

Transitions from School for Young Adults with Disability: Parental Perspectives on
“life as an adjustment”

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Acknowledgement

This study was part of a larger project *Quality Outcomes for Students with a Disability: School to Post-School Transition* funded by Queensland Department of Education and the Arts. The project was directed by Dr. Denis Meadows, with team members Mr Ian Alcorn, Dr. Wendi Beamish, Dr. Michael Davies, Dr. Gordon Elias, Dr. Peter Grimbeek, and Dr Renée Punch. The conduct of this research was a team effort.

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Transitions from School for Young Adults with Intellectual Disability: Parental Perspectives on “life as an adjustment”

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Background: Few studies have investigated transition programs and outcomes for young adults with disability as viewed from the parent perspective. The current Australian study provided a voice for parents to report on the experiences and outcomes for young adults following their recent transition from school into post-school life.

Method: A mailed survey gathered statewide data from parents ($N = 218$) whose family member had completed schooling at secondary or special school. The majority of those participating were parents of young adults with intellectual disability and high support needs.

Results: Findings detail school preparation for employment, community activities, and daily living; parent and student involvement in transition goal-setting; and post-school outcomes for young adults and their families.

Conclusions: Parental reflections on family adjustment and life satisfaction for the young adult since leaving school highlight the lack of post-school options, and the impact of these circumstances on the whole family.

Key words: Transition, adults with intellectual disability, post-school, parental perspective, family adjustment, self-determination

Introduction

The transition of young adults with disability to post-school life demands coordinated planning, collaboration, and decision making among school staff, families, and a network of community agencies (Flexer, Simmons, Luft, & Baer, 2005). Because post-school pathways for this student population are typically complex and constrained, family involvement continues to be considered an essential component of the transition process (Kohler & Field, 2003; Ludlow, Turnbull, & Luckasson, 1988). This involvement in a formal transition process, paired with family experience at home and in the community, places parents in an informed position to

comment on the quality of the transition program and subsequent post-school outcomes for their son or daughter.

In theory, parents are portrayed as valued providers of information and as the prime advocates for the young adults experiencing the transition to post-school life. Yet in practice, parents have been infrequent participants in transition research. A review of the literature reveals that only a small number of international and national studies have invited parents to report on the quality of transition-focused education that their son or daughter received. Even fewer studies have sought the parent perspective on family experiences and outcomes following the transition of their young adult from school into adult life.

Both small-scale (with 30 or fewer participants) and large-scale studies have contributed to this scant research base. Small-scale studies have typically employed a case study or action research approach to systematically examine everyday transitioning issues, especially from a consumer perspective (i.e., family and young adult). In the main, studies of this kind have sought “in-depth understanding of one or a few instances” (Porter & Lacey, 2005, p. 104). Data gathering in these small-scale studies has provided a set of rich findings that should not be generalised to larger populations but that can still be used in some way to evoke empathy.

For the last twenty years, small-scale studies in the United States (e.g., Ferguson, Ferguson, & Jones, 1988; Gallivan-Fenlon, 1994; Keogh, Bernheimer, & Guthrie, 2004) have produced a set of somewhat negative findings related to both the transition process and post-school life for young adults with disability and their families. Parents have consistently reported low levels of family participation in the transition process and poorly co-ordinated transition planning. Parents, especially those with adults with more severe disabilities, have identified concerns related to high levels of unemployment, restricted levels of participation in community activities, and a prevalence of continued living with and dependence upon families. Similar concerns about poor post-school outcomes also have been identified in small-scale studies within Australia (e.g., Burrows, Ford, & Bottroff, 2001; Murray, 2007) and in the United Kingdom (e.g., Smart, 2004).

In contrast, the large-scale studies involving parents have provided few findings related to parent involvement in the transition process or post-school life for the young adult with disability and their families. In the United States, research has been focused on areas such as parent involvement in transition planning (e.g., Geenen, Powers, & Lopez-Vasquez, 2001), evidence-based practices for increasing student involvement in the transition

process (e.g., Lehmann, Bassett, Sands, Spencer, & Gliner, 1999), systems-oriented examinations of US National data (e.g., Wells et al., 2003), and the development of parent surveys about transition (e.g., Glidden & Jobe, 2007).

Two large-scale Australian studies on the transition from school and post-school outcomes involved families, but in both cases, parents were a minority stakeholder group. On the one hand, Riches, Parmenter, and Robertson (1996) provided a quantitative overview of school leavers' demographics and post-school outcomes related to living arrangements, engagement with the community, employment, and further education. On the other hand, Dowrick (2004) identified measurable school-related learning outcomes for special school students who were of leaving age. In both studies, reporting of parent viewpoints was minimal and young adults with high support needs were underrepresented.

In summary, few studies have focused on the issues faced by young adults with disability and their families in the transition-from-school period. Moreover, Ramcharan and Grant (2001) have strongly recommended that disability research have "a continued emphasis on establishing user views and experiences through small-scale studies" so that these views and experiences "can act as a driving force for change" (p. 358). These researchers also have indicated that "research is needed which is capable of accommodating user and carer views and experiences, and which is more explicitly linked to expectant outcomes both at the personal or service levels (Grant & Ramcharan, 2001, p. 375). These circumstances set the occasion for a research agenda to investigate the parent perspective of transition from school for young adults with disability.

The Study

The study reported here attempted to embed the fine grained "life stories" approach more commonly used in small-scale research (Porter & Lacey, 2005, p. 103) within a large-scale investigation to better understand preparation for post-school life and outcomes for the young adult and family, particularly those adults with high support needs. In order to better understand the actual experiences of families with a young adult member recently transitioned to post-school life, this study sought to obtain in-depth information and reflections from a substantial sample of parents throughout Queensland, and in particular those with young adults with high support needs. It was intentionally exploratory in nature, and was not framed by specific research questions.

The study was part of a large, government funded research project that investigated the relationship between outcomes for students with disability and the transition practices in government and non-government schools throughout the state. The project was the first comprehensive Queensland inquiry into transition from multiple stakeholder perspectives, and this particular study was aimed to provide a distinct parent perspective.

Method

Procedure

Parent perspectives were obtained using a state-wide survey methodology. In an attempt to gather data from as many parents as possible across Queensland, a field-based sampling procedure was deliberately employed. This two-part procedure involved contacting relevant schools across the state, and then school transition staff identifying and contacting potential parents. This strategy was adopted because a large number of students with disability exit school informally and tracking their whereabouts has proven to be problematic (Smith & Bost, 2007). For the government sector, the 198 schools (secondary, secondary education units/classes, and special schools) on the Transition Listserv were invited to be involved in the study. For the non-government sectors (Independent and Catholic Education) a designated officer took responsibility to inform and invite participation of their respective schools. Schools across all sectors were asked to play a mediating role in the sampling procedure. Staff involved with transition programs at each school were requested to identify potential parent participants (viz., parents of students with intellectual disability, autistic spectrum disorder, and those with a dual diagnosis who had graduated from their school in the previous 5 years) and to subsequently distribute survey packages to respective parents. Although these staff were experienced in working with families, they were not required to answer any questions about the purpose of the survey or in relation to any survey content. Material in the survey package encouraged parents to directly contact a designated university researcher if they had any queries. Altogether, 800 surveys were distributed to families.

Instrument

A survey was designed to gather the parental perspective on the transition experience and outcomes. It comprised three sections. The first gathered demographic and background information on the young adult (e.g., diagnosis, age at leaving school, program type, current living arrangements, and sources of income and

funding). The second gathered parental comments on the transition-focused educational program for their young adult. The third section gathered data on outcomes in terms of post-school activities, the life satisfaction of the young adult, and post-school adjustments for the family. Overall, the survey contained 50 questions, combining fixed-response (Likert-type and Yes/No) with open-ended (comments). The latter were designed to capture family “life stories”. The survey was trialled with three parents and a highly experienced School Transition Officer. Minor revisions were subsequently made. The final package comprised the survey, together with an introductory letter explaining the purpose of the study and a university reply-paid return envelope.

Participants

In total, 218 parents returned a completed and useable survey regarding transition experience and post-school outcomes for their young adult and the family. The response rate of 27% was considered acceptable given that the survey was voluntary and distributed through per favour of informal networks to potential parent respondents. In general, international data have shown a continuing decline in the willingness of people to respond to surveys (Dey, 1997). In particular, although a higher response rate might have resulted, it was not possible to attempt contact with non-respondent parents (likely already highly involved or over-burdened with care for their young adult) deleted “even once within a few days after the first attempt”. Nor were the researchers able to offer parents “relief time,” one of the most powerful of inducements. The sample of parents who did respond was over-represented by those with young adults with intellectual disability and high support needs who had previously attended government special schools. The involvement or self-selection of these parents could indicate that they were highly motivated and well placed to communicate difficulties experienced by the family since their young adult had left school.

In acknowledgment of the additional burden that survey completion placed on targeted families, demographic information was collected only on the young adult with disability, and not on parent respondents. Information on the young adults’ age, gender, ethnicity, disability diagnosis, type of school attended, current living arrangements, and sources of income is displayed in Table 1. This sample of young adults was in their early twenties. The gender breakdown was similar to that in the more comprehensive Riches et al. (1996) study of 863 young adult school leavers (64% males, 36% females), and is consistent with Australian data on disability levels (AIHW, 2006). Few came from indigenous families or those with English as a second language (ESL).

The majority (86%) of the sample had an intellectual disability, and over two thirds had attended a Special School, indicating high support needs. Since leaving school, this sample lived at home, and those living independently were living within 30 kilometres of the family home. The majority of young adults were on a disability pension, with the majority receiving the maximal entitlement, indicating financial dependence on government and family.

Table 2. Demographic information of the young adults ($N = 218$)

| Characteristics | | Number | Percentage |
|--------------------|--|----------|------------|
| Gender | Male | 130 | 60% |
| | Female | 88 | 40% |
| Age | Modal age | 21 years | |
| Language | English as a Second Language (ESL) | 5 | 2% |
| Ethnicity | Indigenous | 8 | 4% |
| Disability | Intellectual Disability | 152 | 72% |
| | Autistic Spectrum Disorder | 28 | 13% |
| | Dual diagnosis | 30 | 14% |
| Schooling | State Special School | 150 | 69% |
| | Special Education Unit (High School) | 51 | 23% |
| | State High Schools | 13 | 6% |
| | Independent/Catholic | 4 | 2% |
| Living Arrangement | At Home | 153 | 70% |
| Funding/Income | Disability Service Queensland funds | 113 | 53% |
| | Australian Government case based funding | 27 | 13% |
| | Australian Disability Support Pension | 202 | 93% |
| | Maximum entitlement (earn < \$124 p.w.) | 170 | 78% |

Data Analysis Procedures

The quantitative components of the survey were analysed using SPSS. Descriptive statistics using frequency counts and percentages of responses were undertaken so that trends in the data could be better understood. The qualitative component was analysed systematically across two phases. First, comments from the open-ended questions were automatically analysed using the software program *Leximancer 2.2* (Smith, 2005) in order to provide a general conceptual framework. Second, a more specific and manual analysis of comments was then undertaken in order to extract evidence of real-life transition experiences and outcomes as expressed by parents in their own words. The manual analysis supported the notion that “qualitative research should produce explanations which are generalizable in some way, or which have a wider resonance” (Mason, 1996, p. 6).

Leximancer is a data-mining software package that generates a series of automatic analyses of comments and responses, converting them into semantic patterns displayed in word frequency lists and 2-dimensional concept maps. Parental comments from each question were placed into word files and content analysed to identify the

main themes and their respective relationships for each data set. *Leximancer* examined the text to select a ranked list of important lexical terms on the basis of word frequency and co-occurrence usage. A bootstrapping thesaurus builder then learnt a set of classifiers from the text by iteratively extending the seed word definitions into weighted term classifiers, referred to as *concepts*. The text was then classified using these concepts to produce a concept index for the text, and a concept co-occurrence matrix. By calculating the relative co-occurrence frequencies of the concepts, an asymmetric co-occurrence matrix was obtained. This matrix was used to produce a two-dimensional concept map via a novel emergent clustering algorithm. The resultant concept map provided a visual representation of the most meaningful patterning of the text. Visual interpretation of a *Leximancer* concept map (see Figure 1 below) has been based on brighter and larger dots for higher frequency words, closer positioning of dots with stronger relationships that were spoken about in same text segments of about three sentences, and more centrally located words being most central to the text meaning (Smith & Humphreys, 2005). In Version 2.2 of the *Leximancer* program, the connectedness of each concept in the semantic network is employed to generate a third hierarchical dimension, which displays additional parent concepts or thematic circles at the higher levels. These thematic circles provide visible boundaries around groups or clusters of related words, facilitating examination of relationships between frequently occurring words in each map (see Figure 2 and 3 below).

Manual analysis was employed to identify pertinent comments that supported themes and major concepts generated by the *Leximancer* analysis. Care was taken to identify the relative balance between positive and negative statements related to themes and concepts, and then comments were selected to represent this balance of views. In the results which follow, conceptual maps from the *Leximancer* analysis and quotations from the manual analysis are presented in tandem. The maps provide the background context and the quotations provide the foreground narratives of the data.

Results

Parent responses to the 50 fixed-response and open-ended questions generated a substantial volume of data. Findings are presented in two key areas: preparation for post-school life and outcomes for the young adult and family. Each area contains a number of specific subareas.

Preparation for post-school life

The extent of school preparation for transitioning to post-school life was examined in terms of preparation for employment, community activities, and daily living, and the extent to which schools involved families in the transition planning process. Parents ($n = 196$) reported evenly across the range of responses (from *not at all* to *a great deal*) about how well the school had prepared their young adult for employment.

As part of preparation for employment, two-thirds of young adults ($n = 147$) had participated in work experiences, most commonly two in number, while at school. Of the total sample, the majority of those from state high and non-government schools (82%) and special education units (86%) were involved in work experience at school. Not surprisingly, a lower percentage of leavers from special schools (59%) experienced work while at school. Almost a third of parents ($n = 65$) commented on preparation for work, with a balance of positive and negative views. Positive comments expressed satisfaction with teachers and school programs. For example, “*They helped her to get on with people*” and “*Considering limited resources the teachers did an outstanding job. Very caring.*” Negative comments indicated dissatisfaction with staff (teachers, transition officers) and programs provided. For example, “*Most of his teachers didn’t even know he had Aspergers Syndrome*” and “*a Transition Officer offered brochures but nothing substantial.*” Twenty-seven comments expressed the view that severity of disability precluded employment after leaving school. For example, “*Employment was never an achievable goal due to severity of disability.*”

By comparison, parent reporting ($n = 211$) about the preparation for community activities was skewed to a more positive view, with more than half responding *much to a great deal*. Of the 44 comments made, some positive comments included “*Combined effort with family support*”, “*Got him used to being in the community*”, and “*Many school activities conducted to familiarise the person with the community.*” A similar pattern of positive responses was reported for daily living preparation, with more than half of parents giving ratings of *much to a great deal*. Forty-four parents commented on the extent to which the school program prepared their young adult with skills for daily living. Positive comments indicated that “*The school worked very hard on this*”, “*He was self sufficient on leaving school*”, and “*Combined effort with family support.*” A number of comments indicated, however, that the home played the greater part in the teaching of skills for daily living. For example, “*Could do these skills by self. Taught by mother.*” Others were critical of the programs for preparation for daily

living: *“School is irrelevant to life... they cannot possible prepare a person for the real thing. Washing three tea-towels or shopping for biscuits just isn't what it is like.”*

A majority of parents reported high involvement levels (*much to a great deal*) of family (69%, $n = 149$) and teacher (66%, $n = 143$) in goal-setting for post school life. In contrast, parents reported low levels (*not at all to a little*) of student involvement in this activity (42%, $n = 86$). Parent ratings for how consistent their young adults' current work and community activities were with the goals set during final years of schooling were evenly spread across response options. Thirty-five percent of parents ($n = 77$) made concluding comments about preparation for post-school life. In the main, general comments on school activities and specific comments on goal setting were provided. A majority of parents commented positively on the general nature of school activities and on relationships with school staff. Typical comments included *“The special education unit was a safe positive environment for my daughter, it promoted self esteem essential for post school transition.”* Many parents were very appreciative of the efforts made by the school staff in relation to the transition process, as indicated by this comment: *“Teachers were excellent in motivating my child to step out of her comfort zone.”*

Post-school outcomes for young adults and families

Outcomes for the young adults in post-school life were examined in terms of paid work, activities other than paid work, and young adult satisfaction. Outcomes for families were focused predominantly on family adjustments made in response to the young adult moving into post-school life.

Specific data on open or supported employment experiences (type, length, additional comments) and weekly income were identified. Almost 25% of young adults ($n = 53$) had paid jobs in regular community settings. Of the total sample, 53% of those from state high and non-government schools were in paid employment, 44% from special education units, and 15% from special schools. In all, 35 types of work were identified. The most frequently mentioned jobs were kitchen-hand, working at a supermarket, and shop-assistant. Almost a half of young adults in open employment earned under \$100 per week, and almost two thirds worked for less than 20 hours per week. Thirteen percent of the total sample of young adults ($n = 28$) were in supported or sheltered employment with a community agency that provided employment within their organisation. Of the total sample, 18% of those from state high and non-government schools were in supported employment, 8% from special education units, and 14% from special schools. Sixty-three percent of those in this type of employment earned

less than \$50 per week, and 30% between \$50 and \$100. Forty-four percent of these individuals worked for less than 20 hours per week. Over 10% ($n = 22$) of parents commented on the open or supported employment of their young adult. Comments overall addressed the positive and negative aspects of these types of employment. Some positive comments conveyed the view that participation in work was a worthwhile experience despite only small amounts of money being earned. For example, *“I believe the wage my son receives is not important - he has a purpose in life/a reason to get up in the morning.”* In contrast, other parents made it clear that payment for work completed was insufficient. *“She works 42 hours a fortnight and receives \$49.00.”* Other parents made comments about lack of employment opportunities: *“He is stagnating and I can see him spending his life as a blimp in front of the computer or TV, from this point on there are very, very few employment opportunities these days for our special young adults. Very, very distressing!!”*

Engagement in community-based programs, tertiary education, and in more general daily activities also was specified. Over half of the young adult sample ($n = 110$) currently attended a community centre-based day program with no resultant income. Of the total sample, 27% of those from state high and non-government schools attended a day program, 16% from special education units, and 68% from special schools. Half of this subset attended centres for between 10 and 20 hours. Activities of the highest frequency were community outings and life-skills, physical, and arts programs. Less than a quarter ($n = 47$) of young adults attended a tertiary institution. A comparison across school types indicates little difference in tertiary participation. The majority of this subset attended Technical and Further Education (TAFE) Colleges, mostly studying a certificate course. In contrast, only 7% of the subset were enrolled in a university degree or diploma. The vast majority of young adults (83%, $n = 180$) engaged in community activities, with the largest subset ($n = 71$) participating in these activities for 2-5 hours per week. Most of the young adults (55%, $n = 113$) required substantial amounts (*much to a great deal*) of supervision to engage in these activities. Moreover, over a third of this subset typically interacted minimally (*not at all to a little*) with other community members.

Sixty-four comments were made regarding community activities, with a balance of positive and negative perspectives. The *Leximancer* analysis of these comments produced a comprehensive conceptual map (see Figure 1). The top quadrants of the map include concepts related to more positive comments and some of the activities that individuals enjoyed in life after school (e.g., Special Olympics, movies, outings). By comparison,

the bottom quadrants identify concepts related to more negative comments that focused on lack of support, the need for supervision, and issues regarding the disproportionate amount of time at home and at work.

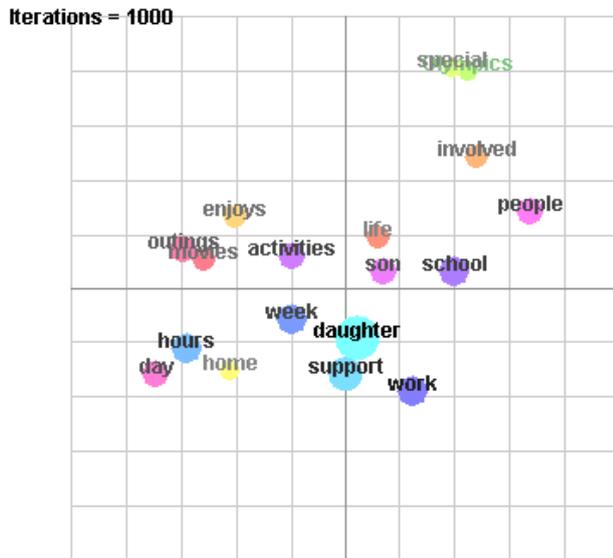


Figure 1. *Leximancer* analysis of parent comments regarding community activities.

Current life satisfaction for the young adults was reported as *much to a great deal* by 64% of parents ($n = 132$). Satisfaction ratings did not differ according to type of school attended. Positive comments alluded to the young adult as: “*Appears to be happy and confident with things at the moment*”, “*He is enjoying his new life very much.*”, and “*Getting better*”. Only 13% of parents indicated that their young adult was not currently satisfied with life (*not at all to a little*). Negative comments included “*I feel he is going backwards and becomes very lonely. Has no friends. Post school grant does not give many hours*”, “*Bored as he is not in a program daily as he needs a lot of structure*”, and “*My son does not get very much stimulation, he spends much of his time with older people, it’s very sad really.*”

Almost a half of parents ($n = 102$) reported that considerable family adjustment (*much to a great deal*) was required when their young adult left school. Parents with young adults who had attended special schools (55%) reported higher adjustments compared to those whose young adults attended special education units (34%) and state high and non-government schools (31%).

A third of parents made some comment about this issue. Figure 2 illustrates how key concepts are clustered to form a series of themes around family adjustment. Two interrelated themes identified from the analysis of

comments were: work (with a connection to mother) and hours-time (with a connection to transport). Three supplementary themes impacting on family lives also were identified: care, lives, and week.

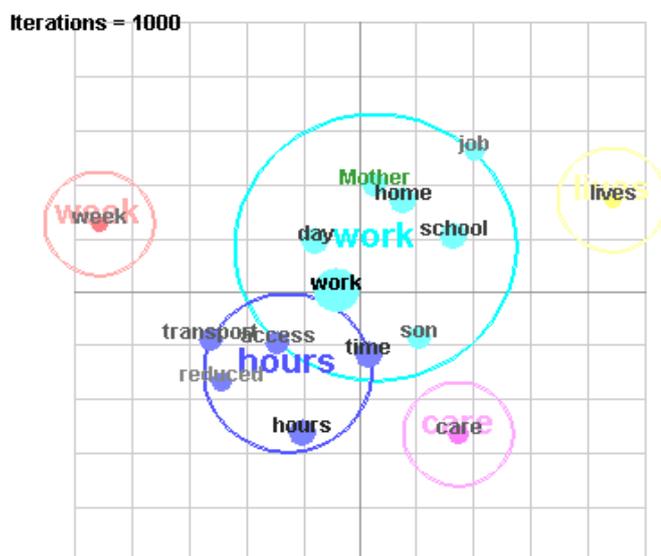


Figure 2. Leximancer analysis of comments about family adjustments.

A raft of comments supported and extended notions associated with these adjustments. First, comments about parental reduction and/or cessation of work for mothers (so as to be home during the day) were frequently reported. As an example, one parent stated *“The family became emotionally dysfunctional and were unable to cope. Mother resigned from \$60,000 per/year job (and RESENTS it) to assist.”* Second, transport, access, and time involved were frequently embedded concepts within many comments. An illustration of the impact on families was *“Because we resided about 54kms west of (regional city) there was no transport to bring her into Endeavour. We tried bringing her in each day 1,000kms/week, but we found this was too expensive and wearing, so we moved into (regional city).”* Third, the disruption to family life resulting from an increase in the caring role was repeatedly highlighted throughout parent comments. For example, one parent described these demands as *“Organisations dictate the hours of care, 10-2pm. Anything I need to do must be accomplished in 4 hours.”* Moreover, another parent provided a stark summary of her situation: *“My whole life is an adjustment.”* Frustration resulting from a lack of options following transition was evident across a number of themes when final parent comments were analysed. While school and skills were identified as important themes connected to past student life, help and funding were interconnected themes that highlighted elements of concern for families in current post-school life (see Figure 3).

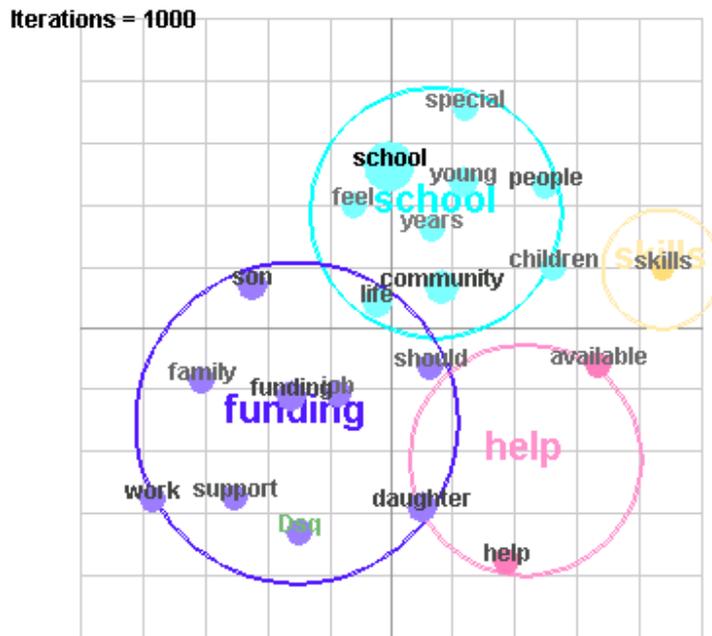


Figure 3. Leximancer analysis of final parent comments.

Lack of post-school funding and lack of post-school options were areas of specific concern identified within comments. Post-school funding emerged as the major concern, especially in terms of government responsibility, as illustrated by this statement:

Post-school funding is not enough to prepare persons with an Intellectual disability for independent living. The dollars drop each year with support staff wage increases and this gets families more frustrated especially if their son/ daughter wants to live independently.

Expressed frustration also tied a lack of funding to limited post-school options. Examples included:

Very little activities due to lack of government funding. He doesn't want me to take him out, he wants to be with his peers. Government cut backs were upsetting for him as he lives for his involvement in community participation. He has 4 days at home and 3 six hour days at CP (community) program.

The options available will remain second rate until sufficient funding is allowed to train and employ full-time staff such as in the education system. No one stays in a job that is poorly paid and lacks any permanency. I know of no families who are comfortable with the post-school life of their child. No proper trained staff or suitable venues make a farce of the program and funding. No amount of funding package, regardless of how large it may be can be successful if there are not appropriate services to purchase.

In all, concluding comments from two parents summed up the struggles expressed by many parents as their family attempted to adjust to life upon their young adult leaving school. Comments from Parent 1 point to the need for others to understand the overwhelming frustration and disappointment felt by these families.

I think from the comments that I have made that you may understand the level of disappointment, frustration, and down right dissatisfaction that now exists in our family because of our daughter's current situation. All of which could change if only we knew who to turn to.

Comments from Parent 2 illustrate the stark reality faced by some struggling Queensland families, especially those in rural communities:

When a child with special needs finishes school, it is like falling off a cliff for the carer and the child. A huge void, living in a rural area makes it ten times harder.

Discussion

Field-based research is demanding work, relying upon the establishing of relationships and involving a series of interactions with significant others. In this study, analysis of the statewide survey data provided initial insights into how Queensland parents, especially those young adults with high support needs, viewed the status of school transition programs and the challenges faced by families when their son or daughter exited school. Except for a few reservations, parents endorsed the transition planning process and preparation-for-life curricula put in place by school staff throughout the state. By comparison, they voiced strong concerns about post-school life for their young adult with intellectual disability and the considerable adjustment made by families when expected outcomes related to employment, community living, and social networking were not realised.

Preparation for post-school life

In general, parents reported high levels of personal involvement in, and satisfaction with, the transition planning process. Yet, many indicated that their son or daughter with intellectual disability had minimal participation in this process. Best practice indicates that, rather than mere adjustment, self-determination, i.e., engaging in goal-directed, self-regulated, autonomous behaviour (Algozzine, Browder, Karvonen, Test, & Wood, 2001), or the involvement of students in transition goal setting activities leads to more positive post-school outcomes (German, Martin, Marshall, & Sale, 2000; Loyd & Wehmeyer, 2004; Smart, 2004; Wehmeyer & Palmer, 2003). In a major review of transition literature, Meadows, Punch, Elias, Beamish, and Davies (2005) found substantial evidence of the value of teaching self-determination skills and behaviours to students with disability. More recently, Gil (2007) has concluded that self-determination training should be a critical component of every transition-focused education program.

Generally, parents were positive about school preparation for post-school life, particularly in relation to preparation for community participation and daily living activities. Preparation for employment, however, was not viewed in a similar manner. Parents signalled that work experience was not available to almost a third of their sons and daughters, especially those with high support needs. This finding is of concern because the amount and type of work experience or vocational training experienced by students while at school have been identified as the most common predictors of post-school employment (Kohler & Chapman, 1999; Phelps & Hanley-Maxwell, 1997).

Post-school outcomes for young adults and families

Reported outcomes for employment and living were similar to those documented by Riches et al. (1996) in New South Wales, Australia. A decade later, Queensland parents indicated that little had changed. In this study, parents reported that the vast majority of the young adults with intellectual disability and high support needs still relied heavily on the Australian government pension, with most receiving a maximum entitlement because their earnings from either open or supported employment were minimal. In addition, most young adults lived at home with their parents and those that had left home lived within 30 kilometres of the parents.

Many young adults participated in a range of community-based activities, but the engagement time per week was often limited (less than 20 hours each week). In the main, most attended day programs (e.g., involving

community outings, or life-skills and art programs) on a part-time basis. Parents reported a lack of adequate full day adult services and called for increased funding for service provision in this area. Similar findings have been echoed in a number of recent North American studies (e.g., Brown, Shiraga, & Kessler, 2006; Kraemer & Blacher, 2001).

Low community-based participation, combined with the need for high levels of supervision, raises the question as to who interacts with and supports these young adults when they are not engaged in work or other community activities. Parents in this study made it clear that they were the ones left to attend to these tasks, and that these ongoing demands inevitably exerted excessive pressure on the whole family. Not surprisingly, almost half of the parents reported that considerable family adjustment had taken place following their son or daughter leaving school, and that most adjustments were related to supervision demands. A number of parents reported giving up employment in order to look after their son or daughter and this arrangement resulted in substantial financial hardship and personal modifications.

In recognition of the strain that the transition to adulthood can have on all parents, Glidden and Jobe (2007) reported that compared to parents of students with regular academic competence, those with children from special education had lower Subjective Well-Being (SWB), and lower factor scales for Positive Future Orientation, Community Resources, Financial Independence, and Family Relations. Moreover examination of serial data from the National Educational Longitudinal Studies in the late 1980s (Wells et al., 2003) produced evidence that disability and type of disability profoundly affect the young adult and their pathway to adulthood. Findings indicated that individuals with intellectual or multiple disabilities were more likely to be “totally dependent on their families without taking on normative adult roles” (p. 826). Additionally, family socioeconomic resources were found to have minimal impact on the transition outcomes for their young adult.

Findings from the current study provide cross-national evidence that young adults with intellectual disability and high support needs have poorer post-school outcomes and are at risk of experiencing poorer quality of life compared to that of their same-age peers. Moreover, data are presented that illustrate the strong impact of poor post-school options on the lives of their families. In particular, this study has provided a glimpse into the substantial disruptions to family routines and responsibilities that occur when young adults with intellectual disability and high support needs ineffectively move into post-school life. More fine-grained research is

required to provide detailed accounts and comparisons about “family life transitions” (Ferguson et al., 1988, p. 182) between families in which young adults have experienced effective versus ineffective transition outcomes.

Conclusion

Findings from this Queensland study indicate that the situation for young adults with intellectual disability (particularly those with high support needs) and their families has improved little over the years. The concerns raised two decades ago by Ferguson et al. (1988) in North America highlighted the need for these young adults to develop skills and independence and for their parents not to continue in protective and caring roles. The concerns raised a decade ago by Down (1996) in South Australia highlighted the need for these young adults to follow post-school pathways in terms of employment, training, and leisure and for their parents not to “give up their job and own personal activities to stay at home and provide care” (p. 69). As a consequence, this cohort of young adults and their families continue to be disenfranchised and disengaged from the community in which they live.

The present study confirms that much still needs to be done to provide a comprehensive system of work, educational, and leisure opportunities for young school leavers, especially those with intellectual disability and high support needs. To date, service systems in this state have failed to provide meaningful and reasonable post-school options for these young adults and their families. There is an urgent need for change and change will only happen when there is committed action by cross-government departments and community agencies. Both families and young adults with intellectual disability have a right to a “normal” life. How much longer do they need to endure “life as an adjustment”?

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