

Working and Caring for Children with Chronic Illness/Disability: Stories of Disconnection, Cruelty and "Clayton's Support"¹

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Abstract: This paper reports the findings of an exploratory, qualitative study of the life and work of people who are, concurrently, parents of a child with chronic illness/disability, and working full time. Nine women shared their experiences about the demands of caring for a child with chronic illness/disability while working full time. In light of the demands constantly placed on these women as they manage their multiple roles, it was of particular interest that their stories shared feelings of disconnectedness from others, as well as frank recollections of the cruelty and thoughtlessness of partners, family, friends, colleagues and strangers. They also reported their experiences with "Clayton's support" - the support you get when you are not getting support. These stories are shared in an effort to ameliorate the continuing challenges faced by these women.

Key Words: chronic illness, disability, carers

Working and Caring for Children with Chronic Illness/Disability

The purpose of this paper is to share a cluster of emergent themes from a recent qualitative study. The study was concerned with the experiences of women who worked full time and, concurrently, cared for a child with a significant chronic illness/disability. The paper commences with a contextualisation of the problem. This is followed by an outline of methodological choices. Then, data is shared that depicts the cluster of themes confirming problems for these women relating to social support (and its absence). These include, (a) feeling disconnected, (b) thoughtlessness and cruelty, and, (c) "Clayton's Support". The paper concludes with a discussion about social support, and its whimsical nature, before suggesting why these needs should be addressed.

Living with chronic conditions can be very difficult for the child involved, and for their parents and siblings (Martin & Nisa, 1996). This paper addresses what working parents- especially working mothers-face when caring for children with chronic illness/disability while also trying to hold down a full time job. For the purposes of this study, a "child" is defined as a person between the ages of birth to 18 years. A "chronic illness/disability" is a long term health problem or disability experienced by the child for at least 6 months. This is a significant, ongoing illness/disability, requiring ongoing medical or professional intervention (via pharmacological or other treatment, visits to medical or other professional practitioners, or hospitalization) to treat acute episodes and/or ongoing problems associated with the illness and/or disability. The focus of this study is on the *challenges presented to the carer who is also working full time*, rather than the child's experiences with illness/disability.

¹ The author gratefully acknowledges financial support for this project, via an industry partnership grant between the Children's Hospital Education Research Institute (CHERI), Trauma Research International Pty Ltd and the University of Western Sydney.

Children with chronic disease and illness are a significant group of the population (Martin & Nisa, 1996). Newacheck (1994; cited in Melnyk et al., 2001) reports approximately 31% of children under the age of 18 years have one or more chronic illnesses. Although illness and disability tend to be associated with the aging process, children are at a significant risk of having a disability or long-term health condition due to accidents, environmental factors or through being born with a particular disorder (ABS, 2002). Of particular interest are conditions that occur more frequently in this age group, such as asthma, attention deficit disorder/attention deficit and hyperactivity disorder (ADD/ADHD), intellectual and developmental disorders, and hearing or speech impairment (ABS, 2002). Of the 3.9 million children in Australia aged between 0 to 14 years in 1998, almost one in seven had a long-term health condition (594,600 or 15%), with boys (18%) more likely to be affected than girls (13%) (ABS, 1999).

Overall, as a result of advances in scientific knowledge and technology, the number of children with a chronic illness is increasing (Gibson, 1995). Examples of children's medical diagnoses may include: cerebral palsy; muscular dystrophy; asthma; cystic fibrosis; diabetes; myelodysplasia; hydrocephalus; cleft palate; burns; cancer, or other physical disability as a result of trauma or congenital anomalies (Burke et al., 1999). As with adults, children with chronic illness/disability are not necessarily faced with acute, life threatening situations (although they may be); the central concern is the longer term "care" of the illness (Melnyk et al., 2001). In this study, children had conditions such as severe epilepsy, varying intellectual and physical disabilities, attention deficit and hyperactivity disorder (ADHD), Down syndrome, paraplegia and autism.

Methodology

For this exploratory, qualitative study, a relatively small number of participants were interviewed (nine) who were living the phenomenon under investigation. The numbers for this study were kept small on the basis that smaller numbers of respondents in qualitative studies allow for more penetrating insights. Purposive sampling was used to recruit participants. Respondents could have been either male or female although, of interest, all participants referred for participation were women. Respondents needed to have been engaged in full time employment (or study), or have been in full time employment during the last 12 months. They also needed to be parents of a child with a significant chronic illness/disability.

Respondents were recruited via a word-of-mouth, snowball technique. Success has been experienced elsewhere with this recruitment technique, especially given the small sample size and the sensitive nature of what is being investigated (See, for examples, Watters and Biernacki, 1989; Vickers, 1997, 2001). The investigator(s) contacted "intermediaries", asking them to get in touch with potentially eligible participants. Colleagues, friends, and family known to the researcher were asked if they knew anyone who might be a likely candidate for participation. No one referred declined participation. This was a three-stage qualitative study, as follows:

- Stage 1: In-depth interviews from a *retrospective* perspective focusing on "What *did* you do/have you done?"
- Stage 2: In-depth interviews including clarification of issues/themes; a *prospective* perspective; responses to vignettes. The focus was on "What *would* you do in the future?"

Stage 3: Culminating Group Experience. The focus was on asking respondents "What do you think?" especially in terms of the emerging themes.

Data from all stages was used to develop the themes that emerged. Here, a cluster of related themes is reported: feeling disconnected; cruelty and thoughtlessness, and "Clayton's Support".

Feeling Disconnected

The stories from respondents reflected a life different from many. The women in this study all reported their tremendous struggle balancing work and home life, especially with the enormous physical and emotional burdens placed upon them as a result of their caring responsibilities (Vickers, Bailey & Parris, 2003; Vickers, Parris & Bailey, 2004). All reported, one way or another, feeling different, disconnected or apart from those with whom they worked and related. For example, Evalyn, a 40 year old mother of two, works full time in a university environment in a senior management role. She is married, and while she reports a supportive relationship with her partner, has experienced considerable difficulty dealing with the many challenges that her son's severe epilepsy and consequential intellectual disability have presented. Evalyn confides she does feel different from those around her:

Evalyn: I do feel different. I guess on the whole people are pretty compassionate. They are very compassionate but I just don't think they really understand, you know, my life. And, I guess they don't have the same perspective on life as say someone with a high support needs child has. Like, my child is nine years old now but for another parent with another nine year old child, they probably think, "I've got another nine years of where my child will live at home, stay at home." But I don't know what the future is for my child, what will happen to him and that's something that really worries me, you know, what will happen to Kevin. I obviously can't care for him forever ... So there will be a time when I can't care for Kevin and he will most probably live longer than I will. So, I'm always worried about the time when I can't look after him. And I don't think anyone, I guess they have an idea but they don't really understand unless they've lived it or are living it. [nervous laugh from Evalyn]. (Evalyn, #1: 33)

Dolly also reported feeling "disconnected" from those around her, especially other mothers of children with disabilities she came into contact with at her daughter's school. Dolly, recently separated from her husband and now alone in caring for her only daughter Maggie, felt overwhelmed at times; different and disconnected from those around her. Maggie also has severe epilepsy and a resultant intellectual disability. Dolly raised the issue of not being able to team up with other mothers of children with disabilities for support because of her heavy work schedule, rendering her unable to spend time, for example, at school functions to get to know the other mums better. Dolly owned (in conjunction with her ex-husband) a Human Resources Consultancy firm, a senior role, requiring her to work long hours. For Dolly, working full time is what sets her apart from others in a similar situation:

Dolly: A lot of the parents there are either, they're nearly all single mothers. So many of the fathers have bailed because they haven't been able to handle it, which is

really interesting. And a lot of the mothers don't work. They're on pensions or maintenance or whatever else. So, without seeming precious, they're not corporate women. They're sort of more "mums" that might have two or three other children, and they've had a Down's [Child with Down's syndrome] or they've had a child with a disability. And they're either married and their husband's supporting them to be at home or they're single mums who are living on maintenance and pensions and are able, again, to be more flexible. I'm sure some of them work but most of them seem to have lots of flexibility. (Dolly, #1: 88)

Dolly's disconnection stems directly from her inability to be with women in a similar situation, to share with them, to rely on them, to have the flexibility they apparently have with their caring responsibilities. She continues:

Dolly: Look, I think as a person with children like this, it's really hard working. Maggie's got an Easter Hat thing today, and I can't be there for it... And it would be really nice to go. I went to the swimming carnival last week, but could only stay for an hour, or half an hour... But I do feel almost discriminated against... And last year I was able to go swimming, taking Maggie swimming. So I volunteered and Steven [Dolly's former partner who works with her in their business] was being really supportive of this, of me going down and spending an hour. But it took probably more like two and a half by the time you drive down, you walk the kids from the classroom to the pool, you change them, you swim with them for half an hour, and then you get them dressed, and then you take them back to the classroom. It's a couple of hours and then you come home. And then you have a shower and get dressed and come to work, so probably more like three hours lost all up in that exercise, which is almost half a day's work. But [sigh], I got a little award saying, "Thank you for your participation." And school and the principal just generally they favour more involvement. They really actively encourage you to be really involved, which would be really nice. But then there's that trade-off, like I can't afford to feed her if I can't [work].

Researcher: Do you get a sense that they appreciate, for you, the enormity of taking half a day out of your working week?

Dolly: No, I don't think they do. No, no. (Dolly, #1: 86-87)

It was Dolly who was the one who introduced the notion of being "disconnected". She explains:

Researcher: So you feel quite different from them [the other mothers]?

Dolly: Well, I feel a bit disconnected...

Researcher: Disconnected?

Dolly: Yeah. Well, when I went to swimming it was great because I actually got to meet a couple of them. But even things like, "Can you stay and have lunch?" Well, I *couldn't*. But they all stayed and had lunch with each other. So, the couple of times I did that, it was lovely and then I felt bad because I wasn't working. So it was this constant guilt thing. (Dolly, #1: 89-90)

This comment coincides with Dolly and others confirming their need for strong support networks and a notable lack in this area. Dolly confirmed she had no real network of support, other than her mother who had recently been asked by Dolly to move out and no longer continue in her caring support role (Dolly, #1: 36). Dolly had, for instance, no clue as to who was going to care for her child during the upcoming school holidays (the following week), when she had a full diary of work appointments scheduled (Dolly, #1: 37). This sense of disconnectedness, with colleagues, with friends, with partners and with other mothers, was shared by many of these women. During the culminating group session, both Leah and Evalyn confirmed the magnitude of this issue. Leah said:

Leah: Yes... I was really looking forward to being able to talk with other people about the experiences and how they managed things. When Margaret [the researcher] said there was that third phase [of the research project], I thought, "Oh good," because I don't really talk to anybody else. There isn't an association that embraces our situation. So I thought it would be really good to just talk with other people about what their experience was. (Leah, Culminating Group Seminar: 8)

Cruelty and Thoughtlessness

What was striking in the stories of respondents was that all were able to recount one or more incidents where people had said or done things that could only be construed as either terribly thoughtless or very cruel. The stories that follow include incidents with partners, family members, friends, colleagues and complete strangers. Respondents were asked if there were any particular comments or incidents that came to mind relating to their caring for their child with a chronic illness/disability - either positive or negative. Evalyn had this to say about someone she barely knew:

Evalyn: One person said to me, "How could two really intelligent people have a child like Kevin, like yours?" And I just couldn't believe she said that. I didn't say anything, I just said, "Mmm-mmm." I just couldn't believe someone said that to me. (Evalyn, #1: 53)

Dolly also reported a very callous remark, from her friend about her daughter with an intellectual disability being better off going to sleep and not waking up:

Dolly: Well, yes, it was just the most horrific thing. A girlfriend of mine – and I say that extraordinarily loosely [laughter] –she would always be extremely over the top about Margaret. Oh, you know, "I don't know how you do it. I don't know how you cope." ... She rang me one day and said to me, "Oh, how's Maggie?" "Oh yes, she's going quite well." And something good had happened at the time and I was feeling quite happy about it, some little improvement. And she said to me, "You know, sometimes I think it would be better if Maggie just went to bed one night and didn't wake up." I just couldn't believe it. I mean, I could barely speak. And I said to her, "I can't talk to you. I have to go." And I came home and I just *howled*. And my husband was, "She's never setting foot in our house again. (Dolly, #1: 28)

At the time of our interviews, Dolly had recently separated from her partner. She spoke during the interview of wanting to be in a relationship again. However, Dolly's friends had some thoughtless remarks to share with Dolly about her future dating prospects, related to her daughter Maggie's disability:

Dolly: A number of people have said to me... "Are you going to think about dating?" "Yes." I really loved being in a relationship. I loved the partnership. I loved being married. And I would like, whether I'm married or not is irrelevant, to go back into a partnership again. And I'd actually like, I'd really love, to have another child... And a couple of people have said to me, "Oh, it's going to be really hard for you to find someone who'll take Margaret on." [Pause, Dolly shifts uncomfortably in her chair]. And one person said, "You'll know if they really love you if they take Margaret on."

Researcher: Did you say anything to that?

Dolly: No, I was a bit "gob-smacked" [shocked] to be perfectly honest. (Dolly, #1: 65-66)

Cate describes how her colleagues have stopped talking to her since finding out her son has autism. What is more extraordinary about this situation is that Cate works in a center that supports people with disabilities. One would expect that people who work with people with disabilities on a daily basis might be less discomforted by knowledge of a disability or contact with people with disabilities, and more sensitively disposed towards those who have them, or care for people so placed. Of interest, Cate also cares for her brother with a disability who lives with her:

Cate: Finally, when I went through the whole thing of the evaluations and stuff like that, then I was like, "William has autism." Then after that, we didn't talk any more. Now we still don't really talk. People don't really, we talk a little bit: "My daughter's going to kindergarten now. She's doing this now." They'll bring in their kids, and the kids are like, "Hi, how are you? What's going on?" But William says nothing. Nothing. Sometimes I'll bring him in and he'll visit, and they'll visit with him, but we don't talk in an excited way like we used to. And it's OK. It's totally OK.

Researcher: Does it bother you?

Cate: Yes, kind of. It's kind of like you would think that my co-workers, they know me... and they know about my brother. They know they can approach me. (Cate, #1: 21-22)

Cate is clearly very hurt by her colleagues' behaviour, even though she states that it is "OK" for them not to talk to her. Sally shared similar stories of her colleagues' insensitivity. In the first instance, Sally reports one of her colleagues wanting to gossip about her disabled child, immediately after the child was born. In the passage that follows, Sally is describing the very traumatic period immediately following the birth of her child. Sally's daughter was born with hydrocephalus, a significant facial disfigurement and cleft palate, and a significant intellectual disability. As one can imagine, Sally had a lot to digest immediately following the birth of her daughter:

Researcher: You've mentioned some special friends that you can obviously really count on. Are there any friends or colleagues that have particularly disappointed you?

Sally: Yes. One *beautiful* example. [Laughter]. This one woman. When Natalie was first born and she was transferred to Randwick [hospital]. Because I'd had a Caesarean, I wasn't able to go. I got a day pass on the Wednesday, so I hadn't seen her from the Saturday [when Natalie was born] to the Wednesday, apart from this hideous polaroid shot I had at my bedside. I can remember Janice, my good friend, saying, "Chris [one of Sally's colleagues] wants to go and see Natalie." And I said, "What for?" And [then] I said, "She wants to go and have a look!" And I said, "No!" And it was really interesting that I could even reason at that stage of all the emotional, I could actually read what she was up to. She wanted to "sticky-beak" [a slang term describing one who prys into another's business] so she could go back to work, big-note herself because *she'd* seen the baby – because everybody at work knew... [Sally replied], "I haven't even seen her yet. So no, she can't." So I went to see [Natalie] on the Wednesday, but the sneaky bitch went on the Friday. She did; she went and did it!

Researcher: Even though you'd said "No"?

Sally: Yes, even though I'd said "No." (Sally, #1: 35)

Sally also recounted the real absence of understanding from her family, in particular, her partner's parents. What she describes below was also during the period shortly after her baby was born:

Sally: But yes, I had lots of visitors, lots and lots of visitors, people from work, friends, family. My parents couldn't really cope. Peter's [Sally's partner] parents I don't think understood at all.

Researcher: Why do you say that?

Sally: They're very religious, so it was all about, "God will make it better." And it was kind of like, "Oh, you just don't get it!" And I guess that's probably really unkind, because I tend to be a very practical, while it was devastating and all that kind of stuff, it was, "Well, here it is; just deal with it and get on with it."

Researcher: It must have been very – "distressing" is perhaps a bit too strong – but it must have been very uncomfortable to hear things like that?

Sally: I think for them I was, "Oh, you're just stupid" [laughter]. I just dismissed it. I'm sure Peter's father thought that it happened because I smoked, because I had the odd cigarette.

Researcher: Oh no. It was "all your fault?"

Sally: Yes, it was "all my fault." But that's OK. Again I thought, "If that's what you're comfortable with," you know, "That's OK." My parents, I think that for a long time, and probably still now, my father struggled with the imperfection. Because for many years, every phone call was, "Have you spoken to the plastic surgeon? Have you spoken to the plastic surgeon? She'll be psychologically scarred!" I felt like saying, "She'll only be scarred because you're going to make her scarred. Nobody else is." (Sally, #1: 13-14)

Sadly for Sally, the years ahead did not become easier. She reports below some very cruel and thoughtless incidents involving her and her daughter from complete strangers. Readers will be surprised just how many of these stories Sally could relate:

Researcher: Has there been any particularly negative situations to do with Natalie's condition which spring to mind?

Sally: ... [Laughter] Well, I guess I've had things like – probably before she had any cranio-facial reconstructive surgery – we get used to [how she looks], but you could see other people with their jaws to the ground. You'd be at [a large suburban shopping mall], and the kids would drag the whole family over for a viewing, going, "Look, look, look!" Point, point, point. It was unbelievable.

Researcher: And what did you do when that happened?

Sally: I just thought, "Oh whatever." But I was lucky, because Natalie had well-developed language really, really young. It wasn't just language that I could understand; it was stuff that anybody could understand. So it was good, because she'd come and say, "They're looking at me." And I'd say, "Well, you go over and say, 'My name's Natalie. Hello.'" And you'd just see these people freak; they'd "scarper" [a slang term meaning to depart hastily] or they'd turn bright red on the spot with embarrassment. I can remember there was this little old lady who asked me if I'd hit her. I just was stunned and went, "No." Then only two weeks after that, I had another little old lady say to me, "Oh, did you hit her?" And I just went, "Yes, the sledge hammer missed her forehead and got her nose." Like, duh.

Researcher: It's just so appalling...

Sally: [Laughter] And the ice-cream man. When I was buying ice-cream: "Oh! Oh! What happened to her?" It was like, "She was born like that. You can stick your ice-cream!" Depends on whether I'm having good days or bad days whether I –

Researcher: Engage and have some –

Sally: Yes, or just tell them to piss off. I can remember the man that came to quote for awnings at my place ... not long after Natalie was born. I had this *delightful* [sarcastic] old man come and quote for my awnings. Natalie was asleep and then she woke, and I said, "I just need to go and get my baby." He was obviously a religious man, I think, and he sort of said, "The devil works in mysterious ways. He's certainly thrown a spanner in the basket here." [The term "spanner in the works" is a slang term for an impediment or annoyance]. And I just thought, "You've got to be kidding me." And I said, "It's rather unfortunate for her. I'll get on with life and get on with it, but she has to endure and look like this for the rest of her life." Because he was going on about God, and I said, "Well, I think God sucks at the moment. Because this little kid has to endure this stuff all the time." But that kind of, "Well, God's chosen you because you're obviously a very special person." She was only a few months old; it certainly wasn't anything I wanted to hear. I just thought, "Don't give me that shit!" (Sally, #1: 22-23)

What was particularly disturbing about Sally's story here, were the number and voracity of ugly and cruel incidents she could bring to mind on the spot. She did not pause; she did not have to think about the question. She was able to rattle off numerous hurtful incidents without any difficulty at all. Given the obvious need for support in her life, the hurtful comments and behaviours she had so routinely faced were astounding.

Clayton's Support

"Clayton's support" is defined as the support you get when you are not getting support. This concept borrows from the advertising campaign for a non-alcoholic beverage called Clayton's, where consumers were encouraged to indulge in the drink they are having when they are not having an alcoholic drink. Many respondents confirmed the existence of "Clayton's support" from many sources: partners, family, friends and colleagues. Clayton's support tended to come in the form of support being offered (or reasonably anticipated), but when the time came to act on the offer or obligation,² the support was not forthcoming. Below, are some examples. What is especially troubling is that for these women with caring responsibilities for a child with a chronic illness/disability, who also worked full time, their need for social support was higher than most. Evalyn reports her bitter upset when a family member, her brother-in-law, would not mind her child so she could attend church with her family. Church attendance with her family clearly meant a great deal to her:

Evalyn: I found that I couldn't go to church with Kevin, like, listen to a sermon. And one day, I actually had the hide to do a roster for my family; who went to church. And I said every month, I'd like to be able to sit in with Mathew, and be a family, and listen to the sermon. And my brother-in-law said, "We can't do that, because what about our own family? Who's going to look after *our* kids when we're looking after *your* kids?" It was really, he was really negative about it. And I was just devastated. I was absolutely devastated. And then he, after that, I mean, after that he actually apologized. [Evalyn becomes very upset at this point and starts to weep quietly]. (Evalyn, #1: 54)

Cate shares her experiences trying to get some child-minding support from her mother. Cate's mother had a disabled son herself (Cate's brother, Brian, who Cate now cares for):

Cate: My mother's 66 and I know that she would be... when I think of her, I look at her and I say, "You should be able to watch William" – that's his name – "you should be able to watch Billy no problem because you had Brian." But she doesn't, and I'm not sure why. I think it's because she's just kind of jaded. I waited a really long time to have kids, and Billy's only four. I'm 38, so that tells you how long I waited [laughter]. And she's 66, and I just think she isn't committed about him. I don't think she wants to deal with it. I think she loves him, but I just can't expect her to come and watch him. Where before I had him, I kind of had this thing in my mind and we talked about it, "Mum, are you going to be able to help out? Are you going to be able to come over and stay if we want to go out? You know, will you watch the kids?" "Yes, yes, yes, I'll do that." But when it came down to it, it's not turning out that way. (Cate, #1: 3)

Not only does Cate not get support from her mother, she does not get support from her partner, Colin, either. Not only has Cate overheard Colin tell his mother he was "disappointed" in their disabled child, Cate explains she cannot rely on Colin to care for Billy because she is fearful that he might lose control and hurt him. Consequently, she finds herself having to drop

² The only assumed "obligation" of support in caring for the child was from the child's father.

everything at work from time to time, to return home. Cate ultimately avoids leaving their disabled son alone with his father.

Cate: We knew something was up with William. Once I heard [Colin] say that he was disappointed about it, and that was when he was talking to his mother on the phone, and I heard him say it. And that was kind of hard to hear. And I already said that I'm afraid he'll try to hurt Billy one day in anger and frustration. But ultimately I'm not sure if I trust [Colin] alone with him over extended periods of time. So the way I deal with it is that I make sure he [Billy] has care. Meaning, the babysitter is there rather than my husband. And there's never a time when he has to watch that's over three hours. And I am the controller of that; I am the master. That's something I took upon myself. He said to me, "I can't watch these kids. I can't take it; it's too much. Billy's too uncontrollable. He stuck his hand in his diaper and put poo all over the wall. I can't take it." And there's always a day when the daycare's closed and I've got to work, and he's got both of the kids home. There have been days when he's called me and said, "Listen, I can't take it. You need to come home *now*." And I'll go home. And it's rare, but I always make a point – I say to him – "*You* have to call me and tell me that before something happens. That is your out. You *need* to call me." So he understands. I don't really trust him alone with him for overnight and stuff like that. Like when I had the second baby, I had to be in hospital overnight, and he was home with Billy, and that was really, really hard. Because I asked my mum to stay but she couldn't. But it was fine.

Researcher: Does he know that you have those reservations about his control?

Cate: I don't know. We never talk about it. I never sat down and said, "I don't trust you." I just kind of manufacture our schedule so that it doesn't occur. (Cate, #1: 20-21)

For Cate, not only was support for her in-home duties lacking, her work life was often interrupted unexpectedly and she felt unable to leave her disabled child with his own father for any length of time. She shared one particularly worrying incident. Both Cate's children (a two year-old and an intellectually disabled four year-old) had been left at home alone. Their father had gone out to purchase alcohol for himself (Cate, #1: 64). Cate's situation and caring responsibilities appear overwhelming. While working full time, she must single handedly care for her son Billy who has autism, her grown brother with a disability, her unemployed husband, and her able-bodied two year-old. We have already seen Cate's colleagues are not especially supportive, nor her mother or her husband. Cate had this to say about approaching her mother-in-law for assistance:

Cate: I had to go away twice. Once to bring the kids over there so that Colin's Mum could get used to being alone with [Billy]. And then a couple of months later I could actually go and be able to drop [Billy] off there for a couple of days at a time, because she was intimidated by him too. She was, "*What am I going to do with this four year old kid who doesn't know how to talk, and still uses a diaper?*" Plus I paid her some money, so that always helps... they don't have any money, so they were like, "Whoo-hoo!"... And that's what it took. That's what it took. That's what I had to do. (Cate, #1: 6; researcher's emphasis)

To complete the picture of Cate's overwhelming situation, and the absence of social support she experiences, I include this last passage, where she explains that her employer-sponsored daycare center (which is, I remind readers, an organization that provides support for people with disabilities) denied her son access. Her son, apparently, was "just too much trouble":

Cate: The worst thing was when the employees were told that this was a daycare that you can use for your kid. They said, "You can use this daycare for your kid, and it's going to be great because you'll get this discount on daycare. And it's going to welcome kids with disabilities." And I thought that was just awesome. And then when they started it, I said, "Why don't I send my son to it?" And the person who was running the daycare at the time said that they couldn't handle my son, even though he wasn't even yet two. And they just said that he was too hard to work with for the staff. And they said, "No." And I went to them in writing. I said, "Can you please tell me why you're denying me this?" And the problem I think was that the person running the daycare was a financial guy. He was head of the business office at the time. I don't really think he had very much interest in actually helping kids; I think he was interested in the bottom line. And he was, "Well, this kid's just too hard." But that was the hardest thing. And even that wasn't that big of a deal. It made me grow; it made me branch out into the community for daycare. (Cate, #1: 10-11)

Cate's story is reflected in many other respondents' experiences, although she is the only one who reports support withdrawal from her mother, partner, in-laws, colleagues and the employer-sponsored day care center, concurrently. For Charlene, her experience of Clayton's support was through her ex-partner [the father of their disabled son] who actively worked *against* her, as she struggled to cope with supporting and caring for her two very young children--one of whom had become a paraplegic because his father had run him over as an infant:

Researcher: And do you have the support of your ex-husband for Jamie?

Charlene: I did *not* at the time. My ex was very non-supportive, and he was very hostile.

Researcher: About the cause of the accident?

Charlene: No. My ex-husband ran over Jamie. So he was very guilty. He was very non-supportive of me. When I filed for divorce, he got a lawyer and filed that I was an unfit mother. And the fact that I had shown that the previous five years of income tax, the only person in our household that earned a living was me - that he hadn't worked - helped me. Jamie had a home teacher who had come into our home and wrote a letter saying that she had observed the children at home and that I was a good mother. But I still had to go through court and take care of that. (Charlene, #1: 10)

Conclusion

The question of social support has always been a vexing one in our communities, especially as it pertains to people with disabilities, or those people caring for others with disabilities or chronic illness. We know victims of life crises sometimes have difficulty gaining the support they desire and need (Silver et al, 1990, p. 397). We also know that not all social ties may be supportive (Hobfoll and Stephens, 1990, p. 454; Vickers, 2001) and that social support may have

a mixed effect (Hobfoll and Stephens, 1990, p. 461; Vickers, 2001). We have certainly seen that to be the case here. These women are in dire need of social support. Unfortunately, the literature is distressing in confirming those in greatest need of social support may be least likely to get it (Silver et al., 1990, p. 398). Further, we also know the supportiveness of social ties waxes and wanes as stressful events are confronted and take their toll on the resources of those involved (Hobfoll and Stephens, 1990, p. 455). Perhaps one possible explanation for the sense of disconnectedness and the experiences of "Clayton's support" reported may be that these women continually need to call on support, thus draining sources of goodwill.

However, that does not explain active attempts to thwart these women, to make life more difficult for them and their children, and it certainly does not explain the numerous acts of cruelty and thoughtlessness reported here. The thoughtlessness demonstrated may be a function of the feelings of vulnerability and helplessness evoked in potential helpers and beliefs about appropriate reactions to display towards people experiencing life crises (Silver et al., 1990, p. 398; Vickers, 2001). Having a child with a serious chronic illness or disability would certainly constitute such a life crisis. However, being a product of social relations, social support is likely to have costs and benefits associated with it (Hobfoll and Stephens, 1990, p. 455) and may be dependent upon the perceptions of others of the individual's *need* for support (Sarason et al., 1990, p. 18). The problem may lie, for example, with how to present the problems to others: "If they display their distress and report difficulties in coping, they may drive others away. But if they fail to exhibit their distress, they may not signal a need for support" (Silver et al, 1990, p. 398). In other words, the way these women choose to display their needs for support may contribute to the lack they are experiencing. How much help should they say they need? If it seems too much, they may frighten potential helpers away. If they seem to be handling their lot—as these women did—perhaps others are unaware of their need. It is acknowledged that "social support is not a bottomless well" (Hobfoll and Stephens, 1990, p. 465) and frequently, people who are potential givers of support may not know how to react when dealing with people during a life crisis (Silver et al., 1990, p. 398). The sobering conclusion is reached that these women, and those like them, cannot necessarily depend on those closest to them for support, due largely to the unacknowledged nature of their situation.

Sadly, our ability to imagine the illness experience and to empathise with those who are ill is severely limited (Morse and Johnson, 1991, p. 1; Vickers, 2001). Denial of illness and its consequences by those closest to the person concerned can be frustrating and angering (Szasz, 1991, p. 168). We have seen here that even supportive relationships may be characterised by negative exchanges (Hobfoll and Stephens, 1990, p. 462). However, we have also seen very unsupportive contexts where these women need to continue and survive. What is required is appropriate recognition of the needs of these women for support, at home and at work, by partners, families, friends and colleagues. Policymakers need to acknowledge, when making workplaces accessible to people with disabilities, that they also need to consider the needs of workers who are caring for those with chronic illness/disability to alleviate their trauma. The stories above flag serious and ongoing challenges for these women: surviving on a daily basis; progressing their careers (and, perhaps even, holding down their jobs); maintaining a cordial relationship with co-workers, and keeping a semblance of "normality" in their family functioning and interpersonal relationships. Acknowledgement of such concerns provides an important first step in ameliorating these women's lives.

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