

Anthony D Harman, MSc (DD) Hons

FOR: ASSID - 2006

DATE DUE: 04-09-06

TOPIC:

Investigating the Transition of Children with Autism from School, to the Community, Work,
or Further Education.

LENGTH: 2,000 words

CONTENTS

ABSTRACT	III
Background	1
The Transition Challenge	1
Transition between School, Further Education, and the Community	2
Lessons from Abroad	3
The Perspective from Australia	5
Where to from here	7
Conclusion:	8
REFERENCES:	10

ABSTRACT

The need for better practice in transition is highlighted in reviewing how the past 15 years have reflected an increased focus on improving transition education and services for youth with disabilities. Three initiatives that characterise this development in the USA: (a), federal special education and disability legislation; (b), federal, state, and local investment in transition services development; (c), and effective transition practices research are discussed. Effective areas of transition practice are reviewed: student-focused planning, student development, interagency collaboration, family involvement, and program structures, with the conclusion that developing specific interventions and service arrangements for individual students within each of these areas is essential for post-school success.

"Each person designs his own life, freedom gives him the power to carry out his own designs, and power gives the freedom to interfere with the designs of others"

Eric Berne. 1910-1970, Psychiatrist, Writer

Background

This paper gives an overview of the current transition process in relation to Autism Spectrum Disorder (ASD), asks if the procedure is satisfactory and considers whether it should be standardised.

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disability that typically appears during the first three years of life and primarily affects an individual's abilities in the areas of communication and social interaction. A good deal is known about children with autism but relatively little has been written concerning outcome in adult life, particularly for those individuals of high ability (Howlin, 1997). Furthermore cognitive impairment often co-occurs with autism and 70 -75 per cent of people with autism also have intellectual disability (IQ below 70); also half of all individuals with autism fail to develop functional and communicative language.

The Transition Challenge

Although there has been extensive research covering the autistic spectrum (for example Attwood, 1998; Baron-Cohen, 2000; Bishop, 1989; Connor, 1999; Dempsey & Foreman, 2001; Edelson, 1999; Fombonne, 2003; Grandin, 2000; Griffiths, Stavrakaki, & Summers, 2002; Howlin & Moore, 1997; Jordan, 2000, 2001; Klin & Volkmar, 1995; Volkmar & Lord, 1998; Waterhouse, Morris, Allen, Dunn, Fein, Feinstein, Rapin, & Wing, 1996; Wetherby & Prizant, 2000; Wing, 1981), the majority of studies tend to focus on the pre-school years, early intervention, subsequent integration into school, and teaching methods; with the subject of transition to further education, work, and beyond eliciting sparse coverage. Even in America where legislation highlights the process, Wolters, O'Day, Andersson, Rangel-Diaz, and Hawkins (2000), suggested that 'barriers to successful post-school outcomes for youth with disabilities have persisted, despite federal legislation, research initiatives, and evidence of promising practices (p. 27).

Recent research undertaken by the Home Farm Trust and Norah Fry Research Centre (Heslop, Mallet, Simons, & Ward, 2002) in the United Kingdom indicated that despite legislation and

guidance, whether or not a pupil had received transition planning made little significant difference to the outcome after leaving school. They suggest that the five Cs exemplify elements in a good transition experience, i.e. communication, coordination, comprehensiveness, continuity, and choice.

Transition between School, Further Education, and the Community

The transition period is likely to be of particular stress for individuals with autism, support systems that were available in childhood and adolescence tend to disappear once school or college is complete. Howlin (1997), in the UK context, indicates that studies consistently highlight the development of language as a crucial factor for later outcome in autism with approximately 30 per cent of individuals remaining without useful speech and significant impairments continuing throughout adulthood.

It is important to remember that a student's dreams, interests and goals must drive the transition planning whilst they should also be given every opportunity to understand their options and lead the process; skills they should develop with appropriate supports and opportunities (Twenty-Eighth Institute on Rehabilitation Issues (IRI), 2002).

Nuehring & Sitlington (2003), presented four case studies of individuals with autism and their experiences of transition, including current transition of a high school senior and an analysis of the transitions made by three previous graduates from the same high school program. Significant outcomes that emerged were the choices that students with disabilities had and the fact that each of the programs employed a transition specialist.

Four areas of improvement drawn from the observations of professionals in the field are:

1. Increased education of high school teachers and staff of the adult vocational service providers (regarding characteristics of individual disabilities).
2. The use of assessment data throughout transition.

3. Increased communication among the individual, his or her family, the school, and the future adult vocational service provider, and
4. Aligned programming between the high school and the students' future environments.

Specialist-training at university, discipline-specific training, or agency sponsored in-service programs were also recommended by DeFur & Taymans (1995).

Perhaps the most focused paper in relation to transition and autism comes from the Oregon Department of Education (2003), which looks at student characteristics such as communication and social interaction impairments, patterns of behaviour and unusual responses. They also highlighted the unique needs of students with autism such as auditory processing difficulties, regulating or shifting attention, sensory regulation, impaired speech production and cognitive impairments.

Alberta Learning (2003), suggested that transition should be carefully and thoughtfully planned, not only between activities and settings throughout the day, but from one grade to the next, one school to another, and to adult life.

... it is important that parents, school personnel, and representatives from community agencies and support services consider long-term planning since future goals and plans help direct programming throughout high school (p. 130).

Lessons from Abroad

The Autism Society Of America (2002), suggested four components of a transition plan that are consistent with wider literature on transition planning and are not dissimilar to those outlined above:

1. The plan, including goals and services, must be based on the individual needs, preferences, and skills of the person with autism.
2. Transition planning should be oriented to life after high school, not limited to what will be accomplished before leaving school.

3. There should be a master plan which includes long range goals and a coordinated set of activities for each.
4. The services provided should promote positive movement towards a life after school.

Furthermore, recent US reforms following the *No Child Left Behind Act of 2001* (2002), are based on the four basic principles of increased accountability for results, more choices for parents and students, greater flexibility for States, School Districts, and Schools, and proven education methods. Also in the United States, the Department of Education is currently conducting the National Longitudinal Transition Study-2 (NLTS2). The outcomes should present a national picture of experiences and achievements of young people that will guide future educational policy and programs, and help them to achieve success in adult life. This is an adjunct to the original NLTS, which for 6 years, tracked, collected data from, and reported on the experiences of more than 8,000 secondary school students with disabilities from 300 school districts across the nation (SRI Center for Education and Human Services, 1993).

Kohler and Field (2003), offered a different standpoint in reviewing how ‘the past 15 years have reflected an increased focus on improving transition education and services for youth with disabilities’ (p. 174). They highlighted three initiatives that characterise this development: (a), federal special education and disability legislation; (b), federal, state, and local investment in transition services development; (c), and effective transition practices research.

Looking at the outcomes of these initiatives, which included an expanded perspective concerning ‘transition education and services’ together with an identification of practices that apply this perspective to individual student needs. The authors viewed transition planning as,

... not as an add-on activity for students with disabilities once they reach age 14 or 16 but rather as a fundamental basis of education that guides the development of all educational programs (p. 176).

Furthermore ‘one size fits all’ and ‘check the box’ transition planning strategies do not effectively prepare students with disabilities – who all have unique needs – for successful, fulfilling adult roles (p. 181).

According to Howlin (1997), support services are particularly well established in the US with provision in Britain less advanced although there has been a steady growth in colleges for people with learning disabilities. It could be argued that legislation in the United States whilst not solving all the problems has at least brought the issue into focus.

The Perspective from Australia

Transition first came into focus in Australia following a national workshop held in Canberra in June 1985. The Australian Steering Committee (1986), of the OECD/CERI project, proposed that there were three stages of transition: preparation, the process, and the life situation. This workshop also led to an Australian viewpoint on the transition process for the World Rehabilitation Fund (Parmenter, 1986) and gave ten examples of transition programs. Subsequently, Riches (1996), noted that although there have been a number of changes and refinements in the process it is critical for students, parents, communities, departments, and agencies at both central and local level to work in partnership and improve experiences and outcomes for students with disabilities. The point was also made that as transition planning is not obligatory, the need for constant review is vital for the welfare of students. On the positive side Riches detailed the partnerships forged between the Community Transition Teams and Disability Forums, which have resulted in improved outcomes for many students.

The new Commonwealth State/Territory Disability Agreement (CSTDA) (2003), lays out five key policy priorities:

- ♦ Strengthen access to generic services by people with disabilities;

- ♦ Strengthen across government linkages which aims to improve the interface between employment services and community access services;
- ♦ Strengthen individuals, families, and carers;
- ♦ Improve accountability, performance reporting, and quality;
- ♦ Improve long-term strategies to respond to, and manage demand for, specialist disability services (Australian Institute of Health and Welfare (AIHW), 2003a).

Figures from the AIHW indicate that disability was, on average, associated with lower achievement at school. A higher proportion of young people aged 15 - 24 years without a disability completed Year 12 than did those with a disability - 53%, compared with 32%. A higher proportion of young people aged 20 - 24 years without a disability had post-school qualifications than had those with a disability - 69%, compared with 57%. Approximately 43% of young people aged 20 - 24 years without a disability have post-school qualifications, compared with 31% of those with a disability (Australian Institute of Health and Welfare (AIHW), 2003a, p. 68). Additionally:

- ♦ Around 56% of young people with a disability who attended school were reported to have difficulties at school because of their disability.
- ♦ About 10% of young people attending school needed time off school because of their disability.
- ♦ The most frequently reported difficulty at school was fitting in socially with approximately 25% of young people with a disability attending school reported as having this problem.

The fact that transition planning is not obligatory and that on a given day only 12% or 301 people with autism out of 2,500 who received CSDA-funded services (Australian Institute of Health and Welfare (AIHW), 2003b), were using employment services is cause for concern.

Consumers of CSDA-funded Services on a snapshot day, service group by primary disability group, 2002

Primary disability group	Accommodation support		Community support		Community access		Respite		Employment		Total	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Intellectual	15,589	39.1	5,413	13.6	12,874	32.3	1,668	4.2	12,216	30.6	39,909	100.0
Specific learning/ADD	35	3.8	175	19.2	147	16.1	21	2.3	562	61.7	911	100.0
Autism	541	21.6	1,084	43.4	619	24.8	228	9.1	301	12.0	2,500	100.0
Physical	2,608	32.6	2,519	31.5	1,669	20.9	631	7.9	1,709	21.4	8,002	100.0
Acquired brain injury	913	37.6	514	21.2	608	25.1	169	7.0	496	20.4	2,427	100.0
Neurological	657	29.0	956	42.2	307	13.5	159	7.0	390	17.2	2,266	100.0
Deafblind	43	25.3	47	27.6	39	22.9	12	7.1	55	32.4	170	100.0
Vision	194	11.3	457	26.6	681	39.7	117	6.8	327	19.1	1,716	100.0
Hearing	70	8.2	296	34.7	176	20.6	11	1.3	324	37.9	854	100.0
Speech	16	4.0	330	81.5	33	8.1	6	1.5	32	7.9	405	100.0
Psychiatric	1,607	32.8	129	2.6	1,416	28.9	117	2.4	1,830	37.4	4,896	100.0
Developmental delay	3	0.3	1,085	98.1	3	0.3	23	2.1	0	0.0	1,106	100.0
Total	22,373	34.0	13,211	20.1	18,866	28.7	3,214	4.9	18,242	27.7	65,809	100.0

(Australian Institute of Health and Welfare (AIHW), 2003b)

Where to from here

It is the transition process, employed in the context of those later school years which mark the process of moving from school to work, the community, or further education where we are failing to improve our services and make an important contribution to the future of students with disabilities.

The enactment of the Disability Services Act 1986 (2002), along with a set of principles and objectives put into law the following, underlying the provision of social justice to people with disabilities:

- ♦ Every person with a disability has the same rights as other members of Australian society to realise his or her individual capacity for physical, social, emotional and intellectual development.
- ♦ People with disabilities have equal rights to services, which will support their attaining an acceptable quality of life.

- ♦ Programs and services should promote participation of people with disabilities in the life of the local community through maximum physical and social integration.
- ♦ Programs and services should provide opportunities for people with disabilities to reach goals and enjoy life-styles, which are valued by the community at large and are appropriate to their age.

Additionally Parmenter (1999), drew attention to a number of key consumer outcomes including paid employment, security, and community respect and acceptance as a foundation for program development for people with disabilities when referring to Senator Don Grime's evaluation following a nation-wide consultation (Grimes, 1985).

Person-centred planning is also an increasingly accepted component of the transition process and has been widely documented. Routledge (2001), indicated that experience shows person-centred planning can make a considerable input to better transition support.

Conclusion:

Transition, as one can see, has been extensively explored, and covers a number of fields of enquiry. Overall it can be delineated into the three subject headings covering best practices as suggested by Collet-Klingenberg (1998), namely planning, implementation, and follow-up services.

It is clear that students and families are the primary stakeholders in the transition process and as such, bear the majority of responsibility as well as reward for effective transition. It is therefore essential that students with disabilities and their families are placed at the centre of planning for the future and have access to the full range of options. They are given choices, and learning experiences, which allow them to build careers with adequate provision of support as required (Beach Center on Families and Disability, 2000; Johnson, Stodden, Emanuel, Luecking, & Mack, 2002; Routledge, 2001). In addition, particularly for students with ASD, central to the student's

success must be the ability to match the transition program to the individual student in all aspects (South Australia Ministerial Advisory Committee: Students with Disabilities, 2000).

The National Council on Disability (2004), asks ‘what practices work in transition’? There is unfortunately limited evidence-based research in this area and in reality, ‘research will likely continue to focus in the short term on early education and reading, leaving a void in research for secondary school students with disabilities, and transition’ (p.56).

This also appears evident in reviewing the literature with a distinct lack of specific research in the field of transition in relation to individuals with ASD. A smoother, more integral transition process is required which places the individual and their family at the very heart of the procedure.

Perhaps ultimately, we should consider the challenges detailed by Johnson and colleagues (2002):

- Ensure students with disabilities have access to the full range of general education curricular options and learning experiences;
- Make school graduation decisions based on meaningful indicators of students learning and skills, and clarify the implications of different diploma options for students with disabilities;
- Ensure students access to, and full participation in, postsecondary education, employment, and independent living opportunities;
- Support student and family participation;
- Improve collaboration and system linkages at all levels.

Transition is a life changing experience and is often reached at that point where expectations are at their highest and service levels at their lowest. As Kohler and Chapman (1999), so pertinently remind us,

We can say that there is some evidence to support various practices, but also that no body of evidence exists that unequivocally confirms any particular approach to transition, nor is there any strong evidence to support individual practices. At most, we can say there is guarded support for some practices and that some approaches remain indeterminate (p. 24).

REFERENCES:

- Alberta Learning. (2003). *Teaching Students with Autism Spectrum Disorders* (Vol. 9). Alberta: Alberta Learning and Teaching Resources Branch.
- Attwood, T. (1998). *Asperger's Syndrome A Guide for Parents and Professionals*. London: Jessica Kingsley Publishers.
- Australian Institute of Health and Welfare (AIHW). (2003a). *Australia's Young People: Their Health and Wellbeing 2003* (No. AIHW Cat. No. PHE-50; ABS Cat. No. 8922.0): AIHW.
- Australian Institute of Health and Welfare (AIHW). (2003b). *Disability support services 2002: national data on services provided under the Commonwealth/State Disability Agreement* (No. AIHW cat. no. DIS 31). Canberra: AIHW.
- Australian Steering Committee. (1986). *A Strategy for Disabled Youth in Transition* (National Steering Committee Report). Canberra: National Workshop.
- Autism Society Of America. (2002). *Life After High School*. Retrieved 29 April, 2004
- Baron-Cohen, S. (2000). Is Asperger Syndrome/High-Functioning Autism necessarily a disability? *Development and Psychopathology*, 12(3), 489-500.
- Beach Center on Families and Disability. (2000). *Quality Indicators of Exemplary Transition Programs* (Fact Sheet). Kansas: The University of Kansas, Lawrence, Kansas.
- Bishop, D. V. M. (1989). Autism, Asperger's syndrome and semantic-pragmatic disorder: Where are the boundaries? [Electronic version]. *British Journal of Disorders of Communication*, 24, 107-121.
- Collet-Klingenberg, L. L. (1998). The reality of best practices in transition: A case study. *Exceptional Children*, 65(1), 67.
- Commonwealth State/Territory Disability Agreement (CSTDA), Commonwealth of Australia 38 (2003).
- Connor, M. (1999, 19th November, 2000). *Autism and Asperger Syndrome - Overview and some Classroom Strategies*. Retrieved 2nd June, 2003, from <http://www.mugsy.org/connor1.htm>
- DeFur, S. H., & Taymans, J. M. (1995). Competencies needed for transition specialists in vocational rehabilitation, vocational education, and special education. *Exceptional Children*, 62(1), 38-51.
- Dempsey, I., & Foreman, P. (2001). A Review of Educational Approaches for Individuals with Autism. *International Journal of Disability, Development and Education*, 48(1), 103-116.
- Disability Services Act 1986, Commonwealth of Australia, 1 July 2002 Sess., Amendments up to Act 28 Cong. Rec. 72 (2002).

- Edelson, S. M. (1999, March 31, 2003). *Overview of Autism*. Retrieved 8th March, 2003, from <http://www.autism.org/overview.html>
- Fombonne, E. (2003). The Prevalence of Autism. *Journal of the American Medical Association*, 289(1), 87-89.
- Grandin, T. (2000, March 1998). *An Inside View of Autism*. Retrieved 26th May, 2003, from <http://www.autism.org/temple/inside.html>
- Griffiths, D. M., Stavrakaki, C., & Summers, J. (2002). *Dual Diagnosis: An introduction to the mental health needs of persons with developmental disabilities*. Ontario: Habilitative Mental Health Resource Network. Retrieved, from <http://www.dualdiagnosisontario.org/>
- Grimes, D. (1985). *New Directions* (Report of the Handicapped Programs Review). Canberra: Australian Government Publishing Service.
- Heslop, P., Mallet, R., Simons, K., & Ward, L. (2002). *Bridging the Divide at Transition - What happens for young people with learning difficulties and their families?* (Final summary of research findings). Bristol: British Institute of Learning Disabilities (BILD).
- Howlin, P. (1997). *Autism preparing for adulthood*. London: Routledge.
- Howlin, P., & Moore, A. (1997). Diagnosis in autism. *Autism*, 1(2), 135-162.
- Johnson, D. R., Stodden, R. A., Emanuel, E. J., Luecking, R., & Mack, M. (2002). Current challenges facing secondary education and transition services: what research tells us. *Exceptional Children*, 68(4), 519-531.
- Jordan, R. (2000, 19-20 May). *The Autistic Spectrum: Current Understanding*. Paper presented at the Conference of World Autism Organisation, Glasgow.
- Jordan, R. (2001). Multidisciplinary work for children with autism [Electronic version]. *Educational and Child Psychology*, 18(2), 154-163.
- Klin, A., & Volkmar, F. R. (1995). *Asperger's Syndrome: Guidelines for Assessment and Diagnosis*. Pittsburgh: Learning Disabilities Association of America.
- Kohler, P. D., & Chapman, S. (1999). *Literature Review on School-to-Work Transition*: Transition Research Institute, University of Illinois.
- Kohler, P. D., & Field, S. (2003). Transition-focused education: Foundation for the future. *The Journal of Special Education*, 37(3), 174-183.
- National Council on Disability. (2004). *Improving Educational Outcomes for Students with Disabilities*: NCD.
- No Child Left Behind Act of 2001, 107th Congress, 1425 9601 Cong. Rec. 670 (2002).

- Nuehring, M. L., & Sitlington, P. L. (2003). Transition as a Vehicle: Moving from High School to an Adult Vocational Service Provider. *Journal of Disability Policy Studies, 14*(1), 23-35.
- Oregon Department of Education. (2003, n.d.). *Startegies for Transition Planning for Students with Autism Spectrum Disorder (ASD)*. Retrieved 20 September, 2004, from www.ode.state.or.us/gradelevel/hs/transition/asd.pdf
- Parmenter, T. R. (1986). *Bridges from school to working life for handicapped youth: The view from Australia* (Monograph No. 33): Macquarie University.
- Parmenter, T. R. (1999). Effecting a system Change in the Delivery of Employment services for People with Disabilities: A view from Australia. *Journal of Vocational Rehabilitation, 13*, 117-129.
- Riches, V. C. (1996). A review of transition from school to community for students with disabilities in NSW, Australia. *Journal of Intellectual and Developmental Disability, 21*(1), 71-88.
- Routledge, M. (2001). *Transition and Person Centred Planning* (Report). London: Department of Health.
- SRI Center for Education and Human Services. (1993, 21 July 2004). *The National Longitudinal Transition Study (NLTS)*. Retrieved 28th November, 2004, from <http://www.sri.com/policy/cehs/publications/dispub/nlts/nltssum.html>
- Twenty-Eighth Institute on Rehabilitation Issues (IRI). (2002). *Investing in the Transition of Youth with Disabilities to Productive Careers*: IRI Prime Study Group.
- Volkmar, F. R., & Lord, C. (1998). Diagnosis and definition of autism and other pervasive developmental disorders. In F.R. Volkmar (Ed.), *Autism and Pervasive Developmental Disorders* (pp. 1-31). Cambridge: Cambridge University Press.
- Waterhouse, L., Morris, R., Allen, D., Dunn, M., Fein, D., Feinstein, C., et al. (1996). Diagnosis and Classification in Autism. *Journal of Autism & Developmental Disorders, 26*(1), 59-88.
- Wetherby, A. W., & Prizant, B. M. (Eds.). (2000). *Autism Spectrum Disorders: A Transactional Developmental Perspective* (1st ed. Vol. 9). Baltimore: Paul H Brookes Publishing Co.
- Wing, L. (1981). Asperger syndrome: a clinical account. *Psychological Medicine July, 11*, 115-129.
- Wolters, K. P., O'Day, B., Andersson, Y., Rangel-Diaz, L., & Hawkins, G. (2000, 1 November,). *Transition and Post-School Outcomes for Youth with Disabilities: Closing the Gaps to*

Post-Secondary Education and Employment. Retrieved 19 September, 2002, from
http://www.ncd.gov/newsroom/publications/transition_11-1-00.html