Schooling Transitions Within the Lifespan of People With an Intellectual Disability: Perceptions and Recommendations of Ageing Mothers*

Iva Strnadová[1,2] and David Evans[2]

[1] *University of New South Wales, Australia*

[2] *The University of Sydney, Australia*

In this paper the authors examine the perceptions of mothers about the schooling transitions, including transitions to postschool options, made by their adult child with an intellectual disability (ID). Twenty mothers of an adult child with an ID living in New South Wales, Australia, and the Czech Republic, aged 48 years or older, were recruited to participate in this study. Mothers were interviewed following a semistructured protocol. The audiotaped interviews were transcribed verbatim, and analysed using a constant comparison analytic approach.

The experiences and issues faced by mothers at differing transitions of their adult child with an ID will be discussed, including issues of school selection, lifelong planning, and engaging with professionals. Common and unique themes within and between each country will be drawn, along with a comparison of findings from recent research reporting on transition experiences of mothers with young children with ID. The concluding discussion will focus on lessons learned about lifelong transition experiences, and pose future directions for enhancing the quality of transitions for persons with special needs and their families.

Keywords: transitions, special education, intellectual disability, parenting

Parents play a crucial role in supporting the education process of their children (Akos, 2002). They often work closely with school service providers to assist their child's transition into the early years of formal schooling where meeting key academic, social, physical and emotional goals can set the scene for later success in school. In secondary school, parents often stand back to let their child develop a wider and more sophisticated set of skills, knowledge and values (Akos & Galassi, 2004). It is also a time where postschool opportunities are formulated and pursued. In this context, parental input is usually expressed through interest and guidance.

The role of parents with a child with an ID at each of these stages and transitions is just as important; it is critical at all points during the schooling period and beyond (Dempsey, 2008). The proximity of parental input during schooling and beyond is often much closer and more intense than for parents of a typically developing child.

Correspondence: Iva Strnadová, School of Education, Faculty of Arts and Social Sciences, University of New South Wales, NSW 2052, Australia. E-mail: i.strnadova@unsw.edu.au

*This manuscript was accepted under the Editorship of Michael Arthur-Kelly.

doi: 10.1017/jse.2013.7

These families often report heightened levels of stress (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008; Strnadová & Evans, 2008b), especially at the time of the transition from school to postschool life (Morningstar, Kleinhammer-Tramill, & Lattin, 1999).

Over the decades, parents of a child with an ID have been challenged by variables beyond their control, with new ones continuing to emerge. Their child, for example, is living longer (Dew, Llewellyn, & Gorman, 2006; Docherty & Reid, 2009; Horwitz, Kerker, Owens, & Zigler, 2000), requiring parents to consider and be concerned about what provisions will be in place so their child is safe within their community once 'they are gone'. In living longer, the child with an ID today sometimes outlives their parents, and in some cases takes on the role of carer for their parents. How parents go about preparing their child, and themselves, for a lifespan that has changed over the last few decades, requires further investigation and has potential implications for long-term quality of life for the child with a disability (Lindstrom, Doren, & Miesch, 2011).

The importance of investigating transitions in schools can better inform formal schooling practices, and assist families and educators to plan for beyond-school options (e.g., employment, self-sufficiency, social independence). A key person facilitating transitions through schools is the child's mother (Docherty & Reid, 2009). Examining the experiences of mothers during key transition periods, and their long-term effect, is important in preparing young persons with ID to be active and independent participants in their community.

In this paper the authors examine the experiences of mothers aged 48 years and older caring for an adult child with an ID who made the transition from formal schooling to a postschool facility (e.g., employment, care) 10 or more years prior to the current study. In undertaking this retrospective research, research methods were implemented that allowed data to be collected from multiple sources, and for these data to be analysed to identify major themes, and conclusions to be formed.

Transitions in the Lives of People With ID

All children and young people experience a number of education transitions in their life. Transitions occur from preschool to primary school, primary to secondary school, and compulsory school education to postschool options. As stated by Barron, Violet, and Hassiotis (2009):

> *Transitions occur throughout life and are faced by all young people as they progress, from childhood through puberty and adolescence to adulthood; from immaturity to maturity and from dependence to independence. In addition, some young people experience extra transitions as a result of other life events for example, bereavement, separation of parents, and being placed in care. (p. 1)*

At each of these transition points, cooperation between the family and school optimises the process. This cooperation is important so that the individual needs of students are heard and considered and the actions taken to assist a child meet their needs, are well thought out and family goals considered. It is also important for schools to espouse their goals and aims for educating students.

Transition periods within the lifespan of people with ID and their families bring specific challenges. There are not only status transitions (e.g., leaving/moving school, living independently, getting married, getting a job), but also transitions connected with family life (e.g., moving away from home, parents separating) and bureaucratic transitions (e.g., moving from child services to adult ones; Barron et al., 2009).

Each transition period means establishing new parent–professional relationships that modify the mesosystem (Gargiulo & Kilgo, 2005) and bring new challenges for all parties. Parents become involved with new agencies (e.g., early childhood agencies, school sectors, community services) and have to deal with new regulations, policies and rules (e.g., implementation of the Disability Discrimination Act, Disability Standards for Education in Australia). Moreover, many families have to make a considerable family adjustment, which greatly contributes to anxiety in these families. In a study by Davies and Beamish (2009), almost half of parents reported that considerable family adjustment was required during the transition of their child from school to postschool life. As parents react in different ways, this brings additional challenges for professionals who need to develop ways of coping with the uncertainties and anxiety of parents. A powerful approach includes empowering an active role for parents (and child with a disability) in the decision-making process during the different transition stages (Gargiulo & Kilgo, 2005).

Transitions are periods of stress for families of a child with an ID. Transition into adulthood has been identified as one of the most challenging and stressful periods for families (Heller, 1993; Powers et al., 2007). Sources for this stress include lack of limited postschool services for people with ID, the quality of services available throughout the life of a person with a disability, and the level of cooperation with and between services (Jokinen & Brown, 2005; Strnadová & Evans, 2008a). Parents also raised issues around appropriate social behaviour, sexuality or guardianship, and the vulnerability of their children (Blacher, 2001).

There is no indication in the overall research on transitions if these experiences differ across cultural borders. Much of the literature is drawn from research in the United States of America. A search of the literature, for example, did not locate substantial research evidence about experiences of mothers in European countries. The collaborative research project reported in this paper will examine and compare transition through the eyes of mothers in two countries: Australia (Sydney, New South Wales) and the Czech Republic (Prague).

The Czech Republic, a postcommunist country, has an emerging, inclusive education culture for students with disability. The primary aim of educational services is to enable the inclusion of all children with special educational needs in an educational experience. Students with ID are included by receiving their education program in a mainstream classroom, or in a special class within the mainstream school. Another option is the attendance of the child at a special school for children with ID. It is hoped that the National Action Plan for Inclusive Education adopted by the Czech government in 2010 will lead to more opportunities for students with ID to be educated in mainstream schools (Strnadová & Hájková, 2012).

In New South Wales the development of education services for students with disability over the past four decades has followed the trends evident in many developed countries. In the 1960s, many students with ID were provided an education in segregated school settings, or classes. Parents and disability advocates attempted to gain access to regular or mainstream schools for children with ID, but were often required to access education programs in segregated settings. In 2009, all students with ID were eligible to receive an education program, in a place or setting of their choice or that of their parents or guardian. Changes in the provision of education services over the past four decades therefore needed to consider where students were transitioning to, and identify what the issues, concerns and successes of previous graduates were.

The aim of this study, therefore, was to investigate the experiences of mothers in raising a child, now an adult, with ID. In this study we planned to identify initial variables from this enquiry, and draw some tentative recommendations for future research. The implications for educators will be highlighted through comparing issues raised by mothers about the transition process, and how they related to transition from school to postschool options today. Finally, the stories of mothers from Australia and the Czech Republic were contrasted to highlight cultural differences.

Method

In examining the experiences of mothers of persons with an ID in this study, a specific theoretical model of issues was not proposed. Due to limited research on the reported experiences of mothers in a cross-cultural context, this study aimed to draw key variables and themes from histories reported by mothers. Using these histories or stories, conclusions were drawn about past experiences, and these stories linked with current practices, policies and research developments. A qualitative research methodology was therefore used to assist in achieving this aim. Qualitative research allows for 'a systematic approach to understanding qualities, or the essential nature, of a phenomenon within a particular context' (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005, p. 195). This methodology allowed for the researchers to develop an initial model of transition from school to postschool options based on the stories of mothers who raised a child with ID.

In undertaking this research, the researchers aimed to elicit and understand the issues, concepts and variables that played an important part of raising a child with ID. In this particular study, the voice of the adult with ID is not reported, but the voice of the person most likely to have had an immediate influence in the growth and development of these adults was considered — the mother.

Research Design

A life history approach was used in this study. A life history approach, one of a number of recognised types of qualitative research, permits 'extensive interviews with individuals to collect first person narratives about [the] lives' (Brantlinger et al., 2005, p. 197) of mothers who have raised and lived with a child with a disability. A life history approach allowed the researchers to listen to mothers talk about a diverse and wide range of transition periods in the life of their adult child. The interview process allowed for '... a snapshot of an evolving story ...' (Wells, 2011, p. 45) about different life stages and transitions of the child with ID and their whole family.

The research design adhered to a number of quality criteria outlined by Brantlinger et al. (2005) for conducting qualitative research in special education. The interview questions used as part of a semistructured protocol were '... clearly worded, not leading, appropriate and sufficient for exploring domains of interest' (p. 202). This was achieved through critically examining questions (as shown in the Appendix) used in previous research (see Strnadová & Evans, 2008a, 2008b, 2012). Based on the outcomes of this review, the questions were refined through rewording to address perceived ambiguities in phrasing; questions were added to permit the exploration of specific areas (e.g., transitions at specific areas of schooling).

Twenty participants were recruited to the study. Participant interviews were audiotaped and transcribed verbatim. Participants' views and ideas were reported sensitively, and their views expressed were treated confidentially. All interviews were coded, and potential identifying events and tags removed to ensure anonymity (Brantlinger et al., 2005).

TABLE 1
Description of Participants by Country

	Australia	Czech Republic	Total
No. of participants	10	10	20
Mean age in years (range)	63.6 (48–80)	59.8 (50–77)	61.7 (48–80)
Marital status			
Married	6	7	13
Widowed	3	2	5
Divorced	1	1	2
Education attainment			
University	3	4	7
Completed high school	6	5	11
Completed Year 9	1	1	2

Participants

Mothers were recruited from nongovernmental organisations (NGOs), counselling centres, schools, employment providers, residences for people with ID, and advocacy groups. These groups or agencies identified potential participants — mothers of a child with an ID who were at least 48 years old — and helped the researchers distribute participant information statements to the mothers. The participant information statements, a requirement of the ethics approval gained prior to commencing the study, outlined the purpose of the study, the procedures involved, the time required, and participants' right to withdraw at any time. Mothers who volunteered to participate (i.e., returned a signed consent form) were contacted by the agencies to mediate meeting times with the researchers, or to gain approval for the researchers to contact them directly by telephone to arrange an interview time.

A description of the participants recruited to the study, obtained as part of the initial part of the interview, is shown in Table 1. Across each of the areas of age, marital status and highest education attainment, there is very little difference between the two groups of women from Australia and the Czech Republic.

All adult children had a diagnosis of an ID based on criteria set by the World Health Organization. The mean age of the 21 adult children was 35.76 years (range: 19–56 years). One mother had two adult children with an ID. Eleven mothers had more than two children, with the remaining mothers having two children, or just one child (i.e., a child with an ID).

Procedure

Following the recruitment of mothers to the study, interviews were conducted. Interviews took place in a location convenient for individual mothers, typically at their home, and in the respective language of the participant. Each interview session commenced with the researcher reviewing ethics requirements for the study, including permission to audiotape the interview. At this point the interview was assigned a code to ensure anonymity of participants. Interviews with Czech mothers included the prefix of 'M', and 'Mo' was used for Australian mothers. The duration of interviews ranged from 10 minutes and 49 seconds to 84 minutes and 20 seconds. The average duration of interviews was 44 minutes and 37 seconds.

The first author conducted all the interviews to assist in maintaining consistency in the interview process. This engagement with a number of mothers from differing backgrounds assisted in enhancing the credibility of findings (Krefting, 1991; Lincoln & Guba, 1985). The second author transcribed verbatim the interviews from Australia, and the interviews were analysed in English. A research assistant transcribed the Czech interviews in Czech, which were then analysed by the first author, who then translated the findings into English. Keeping the transcripts in the native language for analysis prevented any loss of meaning through the translation process, and enhanced the trustworthiness of the findings (Chen & Boore, 2010).

Following transcription of audiotapes, data were ‘sorted and coded in a systematic and meaningful way’ (Brantlinger et al., 2005, p. 202), and analysed using a constant comparative analytic approach (Bryman, 2004). Using the constant comparative method allowed the researchers to generate categories and codes to interpret the themes identified in the interview data. Interviews were scrutinised to establish the presence of differing themes (Yin, 2011). This scrutiny of interviews was maintained until the researchers established trustworthiness in the themes.

Two researchers were involved in data analysis for each language to enhance the credibility of the research process (Brantlinger et al., 2005). The first author, in conjunction with a university colleague from the Czech Republic, undertook the analysis of interviews with Czech mothers. The university colleague is a leading professional in the field of ID in the Czech Republic and holder of the Kennedy Award for her lifelong work and contribution to the field. Both authors undertook the data analysis of the interviews with the Australian mothers. The first author, fluent in both Czech and English, ensured that reliability of data coding across all interviews was maintained, and enhanced, to some extent, the dependability of the findings (Lincoln & Guba, 1985).

The systematic analysis of the data was undertaken in two phases. In the initial phase, one interview from each country was selected to establish emerging categories. The two researchers read the interviews independently, and then came together to discuss the emergence of possible categories. This process of comparing and contrasting findings allowed for a series of codes (i.e., actions or chunks of data that best encapsulated the transition process) to be established, to be refined through continuous contrasting with interview transcripts, and for a final set of codes to be finalised (Charmaz, 2008; Yin, 2011).

‘Investigator triangulation’ (Brantlinger et al., 2005, p. 201) was implemented through purposeful implementation of data analysis processes by the authors to maximise the trustworthiness (e.g., credibility) of conclusions drawn. Other approaches to maximising credibility of measures and data analysis were undertaken through external auditors (i.e., discussion of findings with mothers and experts in the field but not associated with the study) and peer debriefing (i.e., presentation of findings to peers and outside persons with interests in the area; Brantlinger et al., 2005).

The authors identified four major themes through a process of constant comparing and contrasting the initial codes. These were (1) experiences with different services for persons with ID, (2) planning for the future, (3) finding a place in the community, and (4) mothers’ coping strategies. Connections between the themes were developed by discussing the findings with some of the participating mothers, as well as with experts in the field. By using techniques of data triangulation, peer debriefing and member checking, the trustworthiness and credibility of the research was maximised (Brantlinger et al., 2005; Erlandson, Harris, Skipper, & Allen, 1993). Both authors then reanalysed data to enhance the reliability of the findings and conclusions obtained. As the focus of this paper was on different school transitions experienced by mothers of adult children with ID, the following discussion will centre on these experiences.

Results

Transitions in the lives of people with ID are viewed by their mothers as a continuum rather than as a certain point in the development of their son or daughter. Throughout the study, mothers referred to ongoing issues, fears, challenges, and positive and negative experiences connected with different aspects and periods of transition. Different transition periods described by mothers were connected with natural life events such as starting school or looking for a job. These transitions were often accompanied with a level of stress, brought on by a number of factors beyond their control. One of the core factors was the number of times policymakers and bureaucrats in both countries changed the provision of services and supports for children and people with disability. This frustration with an unpredictable feature of their lives is well represented by one of the Australian mothers:

> *. . . one the hardest things to deal with is the lack of consistency. The policy changes. The fact that you think you've got something, and then . . . as soon as it sort of settles something comes along. . . . you can't ever relax, you can't ever relax. I mean I am 63 and I still never had a chance since he has been born to actually think that what I've got is actually what I've got and I can be settled that's going to stay. Oh! Every change of government there is a change of systems. It's absolutely nuts. You just can't bank on anything. (Mo5)*

There were many overarching issues like these to raising and caring for a child with a disability; however, this paper focuses only on schooling transitions. Within the first theme ('Experiences with different services for persons with ID'), two major subthemes emerged from the interviews with mothers: (a) schooling transitions, including transitions to postschooling options; and (b) experiences with schools and their role in preparing their child for postschooling transitions. These themes will be discussed in detail with regard to the stories recorded from the 20 mothers in Australia and the Czech Republic.

School Transitions

All adult children in the study completed their schooling in a segregated special education setting; three commenced their schooling in a mainstream education setting and later transitioned to a segregated setting. In all cases, however, mothers reported unanimously that the transition to school provided a time of high stress and anxiety for them and their families.

The *role of schools* at these early times was important. Schools worked with some of the mothers and their families to allay some of their concerns. In one example, a Czech mother highlighted how the director of the special school worked with her to address fears and misinformation about special school programs. In other cases across both countries mothers were encouraged to visit the school and spend time observing the programs offered. An Australian mother described how the school principal helped her to learn to 'let things go':

> *She went to a school called [XY], and the deputy principal's name was [SA]. And she made me let go, which was really good. Because I had never let her out of my sight. Convinced me to let her go on camps, she came back absolutely filthy and so was everything else, but . . . I had to let go. (Mo2C1)*

Mothers of the three students in mainstream settings (e.g., a special education unit in a regular kindergarten) reported that they felt ongoing pressure from school sector personnel to move their child to a specialist, segregated school. The final decision to move their child was due to discontent with the program being offered in the (mainstream) school, usually because schools were unable (or unwilling) to provide appropriate and individualised programs. Other mothers reported a desire to have their child educated in a mainstream setting, but found the choice of programs restrictive, which resulted in them accepting a special education placement in a segregated, specialist school. In one instance, the family moved to another part of the country to try and access a program in a mainstream setting that was more willing to work with the family to design and implement educational programs suited to the needs of their child with a disability.

Another source of stress for many mothers was the *prejudice and stigma* found in the differing societies toward special schools. Mothers expressed concern, on the one hand, about the restricted options that receiving an education in a special school setting would have on their child; on the other hand, they were often torn by the advice and services provided by education sectors as being in the best interest of their child. It was often the inner strength and conviction of mothers that enabled them to pursue a path of high expectations and long-term interests for their child. As expressed by one mother:

> *They [education provider] said she needed [emphasis added] to go to a special school. . . . So she was there . . . she started there when she was seven, and she left there when she was thirteen or fourteen. And we were able to get her out, and get her to a high school . . . into a special class at high school. That was so much better for her. Because she was really wanting to learn and she . . . she didn't want to say she was going to special school to people. And in retrospect it was the best thing we ever did for her because she can now say to people, 'I went to XY High School'. . . . it's not, 'I went to XY Special School'. And it's got her into TAFE courses that she wouldn't have been able to get into, if she had of been presenting from a special school. So, it was terrific. I mean . . . it was hard going, but it was worth it. (Mo23)*

In others cases, gaining *access to an appropriate education program* was a major issue; it is only in recent times, in both countries, that it has become the right for families to choose where they wish their child with a disability to receive their education without being fearful of discrimination. Yet the attitude of mothers at the time of accessing a suitable education program was an influencing factor. Some mothers from both countries were keen advocates of mainstream education opportunities for children with ID; others were worried about the vulnerability of their child.

Based on the interview data collected, it was found that children with a higher level of need resulted in mothers expressing a higher level of concern. One of the concerns expressed by mothers was the possibility of their child being taken advantage of by other members of society. In the words of one mother:

> *X actually has been sexually assaulted, so . . . that will never, ever happen again in that case. . . . Awful. . . . Well there is always the vulnerability of being taken advantage of, but . . . I hope that won't be. (Mo1)*

Mothers reported that the *educational environment* in which their child received their program was an important factor in meeting their child's educational and social needs. The smallest change in an environment could be enough to change the educational dynamics. One mother, for example, reflected on how the graduation of a friend from preschool changed the dynamic for her child:

> *I had a friend, whose little girl was much the same age as my daughter. . . . So, both girls were very close . . . they started together at the preschool. And my daughter settled in well there because her friend was there . . . And her friend helped, you know, her with heaps of stuff. So it wasn't so noticeable. But then when she was five and her friend left to go to ordinary school, I decide to keep my daughter there because the preschool went up to eight year olds. . . . but after*

> *her friend left there wasn't anyone to replace her, and there was no one really who played with her that much. So I used to go up every day and stay for a couple of hours and do some work with her communicating with me. (Mo23)*

In this instance, the success of the education program was dependent on the skills and attitudes of those closest to the child. Initially, the attitudes of a friend enabled the child with an ID to engage with her environment; the graduation of this friend found the child with an ID isolated, with no one to support her continued placement in this setting.

Some mothers highlighted the need to focus on learned knowledge practicalities rather than on its theoretical aspects:

> *He has great knowledge, but it is of no value for him in practical life. He knows the number of inhabitants in our country, he knows where different rivers end, he knows schedule of traffic by heart. He knows he should cross the street when green is on, but when he reaches crossing, he does not dare to look what colour is on. . . . This cause great difficulty at review commission where he answers all their questions, but nobody dares to ask if one roll costs one crown, how much he will pay if he wants 3 rolls. He knows that 3 × 1 is 3, that 10 × 5 is 50, but he is not able to do his shopping. (M86)*

The development of social skills was identified as important for young students with disability. As this mother indicates, it is also important to develop these skills at all stages of learning. As will be highlighted in the discussion of the second major theme, it is essential for students as they move from high school to postschool options.

Schools and Postschool Options

Accessing postschooling options was a source of criticism by mothers. Mothers, for example, reported a chronic shortage of opportunities for their child to gain *appropriate employment*. In some cases, mothers raised the point that their child often had no say or choice on the employment option they were given; other mothers reported their child being given the chance to follow their interests, but ran up against other barriers:

> *. . . she got into a different training program. And, cause . . . my other daughter did childcare, she seemed to be interested in it. She'd . . . had been into a friend's childcare centre a couple of times. And done some work there. And, so we thought . . . oh, maybe . . . childcare maybe something she could get into, . . . (Mo23)*
>
> *And this program . . . training program said they would come in and train her on the job. And she had to become 85% efficient. Which is higher than people without disabilities have to be . . . to do their job properly. Anyhow she was going terribly well, and we got glowing report after a few months, and then . . . the woman who was in charge changed and another person came . . . because the idea was that once my daughter got to a certain stage, she would then start getting ordinary pay. This other woman came in and said oh no, why doesn't she get the disability pension. And then they wouldn't have to pay her. (Mo23)*

In this case the daughter was lucky to have a highly motivated and proactive family. Her parents purchased a preschool and employed their daughter to work in the centre with ongoing employment support. A specific issue raised here, however, is to what extent was the young adult with ID given the opportunity to make decisions during the transition to employment and postschool options. This issue still appears to exist today, despite legislation, with only small gains made in terms of practice to ensure it occurs (Powers et al., 2007).

Entry into employment from school presented further challenges, and was a significant source of stress for mothers. Mothers reported that their child needed to have not only the skills and knowledge to undertake the work allocated, but the social skills and initiative to survive socially. One mother, for example, raised the issue of bullying in the workplace, and the need for her daughter to be skilled to manage this situation appropriately:

> *. . . there was one girl who really, who wanted to boss about. She was a young lass. She thought she could tell my daughter what to do, but the trouble was there was someone else whose role it was to tell her what to do. And the two things were conflicting, two people. And my daughter kept being told to do something by one person, then this young girl would tell her to do something else. So my daughter said to her one day, 'you know, . . . I can't do you what you tell me because Y tells me what I have to do'. (Mo23)*

Another important topic was the *role of schools* in preparing children with ID for future transitions (e.g., developing social skills necessary for maintaining friendships, skills for employment, self-help skills). Although the perceptions provided by the mothers in this study from 30 years ago are still relevant today, the mothers' perceptions and experiences stress the need for education programs to consider the long-term needs of their students from the commencement of an education program. Further, a need for the person with a disability to be involved in the process of determining their future provides another link with practices in the new century (Powers et al., 2007; Wehmeyer, Palmer, Soukup, Garner, & Lawrence, 2007).

Mothers frequently mentioned the *social isolation* experienced by their child in adulthood, and the impact of not developing friendship skills during their schooling years. Czech mothers were pessimistic about the friendships between their child and people without any special educational needs. As one of the mothers stated, the impact of having friends with the same disability was beneficial to her daughter developing positive self-esteem:

> *. . . after leaving the mainstream school for a special school, she literally flourished before my eyes. She suddenly was good, had the knowledge, and was even a bit better than other children. (M87)*

Australian mothers referred to these friendships as possible within schooling experiences, however, these friendships dissipated as friends developed other interests or married and had families.

> *. . . they're all very much into their own way of life. They've moved from being the single person to being married. So, she really needs to have her life opened up more as far as friendships are concerned. (Mo23)*

As a result, mothers and family members maintained a direct engagement with the child with an ID. This contact, in many cases, has been life long, providing few breaks for parents, in particular, from the duties of raising a child to independence in adulthood. A small number of mothers referred to behavioural, emotional and cognitive changes within their child with ID (e.g., during puberty, post 30 years of age) across the lifespan. They also commented that they had little access to respite services to escape sometimes violent and challenging behaviours of their child with ID. Both Czech and Australian mothers highlighted the need for respite services:

> *. . . He never slept more than three hours at any time ever, day or night . . . his behaviour was just completely and utterly off the wall. I mean he just literally wrecked the house. If it wasn't nailed down it didn't survive. (Mo5)*

Behavioural changes influenced the transition process, especially in terms of postschool options. Challenging social behaviours adversely influenced the 'employability' of the young adult with an ID. The support and readiness of an employer to take on a person with an ID has the potential to provide the person with optimum opportunities to develop social skills, and links and friends outside of the immediate family. If social behaviour is perceived or seen to be appropriate in the employment setting, it makes the transitions easier and smoother, as these mothers reported:

> *There was at first, getting him into routine of the work, what to do. (. . .) He's been there five years, and they still go in twice a year just to check. They check with the boss, and people he works with. . . . a few times he wasn't doing the kitchen properly. But that is to do more with his obsession with cleaning, not with cleaning but with his hands. A few times . . . you know, he wasn't keeping work place tidy. (. . .) And his boss will ring me if there are any problems, or for a while there he seemed very dark, very depressed. And they rang me and said, look, what's happening with your son at the moment. (Mo19)*

> *She used to be a little bit aggressive. Maybe sometimes a bit too much. A think a lot of it arose from frustration. (. . .) much more earlier on where she was anti-social here at work. She can't handle being stirred. And she goes off and starts screaming and hitting people back. (Mo2C1)*

The need for developing *social and personal skills* for use beyond school was identified by mothers as a high priority. Social skills were important for accessing employment, as well as to engage in regular social activities. Mothers reported they needed to be continually promoting social skills with their child with ID, as well as for their adult child through to 30 years of age and beyond (e.g., becoming dependent on rituals, routines, known places and people). One mother stated:

> *He needs his stable rituals in his life. He is 35 years old and I have been witnessing for last 2–3 years the change. If you tell him we will have a trip tomorrow, he will not sleep the whole night. If we tell him in the morning, he has a headache, sometimes he even vomits, so he cannot enjoy the trip. . . . He reacts badly to any change. (M86)*

A final point from mothers was about the academic curriculum their child accessed during school. They made it quite clear that although an academic curriculum was important, they emphasised the need for their child to acquire social skills within this curriculum that would be important from a long-term perspective. In this context, a number of mothers not only emphasised the importance of the development of friendships in a school setting, but were critical of the integration of these skills in the curriculum.

Discussion

The results reported in this paper are part of a larger and more extensive research project, and are aimed only at examining the experiences of mothers in observing their child with an ID transition through differing stages of school and beyond. The mothers who participated in this study expressed concerns about the development of friendship skills that they perceived as crucial for the life transitions of their children with ID, be it the transition of leaving school for employment, further education or acquiring independent living skills. This was a neglected area in curricula from the perceptions of mothers in this study. Priestley (2003, as cited in Burgen & Bigby, 2007) comments on this by stating that despite the awareness of the importance of developing friendships for people with ID, transition plans often neglected the development of these social and emotional needs.

Transition is rarely a sudden event (Bigby, 2000); on the contrary, it is a gradual and ongoing process that holds implications in itself. The necessity to help the child with ID build social skills throughout their schooling career was essential, according to the sample of mothers in this study. The development of these skills can assist in the prevention of social isolation, and maximising the opportunities for employment and financial independence (Lindstrom et al., 2011). The ideal would be the conscious effort of educators to build these skills naturally into the curricula from a preschool age. To maximise success in building these skills for use during school and into postschool life, then cooperation among teachers, the student and family is of crucial importance (Dempsey, 2008).

The inevitability for students and their parents to plan the development of skills required by students once leaving school has been highlighted in the literature (Lindstrom et al., 2011; Morningstar et al., 1999); nevertheless, it seems the practice still needs clearer guidelines. It can be argued that mothers interviewed for the purpose of this study were presenting their experiences from a bygone era; however, there are still calls for education providers to enhance current transition practices (Lindstrom et al., 2011; Wehmeyer et al., 2007) nearly 30 years after these thoughts were reported by these mothers. This longitudinal picture of the life of people with ID and the impact of limited preparedness for the transition to postschool life is a lesson from which we can continue to learn.

Mothers referred to behavioural issues as a complicating factor of successful transition, as well as to the difficulties of ongoing care. Mothers called for greater access to respite services throughout the lifespan of their children. The lack of respite care services has been reflected on by the World Health Organization (2007), where respite services were found to be available in 29.9% of participating countries and most common in developed countries.

Conclusions

The results of this study manifest common themes between the two countries of the participants (i.e., Australia and the Czech Republic), despite different political and historical backgrounds. Policies and procedures may still differ in these countries; however, the findings were to a large degree similar. Mothers from both countries highlighted the necessity of schooling providers to focus more on the development of social skills in people with ID. The question of establishing and maintaining friendships with other children without disability was nonetheless viewed differently by Czech mothers compared with their Australian counterparts. Whereas the Czech mothers were rather sceptical about these friendships, underlining the fact that these do not contribute to enhancing their children's self-esteem, the Australian mothers were aware of the limited duration of these friendships through shifting life directions.

The results from this explorative research project provide insights into the perceptions of mothers about the transitions of their now adult child with an ID. The study attempted to uphold the principles of quality qualitative research as outlined by Brantlinger et al. (2005) throughout the research process. The researchers were aware that elements of this project, however, challenged the trustworthiness of the study conclusions. The study, for example, used a small number of mothers. The study also used an independent researcher to provide checks on data analysis for the interviews from Czech mothers, but this same level of independence was not used for the interviews with Australian mothers. Further, due to cost, translation of the interview findings from Czech to English was not back-translated to ensure meaning had been maintained (Chen & Boore, 2010).

Although it is not possible to draw general conclusions due to the small sample in this study, the implication for education providers is the call of mothers for education programs to be adjusted and 'made to measure' in terms of the future of their children with ID. Planning transition to life beyond school is something that needs to start before school. The work can be enhanced through carefully planned, quality education programs that allow access to an appropriate individualised curriculum. These plans can then assist persons with a disability to be contributing, active and independent participants in our communities.

Acknowledgements

The authors express their sincere gratitude to the participating mothers. By sharing their experiences of schooling transitions in the lives of their child with ID, they provided important insights that can be helpful both for the schools and other parents in similar life situations. We would also like to express our thanks to the principals of schools and directors of community agencies who supported us in recruiting the families.

The research was conducted under the following ethics approvals: *Analysis of stress factors within families of children with disabilities living with one parent*. This study was approved by the Grant Agency of the Czech Republic, approval No.: GA ČR 406/06/0779; *Well-being of women with intellectual disabilities: Voices of women and their families*, University of Sydney Human Ethics Protocol No.: 04-2008/10575.

References

Akos, P. (2002). Student perceptions of the transition from elementary to middle school. *Professional School Counseling*, *5*, 339–345.

Akos, P., & Galassi, J. (2004). Middle and high school transitions as viewed by students, parents, and teachers. *Professional School Counseling*, *7*, 212–221.

Barron, D., Violet, J., & Hassiotis, A. (2009). *Transition for children with intellectual disabilities*. Retrieved from http://www.intellectualdisability.info/life-stages/transition-for-children-with-intellectual-disabilities/?searchterm=Transition%20for%20children%20with%20intellectual%20disabilities

Bigby, C. (2000). Models of parental planning. In M.P. Janicki & E.F. Ansello (Eds.), *Community supports for aging adults with lifelong disabilities*. Baltimore, MD: Brookes.

Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. *American Journal on Mental Retardation*, *106*, 173–188.

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children*, *71*, 195–207.

Bryman, A. (2004). *Social research methods* (2nd ed.). Oxford, UK: Oxford University Press.

Burgen, B., & Bigby, C. (2007). The importance of friendships for young people with intellectual disabilities. In C. Bigby, C. Fyffe, & E. Ozanne (Eds.), *Planning and support for people with intellectual disabilities: Issues for case managers and other professionals* (pp. 208–214). Sydney, Australia: UNSW Press.

Chen, H.-Y., & Boore, J.R.P. (2010). Translation and back-translation in qualitative nursing research: Methodological review. *Journal of Clinical Nursing*, *19*, 234–239. doi:10.1111/j.1365-2702.2009.02896.x

Charmaz, K. (2008). Grounded theory in the 21st century: Applications for advancing social justice studies. In N.K. Denzin & Y.S. Lincoln (Eds.), *Strategies of qualitative inquiry* (3rd ed., pp. 203–242). Thousand Oaks, CA: Sage.

Davies, M.D., & Beamish, W. (2009). Transitions from school for young adults with intellectual disability: Parental perspectives on “life as an adjustment”. *Journal of Intellectual & Developmental Disability*, *34*, 248–257. doi:10.1080/13668250903103676

Dempsey, I. (2008). Transition to adult learning. In P. Foreman (Ed.), *Inclusion in action* (2nd ed., pp. 37–62). South Melbourne, Australia: Thomson Nelson.

Dew, A., Llewellyn, G., & Gorman, J. (2006). “Having the time of my life”: An exploratory study of women with intellectual disability growing older. *Healthy Care for Women International*, *27*, 908–929. doi:10.1080/07399330600880541

Disability Discrimination Act 1992. Retrieved from http://www.ddaedustandards.info

Disability Standards for Education 2005. Retrieved from http://deewr.gov.au/disability-standards-education

Docherty, J., & Reid, K. (2009). ‘What’s the next stage?’ Mother of young adults with Down syndrome explore the path to independence: A qualitative investigation. *Journal of Applied Research in Intellectual Disabilities*, *22*, 458–467. doi:10.1111/j.1468-3148.2009.00492.x

Erlandson, D.A., Harris, E.L., Skipper, B.L., & Allen, S.D. (1993). *Doing naturalistic inquiry: A guide to methods.* Newbury Park, CA: Sage.

Gargiulo, R., & Kilgo, J.L. (2005). *Young children with special needs* (2nd ed.). Clifton Park, NY: Thomson Delmar.

Heller, T. (1993). Self-efficiency coping, active involvement, and caregiver well-being throughout the life course among families of persons with mental retardation. In A.P. Turnbull, J.M. Patterson, S.K. Behr, D.L. Murphy, J.G. Marquis, & M.J. Blue-Banning (Eds.), *Cognitive coping, families, and disability* (pp. 195–206). Baltimore, MD: Brooks.

Horwitz, S.M., Kerker, B.D., Owens, P.L., & Zigler, E. (2000). *The health status and needs of individuals with mental retardation.* Washington, DC: Special Olympics.

Jokinen, N.S., & Brown, R.I. (2005). Family quality of life from the perceptive of older parents. *Journal of Intellectual Disability Research*, *49*, 789–793. doi:10.1111/j.1365-2788.2005.00753.x

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy*, *45*, 214–222. doi:10.5014/ajot.45.3.214

Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry.* Newbury Park, CA: Sage.

Lindstrom, L., Doren, B., & Miesch, J. (2011). Waging a living: Career development and long-term employment outcomes for young adults with disabilities. *Exceptional Children*, *77*, 423–434.

Morningstar, M.E., Kleinhammer-Tramill, P.J., & Lattin, D.L. (1999). Using successful models of student-centered transition planning and services for adolescents with disabilities. *Focus on Exceptional Children*, *31*(9), 1–19.

Mulroy, S., Robertson, L., Aiberti, K., Leonard, H., & Bower, C. (2008). The impact of having a sibling with an intellectual disability: Parental perspectives in two disorders. *Journal of Intellectual Disability Research*, *52*, 216–229. doi:10.1111/j.1365-2788.2007.01005.x

Powers, L.E., Garner, T., Valnes, B., Squire, P., Turner, A., Couture, T., & Dertinger, R. (2007). Building a successful adult life: Findings from youth-directed research. *Exceptionality*, *15*, 45–56.

Strnadová, I., & Evans, D. (2008a). Examining the range of coping strategies mothers use in caring for a child with an intellectual disability. In D. Botrell & G. Magher (Eds.), *Researching communities.* Sydney, Australia: University of Sydney Press.

Strnadová, I., & Evans, D. (2008b, August). *Impact of ID on mothers of school-aged children: Different perceptions in New South Wales and the Czech Republic.* Paper presented at the International Association for the Scientific Study of Intellectual and Developmental Disabilities, Cape Town, South Africa.

Strnadová, I., & Evans, D. (2012). Subjective quality of life of women with intellectual disabilities: The role of perceived control over own life in self-determined behaviour. *Journal of Applied Research in Intellectual Disabilities*, *25*, 71–79. doi:10.1111/j.1468-3148.2011.00646.x

Strnadová, I., & Hájková, V. (2012). Striving for inclusive education in the Czech Republic. *Intervention in School and Clinic*, *47*, 307–311. doi:10.1177/1053451211430114

Wehmeyer, M.L., Palmer, S.B., Soukup, J.H., Garner, N.W., & Lawrence, M. (2007). Self-determination and student transition planning knowledge and skills: Predicting involvement. *Exceptionality*, *15*, 31–44.

Wells, K. (2011). *Narrative inquiry.* New York, NY: Oxford University Press. doi:10.1093/acprof:oso/9780195385793.001.0001

World Health Organization. (2007). *Atlas: Global resources for persons with intellectual disabilities: 2007.* Geneva, Switzerland: WHO Press.

Yin, R.K. (2011). *Qualitative research from start to finish.* New York, NY: Guilford Press.

APPENDIX

Interview Questions

1. What period(s) of your life do you consider the happiest? Why?
2. What period(s) of your life was the hardest and why?

3. How did you feel during pregnancy?
4. Did you have any complications while giving birth?
5. When did the first difficulties appear?
6. When were you told the diagnosis of your child? What is the exact diagnosis?
7. How were the first years of your child's life? What was the most challenging?
8. How did your husband act during this time? In what way was your husband supportive?
9. What significance did the birth of your child have on you and your life?
10. What did you learn about your life during this period? What experiences did you gain?
11. In what way did this experience change you, your character, opinions and attitude?
12. What do you appreciate the most about your child?
13. What do feel is the most challenging about your child?
14. What would you consider as the biggest support and help for mothers of a child with ID?
15. What are your three biggest wishes?
16. What are you now looking forward to the most?
17. What are you afraid of the most?
18. How do you relax/gain energy?
19. Would you change anything about your life based on your experiences?
20. What message would you send to mothers in a similar position?