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Transition Post-School: Five Steps Toward Reducing the Hurdles

Marion Shields, Ed.D.

Abstract

This chapter begins with the historical background to current educational provisions for students with disabilities and the significant role that have parents played. The focus then turns to the concept of transition to adulthood for these young people. The chapter addresses such topics as:

- *What are the experiences of students together with their parents, about leaving school and moving to the next stage in their lives?*
- *What are the components of this transition?*
- *How do the educators and providers manage their roles in this activity?*
- *How are the parents involved?*

Enablers and barriers in this process are discussed through Papay and Bambara's (2014) five practices, together with practical suggestions of how parents and professionals can work together to support young adults with special needs.

Keywords: transition to adulthood; child and parent relationships; inclusive education; special needs; disabilities

Introduction

During the mid-twentieth century, courageous parents struggled to gain a pathway to acceptance of and education for their children with disabilities. Nowhere is this more tellingly portrayed than by Rud and Ann Turnbull (2015) writing from the dual perspectives of parents and researchers, whose son was involved in the first wave of the ‘rights for the disabled’ phenomenon in the 1950s and 1960s.

During those early days many parents organised schools for their children with disabilities who had been excluded from mainstream schools. Proving that these children were indeed capable of learning was critically important to the goal of their acceptance as valid members of society. Promoted by John F. Kennedy, educational provisions for children with special needs began to develop; however, parents also renewed their efforts through the judicial process with some state-based, successful legislation being achieved. Eventually, a stand-alone special education law was enacted in the United States—P.L.94-142 in 1975, later to become the Individuals with Disabilities Education Act (IDEA). This landmark legislation mandated free, compulsory education for children with disabilities in the least restrictive environment, and its influence was felt around the world as other countries subsequently enacted their own similar legislation. Turnbull and Turnbull (2015) cite a comment by Sam Kirk, an early researcher, described by the New York Times in 1996 as the ‘father of special education’:

If I were to give credit to one group in the country for the advancements that have been made in the education of exceptional children, I would place the parent organizations and parent movement in the forefront as the leading force. (p. 53)

However, children do not stay in school indefinitely, and the issue of moving into adulthood and the post-school world, a huge transition, is the next hurdle, one which parents and professionals can accomplish together.

The reality of the ‘transition-from-school’ hurdle.

Sadly, despite the intent of the IDEA legislation regarding transition planning in the United States, the reality of transition today is unacceptable “for far too many youth with disabilities . . . they and their parents are faced with inadequate preparation, uncertainty, fragmented information, and lack of services” (Bates, 2014, p. 227). Further, these difficulties are noticeable in other countries as well, such as Australia, suggesting this problem is not restricted to the United States (Strnadova & Cummings, 2014). Compounding these issues

and making the transition process more difficult is the vast range of disabilities that these young people have. Many have sensory or physical disabilities: hearing, sight and mobility to a greater or lesser degree; some may have intellectual disabilities that also follow a continuum; yet another group has behavioural and emotional issues, and those with autism spectrum disorder range from severe intellectual disability to those who are highly intelligent but have significant social and communicative difficulties. However, each child with disabilities deserves the best educational opportunities that will enable him or her to reach his or her potential; therefore, a range of options is essential and a number of common core practices can be utilised by professionals and parents.

Significance of transition: Development of transition programs

Why is transition so important? Most agree that for children with disabilities their first transition to starting school and their second transition to high school are critically important, but the transition from school is even more so (Heatherington et al., 2010; Winn & Hay, 2009) as this leads into the major part of their lives, adulthood. For many youth this is a challenging time, and for those with disabilities and their families, it can be extremely frustrating and disappointing. No longer are they within the carefully managed boundaries of school; instead they are facing a focus on independent living, economic security, and social interaction, all of which may place an increased burden on parents (Boehm, Carter, & Taylor, 2015). Young people with disabilities are particularly vulnerable at this important transitional stage of their lives (NSW Parliament, 2012).

Although transitions occur in the lives of all children from home to school and thence to high school, preparation for the major transition to adulthood begins in the early years of education. Learning practical independence skills, wise decision-making and appropriate social interaction skills are essential competencies for all children, including those with disabilities, for an optimal quality of life in adulthood (Ankeny, Wilkins, & Spain, 2009).

“While it is significant that post-school transition has been the mainstay in recent national agreements on education, it is more significant that the actual process of post-school transition has remained ill-defined and practically unaddressed.”

Children with Disability Australia (2015, p. 14)

Best practice in transition: Barriers and enablers

For over three decades, parents and professionals have been investigating what constitutes best practice in transition programs for young people with disabilities. Consequently numerous evidence-based ‘lists’ have been published that describe the important factors leading to successful transitions for students with disabilities. Papay and Bambara (2014) researching best practices in transition for youth with disabilities, distilled these practices down to five that when combined were found to significantly predict employment, postsecondary education, and enjoyment of life outcomes. These five practices are now discussed in detail. In this context it is assumed that students have been educated in inclusive settings and that transition planning will actually occur. Further, it must be remembered that given the wide variety of individual characteristics across the range of people with disabilities, some additional, individualised practices may need to be included.

Practice 1. The involvement of young people with disabilities in their transition planning programs. Research indicates that although young people with disabilities are increasingly attending transition planning meetings, many are ill-prepared and as a result little meaningful participation occurs (McCall, 2015; Strnadova & Cummings, 2014; Wei, Wagner, Hudson, Yu , & Javitz, 2016).

Authentic involvement requires that young people with disabilities not only attend planning meetings, but that they are prepared by the school for meaningful participation in the process. The omission of this important aspect of transition has been described by Strnadova and Cummings (2014) as “the most alarming finding” of their research study (p. 331). This preparation means that the young people know why the meeting has been organised, they understand what will be discussed and the options available to them. Essentially, they are taught how to express their opinions and are encouraged and expected to contribute to the decision making process. While a lack of self-determination and transition knowledge has been found to be widespread and to negatively affect post-school life for students with disability (Lee et al., 2011), including lack of goals and strategies to achieve this, Seong, Wehmeyer, Palmer and Little (2015) report that use of the Self-Directed Individualized Education Program [IEP] (where young people are trained in leading the IEP process) improved self-determination and self-efficacy within the transition program. Papay and Bambara (2014) noted that youth who were involved in their transition programs were three times more likely to go on to further education and five times more likely to be employed some years after school. A consistent comment by parents has been that transition programs are often ‘too little, too late’ and that they should begin much earlier in school (Heatherington et al., 2010). This was also an issue raised by the Human Rights and Equal Opportunity

Commission (2005) recommending that planning start at age 14. Knowing the importance of student involvement in transition might cause one to reflect on the following question:

What specific steps can parents and professionals take to involve students in their IEP meetings and to develop skills in self-determination in preschool, primary aged, and secondary school students with disabilities?

Practice 2. Family involvement in transition planning.

Research by Landmark, Roberts and Zhang (2013) investigated educators' perceptions about parent involvement in transition planning and noted an inconsistency between the educators' stated beliefs and actual practices. Many parents' discomfort in a school setting was acknowledged with some educators describing their attempts to provide an intentionally welcoming environment for meetings. However, in the same study educators who worked in lower socioeconomic areas had a more negative attitude about transition planning and felt that some of the barriers such as flexibility of meeting times were too difficult to overcome. The educators' attitudes (positive or negative) had a considerable influence on parents' participation; however, there was also the comment: "...educators do not feel they are knowledgeable enough about transition planning to effectively implement it, much less promote parent involvement in the process" (Landmark et al., 2013, p. 121). In a similar vein, Buchner et al.'s (2015) research found some parents have to contend with professionals who do not interact with them as partners, nor value them as knowledgeable contributors. In these circumstances the parents' advocacy was as a response to "professionals' ableist practices and refusal of support" for the students (p. 422). Mueller & Buckley (2014) have documented similar findings from the perspective of fathers. It is essential, then, that open and honest communication and collaboration occurs between professionals and parents without either side being defensive; and that professionals take the initiative to try to overcome these barriers and inform, respect and empower parents to be genuine participants in the transition planning process for their children.

Similarly to the involvement of their children in transition planning, parents need to be actively involved in the process, since they will be the consistent 'bridge' that links school and adulthood for their children. Therefore, accommodations need to be made by educators to support the diversity of parents in the process (Wagner, Newman, Cameto, Javitz, & Valdes, 2012). These accommodations include: ensuring that bureaucratic processes do not disadvantage lower-income parents, such as selecting meeting schedules and locations;

reducing special education jargon (Mueller & Buckley, 2014), and respecting and addressing racial and cultural differences. Papay and Bambara's (2014) research found that parental expectations were highly predictive of post-school outcomes, while Morningstar et al. (2010) suggest, "the more involved students perceived their families to be, the greater the students' perceived levels of locus of control, psychological empowerment and hope" (p. 88).

Knowledge of the importance of family involvement in transition programs, might cause one to reflect on the following question:

What are some of the ways that educators can include parents and caregivers, making them feel valued and welcomed in the planning process?

Practice 3. Instruction and experiences that prepare youth for employment.

Young people with disabilities must have positive early employment experiences after transitioning from high school, to enable them to become financially independent and socially self-reliant (Wagner, Newman, & Javitz, 2016). The alternative, an unsuccessful transition to the working world, is likely to lead to limited employment, continued dependence, and lower self-esteem (NSW Parliament, 2012). Preparation for employment includes practical skills such as travel training, college and job applications, resumes, financial management and work experience. Strnadova and Cummings (2014) found in their Australian research that the most frequent recommendation for change from school staff was for improved funding to permit staff to support students with disabilities in work experience programs in the community and to provide improved facilities for life skills training in the school. Work experience was identified as particularly important in predicting success in the post-secondary environment (Madaus, Grigal, & Hughes, 2014; Papay & Bambara, 2014; Test et al., 2009).

Into this category of preparation for employment must come preparation for tertiary education and also, most importantly, support and accommodations to enable this stage to be successful. For many young people with disabilities educated in an inclusive environment, there is a predisposition to view further education as the next logical step (White, Ollendick, & Bray, 2011). Newman and Madaus (2015) identified a concerning issue regarding accommodations, finding that while 100% of their participants with disabilities received accommodations in secondary school, only 35% informed their post-secondary education facility of their needs; with similar results observed in two and four year colleges. More than half did not consider they had a disability, while 14% chose not to reveal their disability. However, in later follow up investigations, 50% of those who had not asked for help in two

and four-year colleges, and 35% of those in vocational and technical colleges commented that such support would have been helpful. Unfortunately, as Newman and Madaus noted, these statistics point to a number of causes: the lack of ability and experience in self-advocating for support and accommodations, the lack of understanding of their needs and legal rights, and a fear of possible stigma.

In a small study, McCall (2015) found that informal family and peer support became the critical factor in determining students' success in attending and surviving tertiary education, but disturbingly, family involvement was absent in the transition process. Some tertiary students with disabilities have reported that they were often made to feel they should not be at university because of their special needs, and so many chose not to self-disclose and as a consequence did not get the support they needed (Getzel & Thoma, 2008).

In addition to the possible concerns related to lack of disclosure suggested by Newman and Madaus (2015), consideration must be given to the particular needs of the increasing numbers of young people with high functioning autism. With an incidence of one in 110 (Autism Spectrum Australia, 2013) and one in 88 (Centers for Disease Control and Prevention, 2012) of young people diagnosed with an Autism Spectrum Disorder (ASD), the numbers finishing secondary school with good academic results and looking towards university as the next step are rising (Camarena & Sarigiani, 2009). However, the factors associated with the move to tertiary education such as changes in routines, new social patterns and living arrangements, and different learning approaches combined with the particular features of ASD such as communication and social difficulties, extreme sensitivity, anxiety and difficulty with change, cause many to hesitate before commencement and even to withdraw before completion (Madriaga & Goodley, 2010; VanBergeijk, Klin, & Volkmar, 2008).

Many tertiary institutions are not adequately prepared for students with ASDs. For example, Pillay and Bhat (2012) commented: "college personnel typically have neither the resources nor the guidelines for best practices when working with a student who has the diagnosis of Asperger's Syndrome" (p. 142). Guidance for academic staff needs to come from both the secondary school and the parents, with visits and interviews in which the student is included. Prior to leaving school it is essential that the transition planning include an interactive, dynamic process involving the student and his/her parents so that the decision-making is carefully considered, as this is vital in achieving self-determination (Wehman et al., 2014). This consideration includes a choice of career focus to ensure that the characteristics of ASD do not conflict with job requirements, which could entail meeting new people and

frequent change. “Secondary learning support staff and school counsellors can pave the way for and expedite parent and student contact with lecturers and disability officers at the selected tertiary institution. In addition they can supply a report suggesting specific strategies that will support the student in the new educational setting” (Shields, 2015, p. 13).

Collaboration between educators and parents can craft the bridge that young people with disabilities desperately need as the following vignette, Joshua’s Story, illustrates.

Joshua ‘s Story

Joshua was a very challenging little boy, and when the diagnosis of Asperger’s level 6 at age 11 was made the situation became clearer, although not easier. Despite being highly intelligent, he had an aloof, self-centred manner and was further diagnosed with ADHD, which prevented him from being able to concentrate or relax. As a young adult he used slow release Ritalin in the morning to help him focus during the day, and then Catapres in the evening, so that he could unwind and rest.

His mother takes up the story: *The fact that we could move to a small university where I knew people made all the difference. For the first 6 six months I helped him a lot through texting. I think the first day I probably got 50 texts. But now the only text I get is: Mum it’s 5 past 5 why aren’t you here to go home? The new situation was terrifying for him and for me too, it was quite scary, but looking back now it went really well. People have taken a personal interest in him, particularly his lecturers in science. They organised one of the students to help tutor him, for a few hours a week which he pays for out of his disability allowance. He can text me any time. In the current environment, technology has made a significant difference to students with disabilities. For example: Registration is a hard time, a lot of people, sitting around, waiting, noise, confusion..... since then we’ve done it on-line.*

We choose to do some units online to reduce the stress. Note-taking is very hard for him. Not just the fine motor difficulties, as he could use a laptop, but the whole thing.

In first year he had one subject in a lecture theatre with a large class. I didn’t find out until it had finished that he spent most of the time pacing up and down outside. He’d get there and the seats at the back were full, there was nowhere to sit easily and there were people everywhere, it was noisy, and he wasn’t interested in what they were teaching anyway. But in the smaller classrooms in science, all in the one building he’s been fine.”

The collaborative effort and mutual respect between Joshua’s mother and his main lecturer were the significant factors in Joshua’s success and he is currently completing his B.Sc.

Joshua's story demonstrates that with support geared to a student's strengths and preferences, successful transitions can occur. The importance of building skills needed in employment and tertiary education contexts invite reflection on the following questions:

How can students build skills in requesting services and accommodations needed for success in tertiary education and workplace settings?
What specific life skills will each student required to function effectively in these settings?

Practice 4. Instruction and experiences that prepare youth for independent living, including a functional life skills curriculum and community-based instruction.

Darrow (2014) writes of the importance of the 'affective' skills that young people with disabilities need in order to function effectively as adults and notes that music education offers multiple opportunities for the development of social skills that provide a critical skill-set in the transition to adulthood. These social skills need to be embedded in the student's program from the home and early school days. Social skills, such as being able to wait in a queue, modulate the voice, use common courtesies, maintain eye contact, and recognize appropriate proximity to someone else, may take years to attain.

In addition, young people with disabilities need everyday domestic skills in order to be able to sustain a role in employment or further education and eventually, attain independent living. These functional life skills include making purchases (Test et al., 2009); managing public transport (Park, 2010); and budgeting, leisure, home-making, cooking and meal preparation skills (Scruggs & Michaud, 2009) which need to be undertaken in real-life settings, not just in the classroom. Scruggs and Michaud's research in America and Italy noted, as did Strnadova and Cummings' (2014) Australian research, that teachers strongly expressed the need for more funding to provide the time and support to achieve effective life-skills programs in the community. In fact Davies and Beamish (2009) found that for almost a third of the parents of students with disabilities that they interviewed, their children were not offered work experiences.

Transition programs can be a source of encouragement for parents initially, but the experience of many is that the transition is never completed through to employment as the following vignette illustrates.

Anne and Marie's story:

Anne is now aged in her 70s, her daughter Marie has a learning disability and is in her 30s.

Anne's daughter attended a special education high school. Towards the end, she was tested for possible employment. However the government funding was discontinued and they were referred to an employment agency. They were with the agency for about 10 years with no real outcomes, just some work experience here and there. Anne says: *"They always seemed to be following what Marie wanted to do rather than giving appropriate tests and then saying these are your options. Her ideals were unrealistic and they kept encouraging her despite what I would say. I pretty much was tolerated, but not involved. After many years and no employment in sight, we just gave up. I think if they were to do better assessments where they identified the problems and the potentials, and worked out a plan to maximise the potential, and then work towards those limits. I think parents should be enabled to be involved in the program, but when they're not informed or encouraged to be included that becomes unrealistic. And when you have teachers that are less than capable because they haven't fully assessed the child to know their limitations, they push them in a certain direction that the child wants to go, but it can be unrealistic.*

Getting older is very challenging, and you see their dependence level and you think: what can I do? It's an overwhelming concern at times. You feel as if you're a parent on and on and on.....

Anna and Marie's story illustrates limitations that a person with disability may face in adulthood when transition training programs are underfunded and incomplete. This invites parents and professionals to consider the following question.

How might educators identify and personalize instruction in life skills, and how might this training be incorporated in both school and community settings?

Practice 5. Interagency involvement and collaboration.

A critical aspect of transition for young people with disabilities is communication and collaboration between the various entities that affect the transition process and the lives of these young people. Central to the transition process is the young person with disabilities. Figure 1. illustrates the different sectors and players involved, and each of these has the capacity to enhance or reduce the student's future. Each component directly influences the student negatively or positively; and may also influence one or several other players in the

process. For example, the school has a vital role in preparing students for the post-school environment by teaching skills and behaviours that will support the student in work, recreation or further study and parent involvement is likely to enhance the prospects of successful outcomes. The parents are usually the only ongoing player in this scenario and it is essential that communication and collaboration occur to ensure a smooth transition post-school.

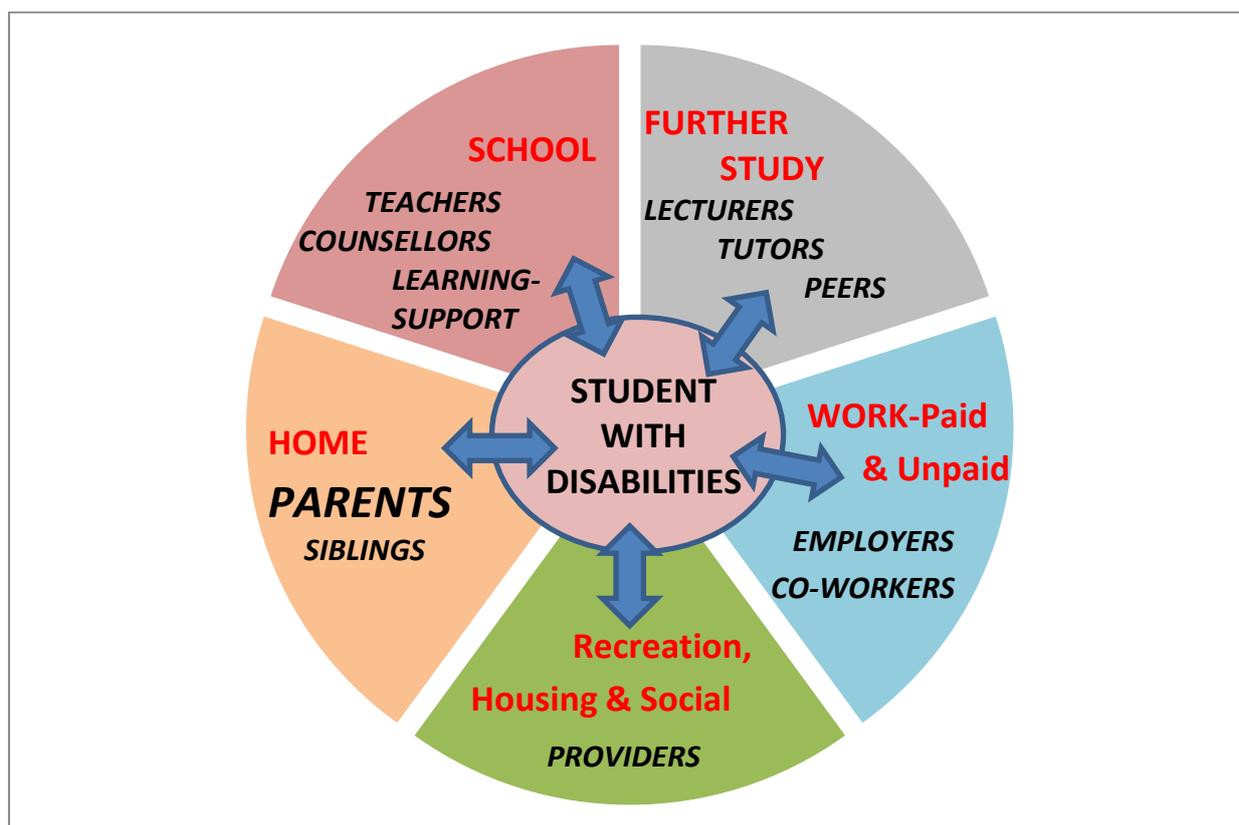


Figure 1. Players in the transition process.

Awareness of the importance of the participation of various stakeholders to successful transition programs might cause professionals to reflect on the following question.

How might government policy be framed to require a greater degree of accountability from schools and collaboration between stakeholders in post school transition planning for students with disabilities?

Coordinating transitions: New strategies

The transition experiences of young people and their families are recorded in many research studies and reveal that best practice in the transition process is rarely achieved (Lee

et al., 2011; Skaff, Kemp, McGovern, & Fantacone, 2014). Apart from the work of secondary school staff and parents themselves there is a clear need for a coordination person; and in an attempt to remedy this, the Australian government has initiated the National Disability Coordination Officer Program (NCDO). I recently spoke to one NCDO who is also the parent of a young person with disabilities.

Michelle's perspective: National Disability Coordinator Officer

"Well my program is funded by the Australian government to promote post-school transition. The research shows that when it wasn't there students with disability weren't coming to university at all, and progressing to tertiary and TAFE there was no articulation and they were falling into a bit of a black hole. Now with our government funded program there are 31 of us across Australia and it's better, but in some regions more than others. I've been around for a while so I've built up networks and people trust me.

With transition, the schools don't approach it in any systemic way. It depends a lot on the teacher. In New South Wales there are support teachers/transition and no other state has that program, but it is up to the school as to how much they want to engage with that role. Some schools see it as someone coming from the outside and aren't as willing to engage. Other schools completely rely on that role for their student transition. That's good for students in support units, but I worry about the kids in mainstream. So I actually organise the careers advisors' meeting in this region once a year.

I see the major problem in the transition program as a lack of awareness. I have 1200 staff (from schools, employment services, TAFE, uni) on my newslist. Yet when an event is on, I nearly always get a family saying they didn't know it was on. The schools need to take more responsibility for circulating the information. There's someone from every school in the region on the list; it's their role to spread the information. It needs to be more systemic; the parents need to be informed. It's in all the sectors, Catholic, State and Independent. So I've built up a huge social media presence to try to get around that.

Some parents aren't happy with the transition program for their children. I think a lot of it is the students are undervalued in what they can achieve. You can work with quite a complex disability; I have colleagues who have extremely complex disabilities and are working successfully and earning good money; so I think we undervalue what they can contribute. Sometimes students with intellectual impairments are funnelled into Australian Disability Enterprises, but my issue is that some are much more capable of getting a job in major grocery or hardware stores. It's just someone believing in them, helping them get the skills and supporting them.

Michelle's experience substantiates reports in the literature about parental concerns related to low expectations for young people with disabilities. Amongst the recommendations of the 2015 Report on Post School Transition (CDA, 2015) is number 14: "Introduction of mandatory professional development for school staff (particularly careers teachers) in post school transition for student with disability" (p. 47). True inclusion does not focus on the difficulties, even impossibilities, as perceived by some educators; instead the emphasis is on finding ways and means to achieve success.

For older teachers the comparatively recent inclusion of more students with disabilities into mainstream high schools has proved a challenge. Naomi, a learning support coordinator (a teacher who coordinates the special needs program) shared these comments:

Naomi's perspective:

"The teachers here work hard but the older staff find it (inclusion into the mainstream) harder. They probably didn't have any special education in their basic teacher training and so as much as they nod and smile, they quietly resist.

The younger ones are a lot easier, they want to know; they'll ask questions."

Another, recent initiative by the Australian government has been the National Disability Insurance Scheme (NDIS) which is currently being introduced, whereby support funds are allocated to individuals to assist with education and training, rather than block grants to providers. As this program is developed nationally in Australia it remains to be seen how effective it will be and how adequately the funding is able to support the needs of individuals with disabilities in general, and in the transition process in particular. The following quote illustrates the challenge that must be met:

"Despite increased investment, increased year twelve completion rates and more involvement by the Commonwealth in youth transitions in recent years, fewer students are making a successful transition from school than a decade ago."

Department of the Prime Minister and Cabinet, 2014.

Moving forward....

This chapter began with comments by Rud and Ann Turnbull (2015), and it seems appropriate to conclude by observing that although pioneering parents of children with

disabilities wanted an education for their children and fought for it, they, in truth, wanted more.

They wanted educators to recognise that they are the foundations for their children; to regard them with empathy; and to convert that empathy into compassion that, in turn, creates ethical communities, places where they and their children are treated with dignity, places where their children ‘get a life’ – a life not just during their elementary and secondary years but, indeed, across their entire lifespan—characterized by equality of opportunity, independent living, full participation, and economic self-sufficiency. (Turnbull & Turnbull, 2015, p. 56)

Poed and Elkins (2012) noted that “arguments in favour of inclusive schooling are rendered ineffective if those students who are included are unable to achieve satisfactory adult lives” (p. 46).

If the last fifty years have seen education accepted as a right for people with disabilities, the next stage, that of vocational and post school options and ‘getting a life,’ must similarly progress. Vital aspects include: transition planning with family and student inclusion to be mandated to start at age 14, both national and state (covering both private and public schools); a national coordination plan for transition from school, with “defined responsibilities, objectives and outcomes” (CDA, 2015); “specific training opportunities for school staff and parents” (Beamish, Meadows, & Davies, 2012, p. 239); and post-school research follow-up with young people with disabilities. However, the transition process and outcomes for young people with disabilities will only improve as parents, family members and concerned professionals continue to work together and pressure governments, voicing the need for improvement through legislation, funding, relevant policies and accountability. It can and must be done.

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