The Dialogues*

It seems probable that Belinda wrestled with a hidden understanding that she was 'different' from other women using the services. Dixon writes, "Parent craft classes are probably as valuable to women with learning disabilities as to any other women. It may seem obvious, but many women with learning disabilities will benefit tremendously from being accepted as part of a group, and to getting to know, and hearing advice from other mothers-to-be. This setting may, however, highlight to the individual just how different they are from everyone else" (Dixon, 1996, p.8).

Interestingly, Belinda seemed very aware of the mutual support possible between herself and other women in caring for their babies and, in her own way, hoped that this might be achieved. For a few months she carried around a vague plan of moving in with another young woman from her local culture that had a slightly older baby. The plan never eventuated. In the end it became apparent that the idea had been birthed during a brief spontaneous bumping into each other on the street one day, and fostered during similar unintentional encounters; a type of superficial social contact that was significant to Belinda's experience of informal supports in her local culture.

Then, on the first night that her baby came home, Belinda felt the cold winds of her isolation. Alone in her new apartment, not knowing her neighbours, without credit on her mobile phone or transport, a situation occurred with the baby that Belinda felt ill equipped to deal with.

~(My baby) was really unsettled last night, I changed her, fed her and she was still unsettled, and then I didn't know what else to do.... she felt really cold on her hands.  
~How did you feel?  
~Oh just, it was just doubt, I didn't know what to do...I was hoping that someone would be here...I had no one yesterday.

From *The Dialogues*

In the end somebody did come over and the situation was worked out. This incident highlights how much the system needs to consider the impact that social isolation has on the parenting experience of women with intellectual disability or learning difficulties.

Among other factors, Booth and Booth include social isolation, harassment, victimisation and lack of support as responsible for many of the parenting problems faced by parents with intellectual disability or learning difficulties, rather than any deficits in their own parenting skills (Booth and Booth, 1993, p.474). It appears that the current service model (and indeed, societal model) doesn't fit. If maternity and social support services only serve to confirm to a parent with intellectual disability or learning difficulties her difference from others, or if she is even excluded from a support circle by other women because of prejudice towards her perceived childlikeness, then it is inevitable that her difficulties in parenting will increase.

## *Being a Woman*

Linked to the myth that women with intellectual disability or learning difficulties are eternally childlike is the equally destructive belief that they are asexual (Burns, 2002, pp.6-7). While this mythology remains unquestioned women are denied the opportunity to

explore “the assumption of roles that give life to sexual expression such as partner, lover, wife and/or mother” (Burns, 2002, p.9).

On the one hand it could be argued that Belinda’s story as a young woman with learning difficulties celebrates the alternative. Prior to and during the research period, Belinda was in at least one long term committed relationship with a man. She continued to ‘explore’ her sexuality in encounters with other men after this relationship ended, and after she became a mother.

The roles of partner/wife, lover and mother, however, demand complex navigating through often restless seas. The research seemed to indicate that, for Belinda, being a ‘woman’ in this way was affected adversely by an unawareness of her personal empowerment to direct and shape her own life, and that of the child she bore. Her position as a woman seemed defined by the same learnt helplessness observed in other areas of her life. Belinda may have personally been experiencing the various roles of a woman in a superficial way, but there remained vast depths to these roles that were largely left unexplored.

A striking example was the conception of Belinda’s baby. The pregnancy was unplanned, and although Belinda was thrilled at the prospect of having a baby, a dark cloud of remorse hovered over her pregnancy, birth and early parenting.

~I had it (conceiving the baby) with the wrong person...this guy, I was with him but I wasn’t with him...it wasn’t like a long-term relationship, as I had with other ones. And anyway, he already had a girlfriend.

From *The Dialogues*

On the one hand Belinda’s sexual encounters with men could be seen as a deliberate exploration on her part of her womanhood. It seems likely that this was at least partly true. If it were fully the case then one would assume Belinda would have had some hold of the reins during these encounters. Instead it seems her sexual relationships with men involved the same level of passivity and lack of personal agency with which she approached the rest of her life.

~ I’ve never taken the pill; I’ve never taken anything, like the pill or...I’ve never been on any contraception and stuff.  
~ Condoms as well?  
~ Umm (pause) sometimes the guys wear ‘em, (pause) but I’ve never been on any contraception and stuff (pause)...I just, yeah, didn’t want to go on it, I don’t know, I just didn’t end up takin’ it  
~ Why do you think you don’t like using contraception?  
~ I don’t know (laughs)  
~ Did you learn about contraception in (a group program on sexual health for women with learning disabilities)?  
~ Yeah.  
~ Do you choose not to use contraception because you wanted to have a baby?  
~ Not at this stage...I mean, I wanted to have a baby, but with my other boyfriend, three years ago  
~ Did guys ever ask you ‘oh, should I use a condom Belinda?’  
~ Umm (pause) some of them did that I was with.  
~ Did you tell them to use a condom or did they just use them?  
~ No, they just did.

From *The Dialogues*

Interestingly, Belinda was very aware of sexual exploitation of women by men. Her first long-term partner was significant in her memory for the absence of pressure that he placed on her for sexual intimacy. Her allusion to 'some people' who might withdraw their attention if their sexual demands were not met is equally significant and might represent the norm in her sexual encounters with men since that time.

~The thing that I liked about him, like, we were together for three years, but he waited until I was ready.

~Before you made love?

-Yep...so it wasn't like, you know, if you don't do this or whatever, see you later, I'll go and find someone else that will...Coz I know that some people are like that. They want it there and then, but he waited for as long as it took me...We just didn't have intercourse or anything like that together until I was ready, 'cause I wasn't ready then, and I was 18 then when we got together, he was going on 19.

From *The Dialogues*

Belinda's potential vulnerability in sexual encounters is particularly evident in the following dialogue. Largely because of the factor of learnt helplessness in her understanding of herself as a woman, the circumstance of the conception of Belinda's baby was more complicated than simply an unplanned pregnancy.

~I had to ring up someone else to find out if it was that person (short laugh) but um, we didn't like, do anything then, so that was okay, coz I had to find out coz I had a fair bit to drink, and...he said nothing sort of happened...and then I found out that it had to be Jerry if it wasn't this other person and um, I told him, and he was all bullshit and lies.

From *The Dialogues*

The facts outlined in the above dialogue reverberated throughout Belinda's experience of having a baby. While the father of her baby oscillated uneasily in his ownership of the child, Belinda found herself being the topic of rumours, gossip and slander from people in her local culture. Then, when Belinda and the baby's father re-entered a tumultuous relationship after the baby was born, the gossip increased and most of what remained of the informal support from friends in her local culture dwindled drastically.

The end of the research period seemed to return to the beginning. As in the conception of her baby where Belinda's exploration of being a woman was limited by learnt helplessness, so did this also occur in early parenting. On the last day of the research project Belinda and her baby were precariously poised in a complicated housing arrangement with the parents of the baby's father. By that time Belinda had moved country towns to be with the father of her baby. Hoping for long-term love, support and happiness, Belinda sacrificed her new and long awaited public housing apartment and became geographically isolated from her own family and from the local services and workers in her home town. A month later the father of her baby decided to end their relationship once more.

According to Burns, for women with intellectual disability or learning difficulties, "mystery surrounds the notions of sexual feelings, love and men" (Burns, 2002, p.16). It seems very important that services and workers consider gender in their support of women with intellectual disability or learning difficulties and encourage such women in their deeper learning needs within it. Burgen agrees: "While most women ...have been happy with their, for most, unplanned pregnancies, clearly there needs to be more work done to ensure that women with intellectual disability are in a position to make informed and empowered choices around their fertility" (Burgen, 2007, p.4).

Belinda had significant learning needs in the area of being an empowered adult, woman, and mother during her experience of having a baby. While feminist and person-centred disability services now focus on demanding and promoting the right of women with intellectual disability or learning difficulties to explore their womanhood as a sexual partner and mother, it seems vital that such services supplement these rights with an understanding of learnt helplessness.

It is clearly important to remove the long-standing barrier of mythology that prevents a woman from exploring her womanhood in the themes of partner, lover and mother. Yet, it seems folly to eagerly beckon a woman into the experiences of sexual partner and mother without providing her with the right map to navigate her way through these roles. Services need to properly equip and mentor a woman, empowering her with the skills she needs to take control over the often complex life that emerges from being an adult, a woman and a mother.

## *Conclusion*

As Belinda walked an unsteady path through her experience of having a baby she looked to the system to show her the way. Belinda's story is an opportunity for the system to consider its own practice in creating or reinforcing learnt helplessness and then, with this understanding, to continue to hold tightly onto a woman's hand and guide her in the path of 'learnt empowerment' until she can walk it alone.

The fostering of skills in advocacy, making complex choices, and exploring the rights and responsibilities of being an adult, a woman and a mother can be encouraged by services and workers in their practice with women with intellectual disability or learning difficulties. This will counteract the learnt helplessness that undermines a woman's experience of having a baby. It seems a much more logical approach than the system simply removing a baby from the mother before an attempt is even made to assist her in these changes. As Belinda's story illustrates, sometimes the wind does blow furiously through a woman's life. The cradle may rock dangerously and, as the nursery rhyme says, sometimes the bow may even break. When this happens the system has an opportunity to catch both baby and mother, before they fall.



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