In Australia, the vast majority of care provided to children with disabilities is provided informally, that is, unpaid and usually by family members. An area of care that is undertaken by families is assisting their children’s transition from school. This paper contains a discussion of the findings of a series of in-depth interviews with families whose children have high support needs and who were leaving or had recently left school.

In Australia, the vast majority of care provided to children with disabilities is provided informally, that is, unpaid and usually by family members in the home and complemented by formal support services. Current Australian government policy suggests that care increasingly will be undertaken in the home (Australian Institute of Health and Welfare, 2004; Australian Institute of Health and Welfare, 2005). For some families, this care is life long and outlasts many of the other milestones that children experience such as leaving school. The care itself is time-consuming and, as noted by Brandon and Hogan (2004), “the financial and time constraints imposed on families with a child who has a disability can be considerable” (p. 433).

The Australian Institute of Health and Welfare reports that 59% of primary carers of children aged 0 to 14 years with a severe or profound core activity limitation provide more than 40 hours of care each week (Australian Institute of Health and Welfare, 2006, p. 13). Moreover, most of this care is being provided by women: 91% of this group of carers are women (Australian Institute of Health and Welfare, 2006, p. 12).

For children with the highest support needs, that is, with severe or profound core activity limitations, care includes providing assistance with self-care, mobility and communication. This means that assistance is provided with activities such as bathing, dressing, eating, bladder or bowel control or using the toilet, moving around at home and elsewhere and being understood and understanding others (Australian Institute of Health and Welfare, 2006). But care entails more than these activities and, at certain points across people’s lives, further additional care activities are undertaken. One of these times of additional care work occurs when a disabled child is leaving school and this paper focuses on this particular period of care provision. While there has been attention paid to the experiences of children at this time (e.g., Fiorentino, Datta, Gentle, Hall, Harpin, Phillips, & Walker, 1998; May, 2000; Mirfin-Veitch, 2003; Thomson, Ward, & Wishart, 1995), less attention has been paid to the experiences of parents as primary carers of children who are experiencing their child’s transition from school (Mirfin-Veitch, 2003; Otis, 2004).

The period of leaving school is an important part of the wider transition from childhood to adulthood and, according to May (2000), is “one of life’s decisive turning points” (p. 76). It is a time during which young people “move from the protected life of a child to the autonomous and independent life of an adult” (Hudson, 2003, p. 259). However, for children with disabilities and their families, while leaving school is also a significant milestone, this “progression cannot be taken for granted” (Hudson, 2003, p. 260). Disabled young people are less likely to live independently, to be in paid work or to be in control of their finances or social lives (Pascall & Hendey, 2004). Hence, as noted by May (2000, p. 76) where adulthood is understood to involve personal autonomy, for people with intellectual disabilities, it is a “problematic concept, at best imperfectly realised and for some postponed indefinitely”. Consequently, many families continue to provide high levels of care for their disabled children long after they leave school.

Despite the difficulties inherent in achieving personal autonomy, the wider policy context of transitions from school for children with severe disabilities emphasises the rights of people with a disability and gives prominence to self-determination (Laragy, 2004). For example, the Victorian State Disability Plan “reaffirms the rights that people with a disability have to live and participate in the community on an equal footing with other citizens of Victoria” (Department of Human Services, 2002, p. i). Similarly, in Tasmania, the other state in which the research was undertaken, the Disability Framework for Action states that “people with a disability have the same rights as other citizens and equal opportunity to participate in the social, cultural, economic and political life of our community and to access the structures, processes and resources to realise these rights” (Department of Human Services, 2002, p. i).
opportunities” (Department of Premier and Cabinet, 2005, p. 5). Thus, both Victorian and Tasmanian governments, as in other Australian jurisdictions, also have in place mechanisms to support families and their children with disabilities who are leaving school. For example, in Victoria, the current program resourcing post-school transitions for children with disabilities is Futures for Young Adults and is underpinned by the notion that leaving school is part of a transition, and that with support, young people will move on to something else (Department of Human Services, 2005; Institute of Disability Studies, 2002).

In this paper I discuss the findings of a series of in-depth interviews with families whose children were leaving or had recently left school. First, after discussing the research methodology, I consider the concept of transition and what this means in the lives of these families and their children. Second, I turn to the process by which these families strove to create the best possible arrangements for their children when they left school. Finally, I discuss the implications for policy and practice that this research has suggested.

Methodology

This paper is based on qualitative research in which individual in-depth interviews were undertaken with parents of a child with a disability who was leaving or had recently left school. Qualitative research is able to reveal the “variety and detail of experience which constitutes the lives of individuals”, material that may be masked in quantitative studies (Thomson, Ward, & Wishart, 1995, p. 333). Much of the published work in relation to the experiences of families and their care of children with disabilities derives from the United States and the United Kingdom; little Australian research has been undertaken to date (Australian Institute of Health and Welfare, 2004; Quibell, 2004). While the international literature can inform other research, the varying policy contexts suggests that Australian research is also required.

The eight participants in this research were recruited in response to an advertisement placed in the newsletter of a support and advocacy organisation, the Association for Children with a Disability, based in Melbourne, Victoria. Other participants were subsequently recruited by personal contacts and the snowball method. The interviews were undertaken in August and September 2005 and May 2006. The interviews were each around an hour and a half in length and were semi-structured, guided by questions that were sent to participants in advance for their consideration. While framed within the topic of their experiences of care work during their child’s transition, the way the interviews unfolded was determined largely by their participation in the interview process. Interviews were taped and transcribed with transcriptions returned to the participants for their review. Transcripts were coded by key themes such as care work during the transition process, access to support and the availability of suitable programs. In addition, other themes that emerged from the analysis of the topic of care work were participants’ involvement in developing and shaping new programs and their understanding of the notion of ‘transition’. A draft version of this paper was made available to all participants for their comment.

Research participants

While female participants had not specifically been sought, all those interviewed were women. This is not surprising as the long-term care of children with disabilities is a highly gendered activity. As noted, the vast majority of primary carers of children with severe or profound disabilities are women (Australian Institute of Health and Welfare, 2006, p. 12). While they had all participated in paid work in the past, for much of their children’s lives, these eight women had been unable to participate in paid work due to the demands of care. At the time of the interview, two were working part-time and two were studying. For the others, as stated by one of the participants, paid work “just wasn’t possible”. This is not surprising given that care work limits women’s opportunities to participate in the paid workforce and nearly two-thirds (62%) of mothers who are primary carers of children aged 0 to 14 years with a disability are not in the labour force, compared to 36% of other mothers with children of the same age (Australian Institute of Health and Welfare, 2006, p. 15; Brandon & Hojman, 2004).

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While recruitment of families to participate in the research project did not specify the gender of their children, all children turned out to be female. This is a limitation to the study in terms of the generalisation of its findings for all children, as there may be different issues for young men who are making this transition. The eight young women, ranging in age from 16 to 24 years, were all identified by their mothers as having serious or profound disabilities. The most common conditions among the young women were neuro-developmental disorders. All of the young women had physical and intellectual disabilities and required assistance with the core activities of self-care, mobility and communication; seven of the eight young women experienced profound core activity limitations always requiring assistance from another person with these activities. In addition, some of the young women experienced associated medical conditions such as epilepsy and heart conditions that required ongoing monitoring. Seven of the eight young women were currently engaged in a home-based, centre-based or combined home and centre-based program, or plans were being put in place...
place for them to move to such a program at transition. One young woman was employed part-time with one-to-one support and was also engaged in a home-based program. All of them lived at home with their families and, for the foreseeable future, it was expected that they would continue to do so, at least partly because of their desire to do so and, for some, partly because of the lack of any suitable community-based residential facilities.

Four of the eight families live in an outer metropolitan area of Melbourne and four live in or near a regional centre in Tasmania. These contrasting sites were chosen to identify some similarities and differences across states and residential locations. Clearly the research does not seek to provide a representative sample of participants across two states, nor does it claim to compare the impact of regional and metropolitan locations across these two states. Moreover, the different experiences revealed by the participants are a result of both state-based policies as well as location. To protect the privacy of all participants, pseudonyms are used and specific localities are not named except as 'Melbourne' and 'regional Tasmania'.

This transition period was a very difficult time as the three main supports in their life – school, hospital and respite care – changed.

Leaving school: Transition or continuation?

As discussed, leaving school is generally acknowledged as a milestone in children's lives. However, for young people with some of the highest care needs, it does not necessarily symbolise the beginning of a time of increasing personal autonomy. Nor does it mark entry to adulthood at which time parents expect increasing levels of independence from their children. While leaving school meant that the young people moved to another setting, for their parents, levels of care were retained. For example, when Vanessa celebrated her eighteenth birthday, Annette was aware again of the difference that having a disability made. Instead of being out "raging with their friends...like most 18-year-olds", she was at home with her parents and "it's not the same." For Annette, it was a powerful reminder that, at 18, her daughter was not becoming more independent but rather that she was continuing to make decisions for her, and that she would continue to do so. For Judy, even though Rosemary was now 22 years old, "she's always going to be totally dependent". The transition period, however, flags the more limited set of options that their children have in comparison to other children who do not have a disability. Not only are there fewer options, but day programs are typically less well- resourced than schools and the young people's skills and physical wellbeing developed in the school environment may not be maintained.

The transition from school is an important milestone because it also marks several other significant changes. In fact, leaving school is just one part of a constellation of changes that affect this group of young people at this time (Beresford, 2004; Geenen, Powers, & Sells, 2003). Some of these young women also have serious health problems that have required long-term medical review and intervention. They have well-established relationships with the local children's hospital and related services and, from around this time, there is pressure on them to turn to adult health services. Around the time of leaving school, access to specialist children's support services such as holiday camps and respite care are also no longer available. As well, there are changes to income support that result in a net decrease in income: while they receive an increase in the Disability Support Pension, they lose their educational allowance and receive less financial support to purchase incontinence aids. As Robyn noted, this transition period was a very difficult time as the three main supports in their life – school, hospital and respite care – changed. Even though they have since been replaced in various other ways, it meant that the long-term trusted relationships that had been established with her and her daughter were lost. So even though in some ways leaving school was a continuation of their former lives, for Robyn and her daughter, Catherine, it was also "a huge jump".

For these young people with some of the highest support needs, there is unlikely to be a transition in the sense of moving on somewhere else. The participants I spoke to were blunt about this. They wanted their circumstances and those of their children to be acknowledged and for there not to be pretence otherwise. At the same time, they wanted sensitivity to their circumstances and dignity for their children. For Kerry, it meant that she should not need to be asked at regular Centrelink reviews if Christine is still unable to go out to work" when "she's always going to be totally dependent". The other mothers felt similarly: for Annette, it was realising that "they're never going to move onto anything better or more advanced"; for Sara, it was not a transition but a continuation and, for Judy, there was "no transition".

The notion of transition, then, seems to have less meaning to the parents of this group of young people. However, the public policy is framed around the needs of those who are most likely to move on to something else over the course of their transition. Victoria's Futures for Young Adults is a funding
program that supports transitioning young people for up to three years, rather than providing lifelong support (Institute of Disability Studies, 2002). Not surprisingly, the mothers of these young people asked, “What happens when my child turns 21?” Because their daughters require ongoing support, Robyn “presumed that things are going to go on indefinitely” but it was not articulated in the policy and it remained a worry in the back of her mind. In contrast, in Tasmania, the funding support provided to Melanie to enable her to participate in a centre-based program was available until she was 40 years old. While the much greater certainty around the provision of ongoing support was reassuring, for Sara it also drew attention to their circumstances: “what other 18-year-old”, Sara asked, “can see their future to 40? and thinking that I’m still likely to be there… and she will still be dependent on me”.

Finding a suitable program

When asked about her experience of trying to find a suitable program for her 16-year-old daughter Gail, Barbara responded that it took a lot of work because “you’re not just sending a child to the local university”. While there is also care work involved in assisting young people to move on to university, Barbara’s comment highlights the time-consuming and emotionally demanding work that she and the other families undertook to find suitable programs for their children. Characteristics of the programs that they sought included that they were safe, within reasonable travelling distance and matched the interests of their children. While the range of options varied significantly between metropolitan Melbourne and regional Tasmania, how people experienced these ‘choices’ was similar: the choices available that would be suitable for their child were extremely limited.

To make the most of what was available, the participants commenced their involvement in the transition process some years before their daughters were leaving school, consistent with a factor that Laragy (2004), in her review of Australian transition programs, identified as enhancing the likelihood of successful outcomes. Several of the participants expressed a desire to know as much as possible about the transition process, as soon as possible. However, despite their preparedness to be well-informed, there were problems in finding out about what it was they were working towards. Barbara, whose daughter Gail was in Year 11 and in the first year of the transition at the time of the interview, was bewildered by the lack of information. She expected that a lot more would happen during this first year of transition and she wanted to take advantage of the time available to consider their choices thoroughly. This expectation that something would happen merely heightened levels of uncertainty.

Part of the process of selecting a program was visiting the agency, meeting the staff and assessing the range of activities on offer. In Melbourne, after Annette had visited eight services that ran day programs, she cried. None of the places she had been to were suitable for Vanessa. However, not only was the ninth place suitable, they could also accept her daughter into the program. Also in Melbourne, Robyn visited seven places and “not one of them offered anything which was what I wanted Catherine to do after school”. In the end, she chose “the best of a bad lot”. Visiting these programs relied on them having the time and resources available to seek out these agencies and to inform their decisions. At times it was also highly frustrating as they dealt with working out the funding, case management issues and finding suitable carers (see also Institute of Disability Studies, 2002).

Women with disabilities are at increased risk for abuse and the interview participants were very concerned to ensure their daughters’ safety.

In both regional Tasmania and Melbourne, the process involved team approaches, typically including staff from the school, service providers, case managers, disability services and, depending on the young person’s disability, other specialist disability services such as those available for people who have vision impairment. The extent to which these staff were well-trained and well-informed—another of Laragy’s (2004) factors that enhanced the likelihood of successful outcomes—also varied, according to the participants. In Tasmania, the teams working with the participants and their daughters seemed generally to be well-known to them and accessible. In Melbourne, some relationships were not as well-developed. Otis (2004) found that poor communication and lack of clarity around roles of the various parties involved in the transition process contributed to the difficulties experienced by parents and improvements in these areas would be of great benefit.

For each of the families, safety for their daughters was a major consideration. Women with disabilities are at increased risk for abuse (Aylott, 1999; Curry, Hassounel-Phillips, & Johnston-Silverberg, 2001) and the interview participants were very concerned to ensure their daughters’ safety. This involved finding a program that was not only suitable to their daughters’ abilities and interests, but that it was also located in a safe environment with staff who they trusted. For Annette, and others, this meant the space in which her daughter spent her day had to be supervised, that it had to be a large open area where everyone was easily visible rather than smaller separate rooms less easily supervised. It also meant having staff who they trusted to undertake intimate activities such as toileting their children and competently performing specialist tasks such as gastrostomy feeding and managing seizures. In both localities, participants spoke of the importance of having qualified and appropriately trained and experienced carers with whom they and their daughters felt safe.
Families’ involvement in developing new programs

I turn now to discuss the care work that was undertaken by this group of mothers in developing new programs for their daughters. In addition to the ways previously described in which they participated in decision making about their children’s futures, several of the mothers initiated and developed new programs that were individualised to meet the needs of their daughters, and have since been of benefit to others in similar circumstances. They were concerned to challenge expectations that their daughters fit into existing services, rather than services being personalised to respond to their daughters’ individual needs.

In regional Tasmania, Sara and Kerry were not satisfied with the choices that confronted them and their daughters. Melanie and Christine were leaving school together and both had high support needs. The choices were to run a program from their home, which suited neither of the mothers nor their daughters, or to attend an existing program that catered for a large group of people with a wide range of disabilities and who were aged up to 70 years. Until then, this was all that was available, and in the past for other families with children with high support needs, this program had tended not to be suitable. By working with their supportive local disability services unit and a local service provider, a more specialised program was developed with a focus on younger people with high support needs, which in turn modified the service system. In their wake, other young people have come to the centre, for whom the program now available is much more appropriate than was previously offered.

Even though Kerry and Sara are pleased with what they have (compared to what had been available previously), it still does not offer what Melanie and Christine had at school, a point also made by Otis (2004) about other day programs. They are pleased that they both have access to transport to take the two young women to the centre but they are aware that not everyone attending similar services receives this support. Moreover, the centre where their program is run is poorly resourced and their children do not have access to the telecommunications technology and other equipment that they had at school. Nor do they routinely have access to regular therapy services that they had when they were at school.

Jane and her daughter, Carolyn, who live an hour from a regional centre in Tasmania, had long experience of travelling to access services. For much of her schooling, Carolyn had travelled two hours each day, two or three days each week to attend the specialist school, with the other days spent attending her local mainstream school. As the transition from school approached, Jane gave much thought to what would work best. One option was to travel two hours every day for Carolyn to attend a less than satisfactory program in the regional centre. The only other option was for Carolyn to have a home-based program but this was not satisfactory either.

In earlier years, Jane and her family had been told to move to a larger centre where the necessary disability support services existed. Instead, she stayed and kept asking for the services, some of which had developed over the period of Carolyn’s schooling. In relation to Carolyn’s transition from high school, Jane started asking early, three years before Carolyn left school. Jane recalled that she told the regional disability services staff that she “would expect and want assistance with Carolyn when she left school”. However, locally, “there was nothing to transition to”. She “kept chipping away” working with education and disability services staff so that by the time she left school Carolyn had a package of funding that paid for carers for an individual program run from a local community centre, including one day each week that she joins in a group program in the centre. Jane reported that “it’s not ideal, but it’s all we’ve got”.

In contrast to regional Tasmania, where a home-based program has to be an option due to the lack of alternatives, in Melbourne, when Judy decided to run...
Conclusion

The transition from school is an important milestone for young people and their families. For those families whose children have severe disabilities, this is a time of care work that includes identifying suitable programs and then re-establishing their child’s daily life patterns post-school. Although the processes of transition are likely to be the same for both male and female children, this study only involved the parents of girls and so there may be some different issues for boys that are making the transition from school. This study has illustrated the ways in which parents have undertaken care work through the process of their children’s transition from school by attempting to find out information, working with educational and disability services and other staff and participating in decision-making around their children’s futures.

More than this though, this study has illustrated the ways in which parents have not only engaged in the process of transition but they have also created programs that have attempted, within the limits of the available resources, to meet the individual needs of their children. While Melbourne had many more options than regional Tasmania, suitable choices for both were extremely limited and necessitated innovation. Mothers’ involvement in creating new programs or remodelling existing ones to better suit the needs of their children was a very important way that preferred outcomes were achieved. This is consistent with both the Victorian and Tasmanian policy frameworks which have as one of their goals the reorientation of services so that they are more responsive to both the needs of people with disabilities and their families and carers (Department of Human Services, 2002; Department of Premier and Cabinet, 2005). These changes not only were beneficial to those directly involved; they have also had an impact on the wider service system in their local areas, providing a model or a new program for others to attend. What happened in these situations lends support to Otis’s (2004) suggestion that there be greater input by parents into disability service delivery, especially when their children have the most severe disabilities and are least able to advocate on their own behalf. Promoting this innovation and acknowledging and supporting parents’ (and their children’s) expert knowledge is an important step in making the service system more responsive and flexible.

Unlike non-disabled young people who, over time, move to circumstances of increasing independence, for this group of young people with severe disabilities, while their circumstances do change at leaving school, the levels of dependence on their families are retained and remain a part of a much longer experience of care. Thus, the problematic nature of ‘transition’ itself is highlighted for this group of young people and their families as they move from childhood to adulthood. As these interviews revealed, the concept of ‘transition’ did not capture the families’ experiences of assisting their child at leaving school. Indeed, from the perspectives of the mothers, it was not a transition but a continuation – but one that still presented new challenges and obstacles. This finding has implications for the policy language used and the funding and resourcing of programs targeting families and their children who have the highest support needs.

References

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