

Destination unknown? Transition to adulthood for people with autism spectrum disorders

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This article, written by Ewelina Rydzewska, a PhD student and associate lecturer at the University of the West of Scotland, draws upon a range of research evidence in order to explore the process of transition to adulthood for people with autism spectrum disorder (ASD). It provides a brief overview of extended and complex youth transitions in different cultural contexts, with particular reference to Scotland. It also highlights particular patterns of vulnerability for people with ASD. The focus here is on the nature of ASD and its impact on the transition to adulthood, the conceptualisation of this process, the characteristics of effective service provision, as well as the ever-changing social, political and economic context of young people's transitions. The article concludes with a summary of principal conclusions drawn from the current literature and some suggestions for future research.

Key words: autism spectrum disorder, transition to adulthood, young adults, objective demographic markers.

Introduction

The move from school to work or tertiary education brings with it many changes. For people with autism spectrum disorder (ASD), the transition is especially demanding and challenging. However, many individuals with ASD who do not have additional cognitive impairments and who are sometimes described as being at the 'high-functioning' end of the spectrum are able to achieve success in adult life. Unfortunately, as the literature reviewed in this article shows, they tend to do so despite a lack of adequate provision (Howlin, 2004).

The literature search was conducted in two phases. The main aim of the first phase was to identify literature pertaining to the transition to adulthood for people with ASD. In the second phase, the focus of the search was broadened to transitions to adulthood for *all* adults. The search was restricted to English-language publications, but no time limit was established since the article discusses contextual change for all transitions to adulthood taking place in the UK in the last six decades. A number of journals of high relevance were searched electronically by using various combinations of key words and wild card prefixes such as adolescence, ASD, young adulthood, transition*, autism, Asperger, and school to work transition.

There is a degree of consensus in the research literature as to what the successful transition to adulthood implies. For most young people this process is traditionally marked by a gradual appearance of *objective demographic markers* (Hendricks & Wehman, 2009), such as entry to further education, marriage, work training or gaining employment (Thomson, Ward, Dyer & Riddell, 1992). However, even the 'conventional' or 'normal' life course brings with it a huge dose of subjectivity in a form of varying degrees of difficulty in coping with these events. For people with ASD, there are usually additional obstacles (Sperry & Mesibov, 2005).

Underlying the hardships of all adolescents and young adults with ASD is the triad of impairments, which refers to difficulties with social interaction, social communication and imagination (Wing & Gould, 1979, cited in Boucher, 2009; Cook, Gerber & Murphy, 2000; Phetrasuwan, Miles, Mesibov & Robinson, 2009). The above may mean that even the simplest personal interactions are fraught with obstacles and barriers. Therefore, it is of great importance to develop the resilience to cope with sudden and unpredictable transitions as it is not always possible to carefully plan and manage all of them.

This article aims to contribute to the understanding of the process of transition by providing an overview of extended and complex youth transitions in different cultural contexts in western countries, with particular attention to Scotland. Effective mechanisms for social inclusion will also be highlighted. However, the main focus is on the patterns of vulnerability that are evident in young people with ASD and their impact on the transition to adulthood.

What is ASD?

Autism spectrum disorder is a term used to describe a group of several pervasive developmental conditions, including autism and Asperger syndrome (Forsythe, Raihm & Bell, 2008). They are characterised by a triad of impairments in social interaction, social imagination and communication and share common traits such as an extremely limited range of activities and interests, repetitive and stereotyped behaviours and low awareness of social rules (Wing & Gould, 1979, cited in Boucher, 2009; Forsythe et al., 2008; Wehman, Datlow Smith & Schall, 2009; Higgins, Koch, Boughfman & Vierstra, 2008).

As Frith (2003) remarks, there are certain behavioural criteria for the diagnosis of ASD which have been made explicit and continuously updated in published reference

works. The main change over time has been widening of the criteria. The most detailed and most recent scheme is the one described in the *Diagnostic and Statistical Manual (DSM)* of the American Psychiatric Association. A similar diagnostic scheme is available in the *International Classification of Diseases (ICD)* issued by the World Health Organization (Frith, 2003).

At the time of writing, the most recent version of the *Diagnostic and Statistical Manual*, first published in 1994 as DSM-IV, is the *Text Revised* version known as DSM-IV-TR, published in 2000 (APA, 2000). A fifth edition of the manual is currently in consultation, planning and preparation. It is due for publication in May 2013 and will supersede the DSM-IV-TR (APA, 2010).

There are five disorders under the umbrella of the term 'autism spectrum disorder' (ASD), also classified by the American Psychiatric Association's *Diagnostic and Statistical Manual* as pervasive developmental disorders (PDDs) (see Phetrasuwan et al., 2009). These are three subtypes of autism:

- autism (or autistic disorder);
- Asperger (or Asperger's) syndrome [the term 'Asperger disorder', used in DSM-IV, never entered common usage. Instead, the term 'Asperger's syndrome', with lower-case 's' (or the acronym AS) has been widely used in its place. It is also common to refer to this condition as Asperger syndrome without the additional 's', and pronounced with a hard 'g' as in the original German (Boucher, 2009)];
- Pervasive developmental disorder-not otherwise specified (PDD-NOS) [in ICD-10 the term 'PDD-NOS' is replaced with the term 'atypical autism'];

as well as:

- Rett syndrome (or Rett's disorder);
- Childhood disintegrative disorder (CDD) (Boucher, 2009; Phetrasuwan et al., 2009).

Since this article focuses on transitions to adulthood for people at the high-functioning end of the autistic spectrum and recent research provides little support for the distinction between Asperger syndrome (AS) and high-functioning autism (HFA), the term 'autism' will be used in this text when referring to any label from the group of the three different autism-related PDDs. Except when otherwise specified, the information, strategies, and recommendations apply to individuals with ASD, regardless of specific diagnosis or level of functioning. Asperger syndrome is not distinguished from high-functioning autism. Nevertheless, when making references to other authors, the original terminology has been retained, whether or not diagnostic criteria are specified.

Conceptualising transition

The analysis and critique of literature on the stage of adulthood, conducted with a specific focus on the period of early

adulthood and higher-ability young adults with ASD, undoubtedly show a consensus, at least to a certain extent, as to what 'being an adult' means. The process of transition from school services to adulthood for youth with ASD is usually claimed to comprise the following areas: completing school, gaining employment, participating in postsecondary education, contributing to a household, participating in the community, and experiencing satisfactory personal and social relationships (Hendricks & Wehman, 2009). Therefore, four broad themes of education, employment, community living and community integration seem to be emerging as crucial dimensions of success in adulthood (Gauthier & Furstenberg, 2002; Hendricks & Wehman, 2009; Wehman, 2006).

Gauthier and Furstenberg (2002) give a more universal definition of transition to adulthood referring to the general population of young adults aged 18 to 34 from nine industrialised countries. They stress the importance of major challenges in lifestyles, responsibilities and autonomy that come with all transitions and add that 'overwhelmingly, the transition to adulthood has . . . been studied from the perspective of *objective* demographic markers (such as entry into marriage and parenthood)' (Gauthier & Furstenberg, 2002).

This article focuses on the subjectivity of these objective demographic markers as well as the continuous nature of the process of transition to adulthood. Since this process can nowadays be very much dependent on individual life choices and lifestyles, it is rather difficult to capture it within any confined time frames. Moreover, a review of the literature in relation to the four key areas of the transition (education, employment, community living and community integration) showed deficiency in investigation of how much progress can be made along the continuum by people with ASD, as little is known about the prognosis or long-term outcomes for adults on the spectrum (Hurlbutt & Chalmers, 2002). Even relatively recent publications highlight that there is still a strong need to research how these adults cope with everyday existence, how they feel autism has affected their lives, and what they think is relevant for parents and professionals to know about being an adult with ASD (Hendricks & Wehman, 2009; Higgins et al., 2008; Howlin, 2004).

Overview of current provision

There are 32 local authorities and 40 Community Health Partnerships (CHPs) in Scotland which are organised into a number of specialist services. People with ASD tend to approach the learning disability and mental health teams in those administrative units in order to obtain health, social and educational help and support (Daly, 2008). The National Health Service Reform (Scotland) Act 2004 (Scottish Government, 2004) stated that every NHS health board should set up CHPs with the broad function of coordinating its various activities. In some areas, CHPs are called Community Health and Care Partnerships (Scottish Government, 2004; Daly, 2008).

It is estimated that around 50,000 people in Scotland have ASD, and that around 35,000 of these individuals are adults

(Daly, 2008). However, the true number of adults with ASD in Scotland is still unknown (Daly, 2008; Kelly 2010) as the majority of local authorities (60%) and CHPs (92%) keep no record of the number of adults with ASD in their area (Daly, 2008). Existing records are very inconsistent as the number of adults included in them ranges from 833 in one local authority (around one in 100 of the local population), to 33 adults in another (around one in 500) (Daly, 2008). The latter figure represents a serious underestimation given the fact that recent national studies suggest that around one in 100 people have ASD (Baird, Simonoff, Pickles, Chandler, Loucas, Meldrum & Charman, 2006; Green et al., 2004 cited in Kelly, 2010).

According to studies conducted by Daly (2008) for the National Autistic Society Scotland, adults with ASD in Scotland struggle to access the support they need to live their lives as fully as possible. The majority experienced problems in trying to receive support from their local authority or health board. Initiatives were undertaken in the past to resolve these issues when Public Health Institute of Scotland (PHIS) published the *Autistic Spectrum Disorders Needs Assessment Report* (Scottish Executive, 2006). The report suggested priorities for multi-agency service planning and delivery. The Scottish Government subsequently established a national Autism Spectrum Disorder Reference Group to inform a programme of work to support and encourage the development of good practice. The Group, consisting of users, carers and professionals, operated until 2008 to take forward the recommendations in the Public Health Institute of Scotland (PHIS) Needs Assessment (Scottish Government, 2008).

As part of its work, the Group sought to build on a number of positive developments and focused on action to put policy into practice and created specific guidance (Scottish Government, 2008). The aim was to provide information for service commissioners on the best available knowledge about ASD and current service provision in Scotland and guidance on how these services might better meet the needs of people with ASD in the future (Kelly, 2010).

The guidance also identifies forms of adult services in Scotland available to people with ASD (Scottish Government, 2008). They include local area coordination responsible for working with people with learning disabilities and ASD and their families; self-directed support, which is part of the mainstream of social care delivery and is targeted at empowering people and putting the principles of independent living into practice; advice and information services; supported living; vocational training and support; day/activity services; employment opportunities; peer support and social groups; and respite and short breaks facilities (Scottish Government, 2008).

A survey conducted by the National Autistic Society (Reid, MacBean & Charles, 2009) showed that although one of main aims of the existing service provision in Scotland is to support people with ASD in obtaining employment, it is generally poorly rated. The online survey was completed by

443 people. Respondents included people on the autism spectrum, parents and professionals, and the majority responded on behalf of an adult or a child with autism. Of those who had a diagnosis, 38% had a diagnosis of autism, while 58% had a diagnosis of Asperger syndrome or high-functioning autism. The main findings can be summarised as follows:

- 95% of respondents thought that more services were needed locally for people with ASD;
- 48% rated their overall experience of services to help them with their autism as poor or very poor;
- almost a quarter (23%) had to go outside their own local authority to get the right services;
- a third had to go to a tribunal to get the right support;
- 42% of respondents rated care professionals' understanding of autism as poor or very poor;
- key elements missing were social support, advocacy, self-directed support, employment support or training, and short breaks/respite (Reid et al., 2009).

There are certain overarching features that appear to characterise effective provision (Furlong, Cartmel, Biggart, Sweeting & West, 2003; Kaehne & Beyer, 2009). Lowden, Devlin, Hall, Head and Lewin (2009) suggest that good practice in provision for people with ASD is characterised by being person-centred, accessible, participative, engaging, flexible, relevant and credible to young people. It addresses core personal and social competencies and promotes self-esteem and aspirations. It is responsive to the views of young people and involves them in the design of approaches and the setting of targets (Lowden et al., 2009). The latter process can be significantly challenged if we take into account some of the core social abnormalities in ASD such as unresponsiveness to people or problems with verbal and non-verbal communication (Baron-Cohen & Bolton, 1993).

The consensus within the research literature is that embedding autism services within a wider strategic framework involving relevant local and national partners should facilitate good practice in provision for people with ASD. These partners include schools, colleges and universities, social work, educational psychological services, employment agencies and supported employment services, transition services and community learning services. This strategic framework facilitates the sharing of ideas, deploying appropriate resources and skills to deliver holistic and flexible provision and to offer progression pathways (Furlong et al., 2003; Lowden et al., 2009; Scottish Intercollegiate Guidelines Network, 2007).

Kaehne and Beyer (2009) suggest that in order to make the holistic provision work best, all key stakeholders should be represented in planning and decision-making. In reality, however, there is insufficient funding to implement this vision. Therefore, in spite of working in creative and effective ways to meet the needs of young people, providers and partner stakeholders face a number of considerable challenges. Autism is often referred to as an 'invisible disability' and its invisible nature is strongly reflected in local service

provision. Eighty percent of people who have heard about autism are unaware how common it is and 49% do not know that it is a lifelong condition (Reid et al., 2009).

Adults with ASD have particular difficulty in accessing appropriate service provision, as getting a diagnosis, which is often a critical requirement for getting support, is particularly challenging and hard for them. The Autism Services Directory provided by the National Autistic Society Scotland identifies just 12 services in Scotland providing adult diagnosis. Scottish Government guidance is clear that this should not be the case, but too often not having a diagnosis creates a barrier. Sixty percent of local authorities agree that having a diagnosis means someone is more likely to get support. Getting a diagnosis, however, can be a very daunting process and can take a long time, as there are few people with the expertise to diagnose autism (Reid et al., 2009). Therefore, the question arises as to whether late diagnosis of ASD is a contributory factor in the development of mental health problems in this group, and hence has an impact on life trajectories. However, such hypotheses need to be supported by large-scale and longitudinal research data and for this reason this matter will not be explored further here.

The planning of a transition from school to college or work can also have long-lasting consequences for young people with ASD. Poorly planned transitions contribute to later exclusion from local services and life opportunities. This can and often does have a devastating effect on the individual (Kaehne & Beyer, 2009). Where a change as significant as leaving school is concerned, there is a great need for effective preparation and planning, as moving to a new environment, often with less structure, and reduced or different forms of support, is extremely difficult.

Unfortunately, as the survey conducted by the National Autistic Society (Reid et al., 2009) demonstrates, the majority of young people with ASD still do not receive the support they need. There are a number of reasons for this. Frequently, information on children and young people is not passed on to local authority adult services teams. This often leads to young people with ASD being left without a transition plan. In addition, many of the key authorities, such as health, social work or housing, are not sufficiently involved in the decision-making and transition planning processes (Reid et al., 2009).

Moreover, many local adult services are organised into separate mental health and learning disability teams (Rose, Howley, Fergusson & Jament, 2009). Although some people with ASD have an accompanying learning disability and/or mental health needs, ASD itself is a developmental disorder, not a learning disability or mental health condition. This means that people with autism may not be able to access these services, or the service may not be able to support their autism-related needs. Learning disability services, for example, are only provided to those with an IQ below 70. This structure discriminates against adults with autism who do not have a learning disability (Reid et al., 2009).

Locating transition

Although the minimum school leaving age of 16 years has not changed since 1972 (Furlong et al., 2003), relatively few young people decide now to leave school at this stage and most enter further education or vocational training. The majority of young people in this situation still live with their parents or carers and postpone decisions about having a family or getting married until later in life. Higher education, once associated with privilege and elitism, has gradually become a mass experience, with half of the population of young people in Scotland now studying at this level (Furlong et al., 2003). In modern society, where the current labour market is very unstable and lifestyles are changing rapidly, young people generally complete education and training prior to, and not in the early stages of, initial labour market entry. Learning and skill development has become a lifelong process and an important key to work flexibility that brings with it a higher standard of living (Furlong et al., 2003).

Changing levels of educational participation, together with the demand for skilled and educated workers, have tightened the bond between education and employment, raising new concerns about social exclusion among the vulnerable and the disadvantaged, including people with disabilities (Furlong et al., 2003). New patterns of participation in education and training have resulted in a greater protraction of youth transitions in general. Few, especially among people with ASD, are able to make the early and direct transitions from school to employment that were relatively common in the 1960s and 1970s (Marshall, 1992). Transitions have become much more complex, resulting in young people's life courses being much less linear (Heinz, 2009). In this context, modern transitions have come to be viewed as marked by discontinuities, uncertainties and backtracking (EGRIS, 2001).

During the 1980s and 1990s the effects of social and economic change which began earlier in the century, especially changes in the industrial structure of Britain, the decline in manufacturing industry and as a result the decline in the number of manual workers, altered the context of education (Corbett & Barton, 1992; Bynner, 2001; Croxford, Iannelli, Shapira, Howieson & Raffe, 2006). Over these two decades the labour market required higher levels of educational qualifications, as an increasing proportion of the workforce nowadays is engaged in white-collar jobs. The need for educators to focus on teaching the skills required in the 'knowledge-based economy' (Croxford et al., 2006) has been emphasised by policy makers. Similarly, young people and their parents have been made increasingly aware of the importance of obtaining relatively high educational qualifications as a means of enhancing career opportunities (Croxford et al., 2006).

Moreover, education policies have themselves made a significant contribution to social change. Increased provision of free public education after the war, and subsequent raising of the school leaving age to 15 in 1947, and 16 in 1972, gave the parents of the school students of the 1980s and 1990s the

chance to experience increasing levels of education (Croxford et al., 2006). There have also been increasing opportunities for women in education and the labour market, following the reduction of barriers by the 1975 Sex Discrimination Act. In consequence, increasing rates of employment and educational participation by women have been observed since the 1980s (Croxford et al., 2006).

The objective demographic markers that used to define the timing of transitions seem to have lost their normative force in the course of the last few decades (Heinz, 2009). Today, most young people's individual biographical timetables no longer follow socially expected and culturally transmitted age norms. The borders between all phases of the life course have become blurred and fuzzy. The timing and duration of all transitions are less age-dependent and rely more on individual choices and lifestyles. What is more, even among those whose life trajectories can be mapped on to conventional transitions, there is considerable variation, not least in terms of their subjective experience. For people with ASD, there are usually additional obstacles in coping with the inevitable challenges associated with life transitions.

Although their transitions may be characterised by risk and uncertainty in general, the question arises as to the extent to which risk is attributable to individual and family characteristics, to educational attainment or to the routes followed by young people with ASD. Some routes seem to be less certain than others, and various individual characteristics and personal experiences serve to heighten or reduce the chances of success. Nevertheless, there is still little known about the relationship between these factors.

Perceptions of risk may extend across the social spectrum within the autism spectrum, yet it is clear that for some young people with ASD discontinuities and fluctuations are associated with marginalisation while others may be able to overcome adverse circumstances. This greater complexity makes it increasingly difficult to identify those who are vulnerable to long-term marginalisation and what are the most effective ways of preventing it. There is clearly a need for further research in this area.

Conclusion

Despite recent advances in knowledge, autism remains a lifelong, pervasive disorder which can greatly affect day-to-day functioning (Billstedt & Gillberg, 2005). The evidence suggests that if these difficulties are to be ameliorated, then it is crucial that the needs of people on the spectrum continue to be recognised and provided for as they move into adulthood and older age. Interdependencies between the nature of ASD, the objective demographic markers still used by young adults, institutions and parents as a means of orientation (Heinz, 2009), and a substantial lack of effective service provision for adults with ASD provide a very valuable insight into core problems experienced by this group. They seem to suggest that these instabilities and difficulties might to some extent stem from the tension between

uncertain life chances and the culture of post-industrial individualism, which expects people actively to shape their biographies (Bynner, 2001).

According to Furlong and Cartmel (2007), there is a greater divergence of life experiences in contemporary society, but the issue of reducing inequalities associated with class still needs to be addressed. However, the inequalities for young adults with ASD seem to exist on a more ontological, personal level. As far as cultural expectations are concerned, there is an ambiguous message awaiting these young adults with ASD. Giddens (1991, cited in Ball, Maguire & Macrae, 2000) stresses the fact that young people are expected to perform their transitions and pathway choices according to market opportunities and institutional and social rules and at the same time they should do this according to their individual, self-determined timing:

'Giddens (1991) has argued that risk and uncertainty are experienced subjectively and individuals are held more and more accountable for their own survival in a time where change is the only certainty. In the late modern period, the self is constantly engaged in a process of self-construction and reconstruction as part of a contingently reflexive life-time biographical project which responds to new risks and new opportunities.'

(Ball et al., 2000, p. 2)

Although misunderstanding, social isolation, unemployment, worsening mental health, financial hardship and reduced life chances are still harsh everyday realities for adults with ASD (Reid et al., 2009), the post-industrial service society expects them to self-direct their decisions regarding education, training and employment so that they could become flexible participants in a very volatile and unstable labour market (Heinz, 2009; Bynner, 2001). This, however, cannot be done without identifying the most promising pathways to adult independence or enabling people to navigate multiple transitions with uncertain outcomes (Bynner, 2001; Worth, 2009).

Since transitions have become much more complex and young people's life courses less linear (Heinz, 2009), it would be worth exploring whether adults with ASD can relate to the objective demographic markers most commonly used in the literature to define all transitions to adulthood (Gauthier & Furstenberg, 2002; Hendricks & Wehman, 2009; Wehman, 2006). Another issue worth investigating is the difficulties experienced by people with ASD in their everyday lives, as these impact upon their transitions. Other themes identified in the literature review are the availability of service provision tailored to individual needs; the process of obtaining and coming to terms with a diagnosis of ASD. This is particularly important, given the high incidence of mental health problems among this group, and the impact of these on individuals' abilities to respond positively to social expectations. There is a need for empirical research to explain why the transition to adulthood can be very challenging for adults with ASD and why they encounter more obstacles than other adults in transition.

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30 th & 31 st Jan 2013	Chester:	6 th & 7 th Mar 2013	26 th & 27 th Sept 2012	Kidderminster:
	3 rd & 4 th Oct 2012		Worcester:	27 th & 28 th Feb 2013
	Warrington:		10 th & 11 th Oct 2012	Midlands Education Show:
	10 th & 11 th Oct 2012			14 th , 15 th , 16 th Mar 2013

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Training is currently only available in England and a standard package of training will be delivered across the country.



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