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Working and Caring for a Child with Chronic Illness: Challenges in Maintaining Employment

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Abstract This paper shares some pertinent findings from an initial, qualitative stage of a larger, national study currently being undertaken in Australia, exploring the support needs of parents who are working full time and caring for a child with chronic illness. The findings presented here depict the negative impact of these parents caring responsibilities on their work life and the increased stress they experience trying to maintain full time employment. In-depth interviews revealed how these parents had to rearrange their working hours, use up their leave entitlements, work unsatisfactory hours, sacrifice their careers and even change their jobs in order to balance their dual roles. In addition, the findings also highlight the negative and unsupportive attitude that employers had towards these parents. These employment conditions were extremely stressful and frustrating for parents affecting their physical and emotional well being.

Key words chronic illness · disability · employment · stress · caregiving

Introduction

Over the last 20 years, advances in scientific knowledge and technology have resulted in an increased number of children being identified as having and living with a chronic illness (Blum

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1991; Gibson 1995; Isaacs and Sewell 2003). Estimates indicate that approximately 31% of children under the age of 18 years have one or more chronic illness (Newacheck 1994; Melnyk *et al.* 2001; Vickers 2006). More specifically, in Australia, there are almost 300,000 children aged between 0 and 14 years (7.5%) that have a disabling chronic condition, most of whom are cared for at home [Australian Institute of Family Welfare (AIHW), 2002].

The impact of caring for a child with a chronic illness has been widely investigated (Freedman *et al.* 1995; Iever and Drotar 1996; Padeliadu 1998; Burke *et al.* 1999; Kurnat and Moore 1999; Melnyk *et al.* 2001; Hedov *et al.* 2002; Meleski 2002). Several studies have shown that parents who care for children with chronic illness experience greater emotional and psychological distress than parents of healthy children (Cheng and So-Kum Tang 1995; Silver *et al.* 1998; Pelchat *et al.* 1999; Isaacs and Sewell 2003). Furthermore, in recent years, several demographic trends have impacted on the caring responsibilities of these parents. The rise in single-parent families (Bianchi 2000; Australian Bureau of Statistics [ABS], 2004), the increase in women employed outside the home (United States Bureau of the Census 1992; ABS 2004) and the rise of dual-earning families (Googins 1991; Hughes 1998; Lewis *et al.* 2000) have increased the number of parents who are working and caring for a child with a chronic illness. For these parents, coordinating their work and caring responsibilities can be extremely demanding in terms of time, energy and commitment which can affect their employment.

Although there is much evidence that highlights the stresses and strains facing parents of children with chronic illness most of the research has neglected the issues facing such parents who are also working. The few studies that have tackled this area of family life have shown that, for parents who are working, the stressors involved in caring for a child with chronic illness are exacerbated (Cuskelly *et al.* 1998; Thyen *et al.* 1999; Einam and Cuskelly 2002). Various challenges confronting these parents have been identified with the most common being locating appropriate and affordable child care. Although parents of healthy children also need to deal with issues of child-care quality and cost, parents of children with chronic conditions face additional constraints, such as limited availability of child care due to the inability or unwillingness of child-care providers to accept children with chronic conditions especially those requiring constant supervision (Berk and Berk 1982; Chang and Teramoto 1987), logistic problems like distance from home, and the lack of well trained caregivers that can provide optimal care for their child (Freedman *et al.* 1995; Cuskelly *et al.* 1998; Chavkin *et al.* 2002). The situation is further aggravated during school holidays when working parents need to make alternative arrangements to care for their child.

Working parents also face the challenge of attending their child's medical appointments and meeting job responsibilities. Frequently, due to time restrictions, parents must rely on their sick leave entitlements to care for their child and in some cases even have to choose either missing work or attending medical appointments. To add to their woes is the huge financial burden that these parents endure caring for their child. Reports indicate that out of pocket expenses are *three times higher* for parents of children with severe chronic illness compared to other parents which explains why many of these parents work full time (Leonard *et al.* 1992; our emphasis). In order to cope with the challenges of caring for a child with chronic illness parents are forced to modify their working arrangements. Studies have shown working parents choosing part time work, moving from the private to the public sector (Vickers 2006), cutting back on their paid hours of work, as well as rearranging work schedules, taking time off and, in some cases, even ceasing work in order to meet their child's needs (Hirst 1985; Jutras and Veilleux 1991; Barnett and Boyce 1995; ABS 2000; Leiter *et al.* 2004).

Unfortunately, very little has been reported about the experiences of parents of children with chronic illness who are working full time. The main limitations of the existing studies have been the lack of focus on parents who are working *full time* as most have either not stressed this criteria (Cuskelly *et al.* 1998; Thyen *et al.* 1999; Einam and Cuskelly 2002; Hedov *et al.* 2002; Leiter *et al.* 2004) or have lacked clarity as to whether the parents are working full time or part time (Lewis *et al.* 2000). Other limitations have been: the focus on specific chronic conditions only (Freedman *et al.* 1995; Shearn and Todd 2000) and the lack of any generalizable findings. This paper aims to further explore the experiences of parents who are working full time and caring for a child with chronic illness. More specifically, the paper aims to examine the challenges these parents face trying to maintain full time employment. Implications drawn from these findings will then be proffered to assist in improving the employment conditions of these parents.

Method

The study involved qualitative, in-depth, semi-structured, phenomenological interviews exploring the experiences of parents who are working full time and caring for a child with chronic illness. This forms part of a larger mixed method study currently being undertaken in Australia that examines the support needs of parents who are working full time and caring for a child with a chronic illness.

Recruitment

For inclusion in this study, parents had to be working full time or equivalent, taking care of a child, defined as 18 years or younger who has a chronic illness, living in a capital city or metropolitan area of Australia, and be fluent with the English language. The term “full time or equivalent” was used to include parents who were self-employed, undertaking multiple part-time/casual roles, full-time study, or were in the full-time permanent paid labour force. Chronic illness was defined as a significant illness or disability, which may be physical, emotional or cognitive and continues for at least 6 months, requiring ongoing medical intervention to treat acute episodes and/or ongoing problems (Vickers 2005; 2006). Metropolitan areas were chosen mainly because over two thirds of Australian children live there (Al-Yaman *et al.* 2003, ABS 2003). In addition, studies have shown that the support needs of people living in rural and remote areas of Australia are different to those in metropolitan areas (Wilkes *et al.* 2000, 2004, 2006). Purposive sampling was used to select parents for the study. Parents were recruited through informal contacts of the study investigators, word of mouth and snowballing techniques (Watters and Biernacki 1989). Recruitment was also carried out through a large children’s hospital in Sydney, Australia.

Data Collection

In-depth, semi-structured interviews were conducted, taped and transcribed verbatim. Brief demographic details about the child and the parents were collected prior to the commencement of the interview. During the interview, parents were asked about their lived experiences with special attention directed to the identification of areas where support was required. A number of focus areas were used to guide the discussion including: caring responsibilities; getting carers; financial implications; family and partner relationships; dealing with professionals; work life; workplace conditions; grief/sorrow; sources of information; and practical needs. Probing and story telling were also used to encourage parents to talk more about their experiences. Interviews were conducted until a point of information redundancy was reached (Lincoln and Egon 1985). That is, when the interviews no longer provided any new insights into the experiences of these parents.

Data Analysis

All interviews were transcribed verbatim and then analysed using thematic analysis (Van Manen 1990). Transcripts were read line by line and coded using NUD*IST Vivo software (NUD*IST Vivo 2003). Significant statements from each transcript were extracted, meanings formulated and then organised into various themes. Evidence of these themes was explored in each of the transcripts. Sub themes were also identified. The study investigators coded each transcript individually and a consensus of the final list of themes and sub themes was made. This process added to the rigor of the analysis.

Findings

Eight females and three males participated in this study. The ages of the parents ranged from 30 to 50 years with an average age of 42. All parents worked full time (or equivalent) with ten of the parents having partners who also worked full time. Two respondents had to care for another adult as well. Parents had being caring for their child with chronic illness for varying periods ranging from 2 to 18 years. The children were aged from 3 to 18 years and had diverse chronic conditions including significant physical, genetic, neurological and systemic impairments.

Several themes emerged from the thematic analysis of the data including caring responsibilities; issues with carers; money; relationships; work life; workplace; grief; dealing with health professionals and information. As the focus of this paper is on employment, two intertwined themes are reported here: (1) working; and (2) the workplace. Described here are the parents' lived experiences. There were no distinct gender-wise differences in the experiences of these parents. Exemplars from the analysed text with pseudonyms for the parents' names are used to illustrate themes.

Working

All the parents interviewed agreed that employment played an integral part in their lives. Amidst the stressors of caring for a child with chronic illness, work was viewed as a welcome source of relief from their unending caring responsibilities, providing them a chance to regain their sanity. For Molly who had a son with spina bifida, work was an opportunity for her to forget all her problems and talk about other issues with colleagues:

> **Molly**: My own space…that is what work was all about for me, the money we needed but also it was all about finally me having adult conversations, not talking about all the problems with Mark [her son], not talking about all the problems with the other kids, just talking about work problems, work issues, you know. Yeah, the best thing I ever did was go to work.

Unfortunately, maintaining full time employment while caring for a child with chronic illness was extremely stressful for these parents. The caring responsibilities impacted upon their work life in numerous ways. Difficulties in finding appropriate and affordable carers forced most parents to rearrange their work hours by working on weekends, only working during school hours and even working shorter days in order to care for their child. The stress experienced was exacerbated for parents of children with severe chronic conditions, due to the shortage of well trained carers and the unwillingness of many schools and day cares in accepting these children. For parents in such situations providing constant supervision to their child as well as maintaining their employment meant working inconvenient and inappropriate hours. Molly had to sacrifice her sleep and work night shifts while her husband worked day shifts, in order to care for her son:

> **Molly:** I used to start work at midnight and I would finish at 8.00 in the morning. His father would be at home while I was working…I would go to bed at 7 o'clock at night and put the kids to bed and I would sleep from 7 to 11 and I would function on 3 hours sleep a day.

For some parents the unending care giving tasks had a profound effect on their work life which resulted in job loss. Rearranging working hours was not a viable option for Susan who, along with her partner Alan who was also working full time, was caring for a child who was developmentally disabled. She was unable to cope with the pressure of working odd hours and had to leave her job after struggling for 6 months:

> **Susan:** I worked a job that I started work at 4.00 A.M. in the morning and I finished at 1.00 P.M. in the afternoon. So I was home, or Alan [her partner] was home with Ben [her son]. But, the problem with it was, that I just…wouldn't get enough sleep. You know, working really strange hours, it becomes hard work after six months of it.

Flexible working hours was not feasible for some parents due to the nature of their work. These parents found it extremely stressful balancing the demands of their job and their caring responsibilities and had no option but to resign. David, who had a son born with cerebral palsy, had an inflexible job and found it impossible to juggle his work commitments and the numerous hospital appointments that were necessary for his child, even though his wife was staying at home to provide care. These stressors coupled with the mental anguish of having a child with a disability made it extremely difficult for David to concentrate at work and eventually influenced him to leave his job:

> **David:** I was working with a machine tool company at the time when he was born. It was a full time employment but, you know, when all this happened we were totally devastated with the affect and then…we had to regularly go every day, three times to the hospital and he was there for almost six months in the hospital. It was highly difficult to concentrate here and there. So, that time because of the pressures I had to leave the job.

Some parents who were casual employees voiced their concerns about the lack of permanency in their jobs, and the stress and frustration it evoked. The fear and uncertainty regarding the availability and timing of work shifts made it impossible for these parents to arrange appropriate day care and even schedule medical appointments. For Leanne, who was caring for two children, one child with neurofibromatosis type 1 (NF1) and one with attention deficit hyperactivity disorder (ADHD) and a husband who was suffering from post traumatic stress, working night shifts was her only alternative. Unfortunately not being a permanent employee meant that every week, she constantly worried that her roster would be changed:

> **Leanne**: It is just very disruptive having to work a different time each week because you can't make any arrangements for anything…if you don't know when you are

> working. I am constantly worried that they are going to take my nights away. Like, every week, where is the rosters? Where is the roster?

Whenever David, who was the sole earner for the family, had to miss shifts when his son's condition deteriorated, he feared he would be viewed as unreliable and be denied further work:

> **David:** When I was working as a casual they said, "If you cannot turn up regularly for this one you'll be loosing the job or you may not be called next time". That was always a fear because they don't try and understand what you go through or what your family circumstances or situations are. They say "It is none of our business. It is your business. So, as long you are able to work for us that's fine."

A number of parents highlighted the negative impact that caring for a child with chronic illness had on their careers. The need for flexible jobs limited the job prospects for many parents and was a source of stress and anxiety. For Vicky, who had a child with renal failure, finding a flexible job especially in the information technology (IT) industry was extremely difficult and resulted in her working any jobs that were available even if it meant low wages and unsatisfactory conditions. Vicky's situation was further exacerbated by the fact that her husband was working long hours and rarely provided any support:

> **Vicky:** You know, just casual, just simple work, low paid…it was just work any odd job. I couldn't look for anything that had a proper career in it.

Having a child with chronic illness had a huge impact on parents with secure jobs also. Michelle, who had a managerial role before her son was diagnosed with a life limiting disease, had to, along with her husband, sacrifice their careers in order to continue working and caring for their child:

> **Michelle:** Well, my career has suffered. I suppose it is the sacrifices that I have made…I have changed from what I was originally doing and what I wanted, the career path that I planned for myself that I wanted to do has done a nose dive [Michelle places her hand on her head looking disappointed], so yeah,…I have had to find an area that would accommodate my family needs.

One parent (Jason) even recalled how he deliberately avoided career changes like seeking promotions that could have jeopardized his precarious work–family balance, especially as his wife was also in full time employment. Such decisions although necessary at the time, were stressful and unfortunate, especially for Jason who had several years of experience:

> **Jason:** I made a conscious decision to not go on and not to seek promotion, to look after him [his son], I probably made the wrong decision, but that is the decision I made, because I wanted to be in the position where I could come at the drop of a hat, you know. Because it has been five or six years, I would have got promoted easily if I hadn't made that decision.

Another area of concern for parents was the availability of leave entitlements. Parents who could take paid leave often utilized it to either care for their child whenever the chronic condition deteriorated or attend the numerous medical appointments and tests that were needed. This resulted in parents using up their leave prematurely leaving them no opportunity to take a break or a day off. As Reina recalls, "I don't have much annual leave. I've had to use annual leave for clinic appointments and those kinds of things". Some parents, like Jane who had a son with a severe muscular disorder, even avoided using their paid leave for personal purposes like going on holidays in order to preserve their entitlements:

> **Jane:** We never get to spend a holiday. If the kids go away we can't do anything together, I can't take time off and he [her partner] can't take time off, because whatever we do have [leave] we need it, so we can look after Lennie [her son].

The Workplace

In addition to the challenges faced in maintaining full time employment, many parents also revealed the unsupportive workplace conditions they were enduring. Most parents felt their employers neither acknowledged their family situation nor had any comprehension about the unrelenting stressors that were involved in caring for a child with chronic illness. This lack of understanding was evident as employers, knowing the circumstances of these parents, still offered little flexibility which was vital for these parents to maintain their precarious work-family balance. For example, David received no flexibility in his previous causal jobs and found it extremely difficult balancing his work and family tasks especially during the initial stages of his son's diagnosis when frequent hospital visits were required:

> **David**: It is highly difficult because although they [his employers] have got proof that you have got a problem, they say it's not their business requirement, they cannot compromise.

Employers seemed to assume that these parents could easily separate their family life from work life. As some parents pointed out, the demands of caring for a child with chronic illness made it impossible for them to neglect their family responsibilities even while they were working:

> **Leanne:** They have this funny attitude, like, they think that your job is your whole life and they just don't understand that it doesn't mean that you don't care about your job but that it is not your whole life and that you do have other responsibilities.

> **Susan:** She [Her employer] doesn't have this comprehension that you still have a child to care for even though they are in hospital. You can't not care for them and stay home and do all this work.

Even in some government organisations that had family friendly policies, the attitude of managers played an important part in putting these policies into practice. This was reflected in Leanne's experiences with her nurse unit manager. Financial constraints, lack of family support and difficulty in getting affordable child care meant that Leanne, who was the sole carer and earner of the family, had no choice but to stay at home during the day and care for her children. This predicament forced her to constantly request night shifts at work whenever the rosters were prepared. Often, however her manager would deny these requests and sometimes even change her shifts to day time at short notice without taking into account her family commitments. This angered Leanne and exacerbated her problems, aggravating an already stressful situation:

> **Leanne:** Work can be annoying because, working for the State Government in disabilities, they get really uppity about, "You shouldn't be only working nights you should be working days as well"…They were very family unfriendly employers. They were always

> saying, “You have to come and work this certain shift. Every one should work all shifts”. Well that is not family friendly employment…because they say you have to do a seven o’clock start and I can’t do it. So, I have to get like my poor 80 year old mother-in-law to come and stay with the kids and, like, she can’t mind him. So, you know, it is a big drama.

This uncaring and inconsiderate attitude of Leanne’s employer was further exhibited when she and her husband, who used to work in the same hospital, were often rostered on the same shifts making it impossible for them to care for their children:

> **Leanne**: My husband and I were working together in the same place and they didn’t even always coordinate that…they wouldn’t necessarily roster to, like, coordinate.

Some parents also recalled instances where employers were unsympathetic, making comments that were hurtful and thoughtless whenever parents took leave or modified their working arrangements. It was clear that these employers had no empathy for these parents nor did they acknowledge their precarious position. For example, Susan gave an account of her employer’s response when she requested a few days leave when her son’s condition deteriorated and he had to be hospitalized:

> **Susan:** My immediate boss is like, “So, that means you are going to be away for a couple of days?” Not a caring way that she talks. It is like an inconvenience to her. Even when I am taking work home on the weekend to do, she was like, “Well, will you get all this done on the weekend?”

For Molly, the insensitivity and lack of understanding from her manager was hard to comprehend despite being a dedicated employee and fulfilling all her job responsibilities:

> **Molly**: The head lady would say, “What would happen if you weren’t around? You have a job here. You have a responsibility.” It is like they are paying for you out of their own pocket to do the job. If I wasn’t doing the job I could say, “Well, fair enough” but I *was* doing the job.

Even during emergencies, parents seemed to receive little or no understanding from their employers. This was reflected in Jane’s experiences of trying to juggle full time employment and care for a child with a severe muscular disorder. Due to the severity of her son’s condition, Jane had to rely on professional carers like Home Care while she and her partner worked. Unfortunately, these services were unreliable and often resulted in her leaving work unexpectedly whenever carers were unavailable to care for her child. These disruptions were seen as unacceptable by her employers:

> **Jane**: They knew the circumstances before I went there and I had organized so I could be there for the whole day, until 4.30 P.M.…But then it was the days like, if I got a phone call in the afternoon that Home Care is not here, I had to go home. Then I had to go upstairs and say, “I have got to leave. Home Care has not shown up. I have to go”…They got frustrated with that. They got very frustrated that I had to go.

One employer even resorted to drastic measures to limit the flexibility in the workplace. As Leanne explained, her manager would often intimidate and threaten serious consequences for her whenever she requested night shifts instead of day shifts. These actions threatened her fragile work-family life causing further unnecessary stress and leaving her feeling scared and helpless:

> **Leanne:** When we had this other boss, she would always write these intimidating letters saying, “You must work days and we will stop you working nights and make

> you work 24 hour a day rotating shifts. No set shifts." And things like that. And the silly thing was they didn't have anyone wanting to do the shifts that I was doing but she still did it. The mentality is like put a fear into you like, "We will make it harder for you to work," and saying you have to do things that are totally unrealistic…it causes a lot of unneeded stress.

It was clear that Leanne's employer had no regard for her family situation and was actually making it harder for her to manage her work and family responsibilities. Leanne's traumatic experience exemplifies how the challenges faced by these parents in maintaining full time employment are exacerbated by the attitude of employers.

Discussion

This study has provided valuable insight into the experiences of parents of children with chronic illness who are working full time. Firstly, the findings support other studies in showing that employment does have a positive effect on these parents by providing them temporary relief from their caring role, improving their emotional well being and allowing an opportunity for increased social networks (Thyen *et al.* 1999; Einam and Cuskelly 2002). Secondly and more importantly, the study also highlights the negative impact their caring responsibilities have on their work life. Parents are forced to rearrange their working hours, use up their leave entitlements and even change their jobs in order to meet the demands of their dual roles. Although these findings concur with other studies (Barnett and Boyce 1995; Leiter *et al.* 2004) it also confirms and extends the work of Vickers (2005), highlighting the enormous stress and frustration that parents of children with chronic illness are enduring trying to maintain full time employment. What seems to distinguish these parents from other parents who are not working or working part-time, is the intensity and complexity of the arrangements required to balance work and home responsibilities and the sacrifices these parents make regarding their careers. The need to constantly monitor these children, especially those with severe conditions coupled with the difficulty in locating appropriate and affordable child care compels parents to seek only flexible jobs.

Unfortunately it is evident that having a flexible job does not necessarily alleviate the stresses these parents are experiencing. Pursuing flexible employment evokes frustration in many parents as it involves disregarding their ambitions and aspirations and opting for any odd jobs that are available even if it involves working unsatisfactory hours and conditions. To add to their woes, often flexible jobs are only available on a casual basis which unfortunately means no leave entitlements and no guarantee of work. The findings also show that despite having flexible working conditions many parents experience greater stress due to the negative and unsupportive attitude of their employers. Employers were seen to be uncaring, inconsiderate and unsympathetic and had a definite lack of understanding about the unrelenting pressures and responsibilities these parents were bearing. It thus seems almost impossible for parents of children with chronic illness to continue working full time, especially considering the numerous challenges they face. Not only do these parents face difficulties in securing suitable employment but have to endure unsupportive work conditions as well. Yet despite this, parents are still willing to bear these stressors and continue working, which is quite remarkable and highlights just how important employment is for them.

It is quite obvious that these parents are in desperate need of greater support to help ease the pressures they are facing trying to maintain full time employment. One of the important avenues where crucial support can be provided is at the workplace, through employers. As the survival rates of children with chronic illness improve (Gibson 1995) and more parents enter into the work force (Lewis *et al.* 2000), it is clear that employers can no longer be inconsiderate and unsympathetic to these parents and ignore their needs. It is critical that organizations be educated and made aware of the numerous challenges confronting parents of children with chronic illness who are working full time and realize that their support needs are far greater and more complex than other parents. Employers should also realize that overlooking the needs of these parents is not beneficial to their organization. A lack of employer support can create anxiety for these parents and reduce their morale and effectiveness at work. As one parent said, ‘They have this silly attitude that if people are unhappy they will get more work out of them but it doesn’t work that way’ (Leanne). Instead, if employers provided a more supportive workplace, parents could make a full contribution at work and improve the productivity of the organization. Appropriate acknowledgement and a shift in thinking will find employers more willing to implement supportive policies in the workplace. The present findings have highlighted various avenues where employers can provide extra support to these families. These include offering flexible working hours, allowing changes of shifts on short notice, providing easier access to leave entitlements, allowing leave entitlements to be used for caring duties, allowing parents to leave work during emergencies, offering greater flexibility and entitlements for casual employees, providing informal support and offering professional counseling at work. In addition to providing these services, organizations should also look beyond the workplace and explore the possibilities of providing greater support, both informal and formal, within the community (Lewis *et al.* 2000). Having affordable and appropriate childcare and greater flexibility among heath care and other professionals can enable these parents to develop appropriate strategies to manage their multiple commitments.

Lastly, the government can also play a more active role in supporting these parents. There have been claims that the Australian work force is under immense pressure because of the lack of government support for people with caring responsibilities (ABC online 2005). Many existing government policies do not cater to the needs of working parents that care for a child with chronic illness, especially those who are casual employees or work in the private sector. The government can offer more support by awarding incentives to employers who offer greater flexibility and implement policies that is more family friendly like the recently introduced child care rebate (Australian Taxation Office 2005) and the latest amendments in the public health sector providing family and community services (FACS) and carers leave to casual employees as well (New South Wales Health 2006). In addition, legislations like the Family and Medical Leave Act in USA (United States Department of Labor 2007) could be passed in Australia that would allow working parents with caring responsibilities up to twelve weeks unpaid leave over a twelve month period, irrespective of whether they are working in the private or public sector. Such initiatives from the government would provide valuable support to working parents of children with chronic illness.

Conclusion

This study has revealed that it is extremely stressful for parents of children with chronic illness to sustain full time employment. It is evident that these parents have been neglected and are lacking much needed support, especially in their employment, that could help alleviate the stressors they are experiencing. As one parent explained, ‘We are being punished for having a child with a disability and that is wrong' (Jane). There is an urgent need for strategies to be implemented that will enable parents of children with chronic illness to locate suitable full time employment and work in a more supportive environment. These findings have important implications for policy and practice in the employment sector and highlight the need for further investigation into this neglected area of work life.

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