SUPPORTING ADULTS WITH AUTISM SPECTRUM DISORDERS: LESSONS FROM SIX DECADES OF INTERNATIONAL RESEARCH

Kenneth K. Poon
National Institute of Education
Nanyang Technological University

Research focusing on the intervention and support of children with autism spectrum disorders (ASD) has grown exponentially but this increase research has not been mirrored for adults with ASD. With the aims of informing intervention planning, improving quality of life, and areas for future research, 18 peer-reviewed research articles reporting the outcomes of adults with ASD were systematically reviewed. Despite methodological limitations, the literature review revealed a surprisingly high level of concordance in findings. Adults with ASD continue to experience significant degrees of impairment in the core deficits and correspondingly poor outcomes in social role attainment. Based on these findings, suggestions for the development of intervention and educational programs were proposed. Whilst no studies have targeted the quality of life of adults with ASD, the findings suggest a poor quality of life based on objective indicators. Directions for future research were also proposed.

Autism spectrum disorders (ASD) represents a group of neurodevelopmental disorders including autism disorder, Asperger‘s disorder, Rett‘s disorder, childhood disintegrative disorder, and pervasive developmental disorder, not otherwise specified (American Psychiatric Association, 2000). The prevalence is conservatively estimated at about 60 per 10,000 children (Chakrabarti & Fombonne, 2001, 2005) but worldwide estimates of prevalence are rising (Wing & Potter, 2002). There is a corresponding increase in the provision of and research in early intervention services in many parts of the world. However, this increase in the corpus of research has not been mirrored for adults with ASD (Eaves & Ho, 2008). This poses to be a problem for the following reasons.

The currently reported increase in numbers of identified cases is likely to lead to a corresponding need for a proliferation of services in adolescence and adulthood. In addition to the level of needs arising from the co-morbid intellectual disability (ID) estimated in between 25 to 51% of the population with ASD (Chakrabarti & Fombonne, 2001, 2005), the chronic nature of challenging behavior present in the population with ASD (Murphy et al., 2005) can limit their participation in major life areas (e.g., employment and community participation). Moreover, the observation from cross-sectional studies of the increased prevalence and intensity of challenging behavior in the late teens and early twenties (Oliver, Murphy, & Corbett, 1987) is cause for concern. An issue related to the increasing prevalence and the presence of challenging behaviors is the high cost of supporting adults with ASD. Recently, Knapp, Romeo, and Beecham (2007) estimated the cost of supporting adults with ASD to range from £32,681 (high functioning, and living at home) to £92, 683 (low functioning, in hospital), not counting the opportunity time costs of family members caring for the person with ASD. Whilst the quantum is likely to differ across contexts of service provision, the report underscores the fact that the support of adults with ASD represents a significant cost to society. Finally, very little is understood about the quality of life of adults with ASD. Little is known about their lives at home, the forms of relationships that they cultivate, and the extent to which they participate in wider community. Whilst this interest in quality of life is gaining momentum among the population with intellectual disabilities (Brown & Brown, 2005), its study among individuals with ASD is just emerging.

There is some research suggesting that adults with ASD can lead productive lives if well supported (e.g., van Bourgondein, Reichle, & Schopler, 2003) but such studies are few and far between. Other reviews have been conducted of adult outcomes (e.g., Howlin, 2005; Seltzer, Shattuck, Abbeduto, & Greenberg,

2004) have focused largely on describing the degree of core and associated impairments and/or the social impact of these impairments. However, there remains a gap between this knowledge and how they may be addressed in programs supporting adults with ASD, particularly those with higher degrees of support needs. As such, this study proposes to shed light on the questions of (a) how do trends in the research literature relevant inform intervention planning and policy, (b) to what extent do published research inform regarding the quality of life of adults with ASD, and (c) what are areas for further research.

Method

A literature search of empirical studies available in English over the past six decades (1940 to 2011) reporting the outcomes of adults with ASD (i.e., autistic disorder, pervasive development disorder) was conducted using bibliographic searches of web-based search engines (PSYCINFO, Medline, and Academic Search Premier). Subject headings and keywords were searched for terms relating to outcomes particularly in the core impairments (e.g., social interaction, communication, and repetitive behavior) and social role attainment (e.g., employment, living arrangements) in adolescence and adulthood. Due to this study‘s focus on adults with higher support needs, studies focusing solely on the population with high functioning autism or Asperger‘s syndrome were omitted. Furthermore, this step was augmented by a ‗snowballing‘ procedure through hand searches of articles cited in publications already identified in the research articles and review papers. Notwithstanding the broad search strategy, the analysis was restricted to research papers published in peer-reviewed journals.

Results

A total of 21 research reports were identified and reviewed. However, as some of the studies were reported over two research papers, only 18 research reports were reported in this review. Reports from the authors of these studies regarding the degree of impairment in core symptoms as well as the social role attainment of adults with ASD were extracted and summarized (see Tables 1 and 2).

Core impairments

The studies that reported findings pertaining to the core impairments of adults with ASD are summarized and synthesized in Table 1. Adults with ASD continue to experience significant difficulties within the triad of impairments (Wing & Gould, 1979), particularly in the social domain, and even in comparison to their peers with ID. On the average, some degree of alleviation in the core symptoms of ASD is reported in a significant proportion of, but not all, adults with ASD. However, no cases of ‗recovery‘ have been reported and the core symptoms typically remain, albeit taking a different form. Moreover, there appears to be a trend that more recent studies are reporting more positive outcomes (e.g., Eaves & Ho, 2008).

Reciprocal social interaction. Difficulties in the use of non-verbal body language for the regulation of social impairment remain for a significant proportion of the population with ASD. For instance, poor eye-contact was reported in between 50% of the participants studied (e.g., Bilstedt, Gillberg, & Gillberg, 2007). A study employing Wing and Gould‘s (1979) typology (Gillberg & Steffenburg, 1987) reported 40% of the study sample being aloof. Impairments in social overtures were also reported in between 79 and 92% (Bilstedt et al., 2007; Shattuck et al., 2007). This was especially manifest in peer interaction where spontaneous interaction is rarely reported (3 to 10%; Bilstedt et al., 2007; DeMeyer et al., 1973). Resultantly, it is understandable that the development and maintenance of friendships is an area of difficulty for many adults with ASD. Between 51 to 93% were reported to have no friends (Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004; Rumsey, Rapoport, & Sceery, 1985) and few in the population with ASD have close relationships or get married (Bilstedt, Gillberg, & Gillberg, 2005; Eaves & Ho, 2008; Howlin et al., 2004). Studies which examine the progress of social symptoms, on the average, report an improvement in social symptoms but this abatement of symptoms is by no means universal, or leading to a full ‗recovery‘ from ASD (Beadle-Brown et al., 2002; Rutter, Greenfield, & Lockyer, 1967; Seltzer et al., 2003; Shattuck et al., 2007).

Reciprocal communication. Between 39.7 and 50.8% of adults with ASD do not use spoken words for communication (DeMeyer et al, 1973; Eisenberg, 1956, Rumsey et al., 1985). Among those who use spoken words functionally, difficulties were reported in the use of language. For instance, about 50% were reported to exhibit prosodic abnormalities (Bilstedt et al., 2007; Rumsey et al., 1985). Furthermore, reciprocity in conversations has been reported as a problem for between 50 to 84% of adults with ASD (Bilstedt et a., 2007; Rumsey et al., 1985). Broadly, studies reporting changes in language skills over time reported improvement in language ability in between 23.8 to 51% of the sample (Rutter et al., 1967; Seltzer et al., 2003; Shattuck et al., 2007).

Table 1. Summary of studies examining core impairments of adults with ASD in adulthood

Author & Year Location	**Participants (Gender) Age (Range) Control group**	**Reciprocal social interaction**	**Friendship & interpersonal relationship**	**Communication**	**Restricted, repetitive pattern of interest, behaviors, & activities**
Bilstedt, Gillberg, & Gillberg (2007) Gothenburg, Sweden	N = 105 (75M, 30F) Autism gp = 78 (61M, 17F) PDD = 42 (23M, 19F). Age = 25.5 yrs (17-40 yrs) Autism vs PDD control group	Eye contact problems - 50 to 51%	One-sided or no approach – 92% No spontaneous interaction with peers – 90% Lack of or inappropriate emotional response to peers – 84% Avoidance of peers – 78%	No conversation with peers – 90% Limited reciprocity in verbal communication – 83% Abnormal tone of voice – 53%	Maintenance of sameness in routines – 62% Reaction to firm touch – 60% Self injury – 51%
DeMyer, Barton, DeMyer, Norton, Allen, & Steele (1973) Indiana, US	N = 105 (85M, 35F) Age = 12 yrs 3 autism gps and non-autistic psychiatric control	Most children improved in social skills but fewer in the autism groups made more progress	Prefer to be alone – most of low and middle autism gp Normal family relationships – 30% Normal peer relationships – 3.8%	Normal = 3.7% Delay = 26.2% Function = 24.3% Echolalia = 6.5% No speech = 39.3% Most children improved in communication skills & less autistic children made more progress	
Eisenberg, L. (1956) Maryland, US	N = 63 (50M, 13F) Age = 15 yrs (9-25 yrs) No control group		Married – 0% Romantic relationship – 10% Close friendship – 33% Spend time with others of similar interests – 31% Regular attendance of community event – 30%	No useful speech – 50.8% Useful speech – 49.2%	
Gillberg & Steffenburg (1987) Göteborg, Sweden	N = 46 Infantile autism = 23 Other childhood psychosis = 23 Age = 16-23 yrs	The aloof group had poor social progress and none qualified for a good or fair outcome rating	Aloof – 40% Passive – 25% Active but odd – 33%	No speech at 5 years – 30% vs 57% Echolalia – 30% vs 13% Communication & echolalia – 27% vs 4% Communication – 22% vs 26%	
Howlin, Goode, Hutton, &	N = 68 (61 M, 7 F)		Frequency: Talk/sharing – 15%		

Rutter (2004) London, UK	Age = 29.3 yrs (all above 21) PIQ > 50 No control group		Activities – 26% None – 56% Quality: Selectivity/sharing – 19% No friends – 51% Unknown – 23% 2x married		
Kobayashi, Murata, & Yoshinaga (1992) Kyushu & Yamaguchi, Japan	N = 201 Age = 21.5 yrs No control group			Very good – 16.2% Good – 30.5% Fair – 32% Poor – 9.1% Very poor – 12.2%	
Rumsey, Rapoport, & Sceery (1985) National recruitment, US	N = 14 (9 with HFA) Age = 28 yrs (18-39 yrs) No control group	Some social impairment – 100% Affective flattening - >50% Aloof – 43%	Lack friends – 93% Some sought friendships but lacked skills Others lacked social motivation	Peculiar use of speech and language – 50% Perservative speech – 50% Little spontaneous speech – 43%	Exhibited concrete thinking – about 75% Obsessional thinking – 29% Stereotyped repetitive movements – 86%
Rutter, Greenfield, & Lockyer (1967) London, UK	Psychotic gp = 63 (age = 15.6 yrs) Control gp = 61 (age = 16.5 yrs)	No change in social abnormalities – 25 to 33% Less ‗autistic‘ – about 50%	Normal peer relationships – 1.6% Normal relationships with parents – 11.1%	Normal language – 15.9% Improved speech – 23.8% No longer speech delayed – 14.3% No change – 49.2% Worsened – 9.5% Among children with useful speech: Echolalia – 75% Pronoun reversal - >50%	Morbid preoccupations Improved – 17.5% No change – 6.3% Worsen – 4.8% Obsessions Improved – 9.5% No change – 9.5% Worsen – 4.8% Stereotypy Improved – 25.4% No change – 19% Worsen – 4.8%
Seltzer, Krauss, Shattuck, Orsmond, Swe, & Lord (2003) Wisconsin & Massachusetts, US	N = 405 Adolescents = 251 (age = 15.7 yrs) Adults = 154 (age = 31.57 yrs) No control group	General abatement of social interaction symptoms but no recovery		General abatement of communication impairment	Reduction in repetitive behavior but increase in compulsions and rituals

Shattuck, Seltzer, Greenberg, Orsmond, Bolt, Kring, Lounds, & Lord (2007) Wisconsin & Massachusetts, US	N = 241 Age = 22 yrs (10-52 yrs) No control group	Inappropriate quality of social overtures – 59.8% Improvement – 32% No change – 53.5% Worsen – 14.5%	No appropriate friendship – 84.2% No interest in people – 78.4% Inappropriate response to others‘ approach – 79.3%	Spont 3-word phrase – 74.7% Verbal communication: Improvement – 51.4% No change – 22.9% Worsen – 25.7%	Improvement – 58.5% No change – 24.1% Worsen – 17.4%
Taylor & Seltzer (2010a) Wisconsin & Massachusetts, US	N = 242 Age = 16.3 yrs Follow up over 4.5 years No control group	Social reciprocity: Reduction in ADI-R mean		Verbal communication: Reduction in ADI-R mean Nonverbal communication: No change	Reduction in ADI-R mean

Restricted, repetitive pattern of interests, behavior, and activities. Although this aspect of the core impairments of ASD has been relatively less studied in outcome studies, studies reporting the behavior, activities, and interests of adults with ASD generally show evidence that these difficulties continue to impact their adult lives. Motor stereotypies were reported in 57 to 86% of the adults in early studies (Rumsey et al, 1985; Rutter et al, 1967). Similarly, 38 to 62% were reported to continue to exhibit a strong preference for the maintenance for sameness in their environment (Bilstedt et al., 2007; Rutter et al, 1967) and 60% were reported to continue exhibiting atypical reactions to sensory stimuli (Bilstedt et al., 2007). Thus, many if not most adults with ASD continue to exhibit the symptoms of repetitive behaviors and thoughts. Studies also indicate a general direction towards an improvement in symptoms with age in many but not all persons with ASD (Rutter et al., 1967; Seltzer et al., 2003; Shattuck et al., 2007; Taylor & Seltzer, 2010a) with a minority losing all forms of repetitive and stereotyped behavior and thinking (Rutter et al., 1967). However, this trend towards improvement, as in the case of the other core symptoms is not universal with a significant proportion either with no change or a deterioration of symptoms (Rutter et al., 1967; Seltzer et al., 2003; Shattuck et al., 2007).

Social role attainment

The studies reporting findings pertaining to the social role attainment of adults with ASD are summarized and synthesized in Table 2. In particular, the education attainment, living arrangement, employment, and community participation of adults with ASD were reviewed. In general, the studies report a low degree of social role attainments (i.e., poor educational attainment, a high degree of reliance on sheltered workshops or supported employment, many fail to attain independent living, and many have limited access to community). Furthermore, studies which examined these social role attainments in comparison with other adults with have indicated that adults with ASD have poorer outcomes.

Education. Two variables complicate the interpretation of the educational attainment of adults with ASD. These are the inclusion of adults with non-impaired intelligence quotients (IQ) and the different policies pertaining to the inclusion of individuals with ASD in educational settings in the reviewed studies. However, the finding was largely similar – that few complete education with any education certification. For instance, Howlin and colleagues (2004) reported that 78% of their sample, which included adults with performance IQs of above 50, left school without any formal qualifications. As mentioned, there is considerable variability in the degree with which the adults with ASD were included with their typically developing peers in educational settings. The range of 1 to 100% of adults with ASD reported to attend schools with their typically developing peers (Beadle-Brown et al, 2002; Chung, Luk, & Lee, 1990; Eaves & Ho, 2008) appear to suggest that inclusion in general education settings to be influenced largely by educational policies as opposed to their functional ability. In general, the educational attainments of adults with ASD were reported to have poorer educational outcomes than expected of their age and/or IQ (Rutter et al., 1967). Furthermore, Lotter (1974) reported that there is a lack of a direct relationship between education and employability, which is exemplified in the following discussion.

Employment. As participants of many studies reviewed include adolescents, it was difficult to ascertain the specific proportion of participants who were employed. However, most studies reported the majority adults with ASD being unemployed or spending time in sheltered workshops or day activity centers (Beadle-Brown et al., 2002; Chung et al., 1990; DeMeyer et al., 1973; Howlin et al., 2004; Rumsey et al., 1985; Taylor & Seltzer, 2010b). In contrast, adults with ASD in competitive, open employment formed a small minority (Beadle-Brown et al., 2002; Chung et al., 1990; DeMeyer et al., 1973; Lotter, 1974). The one exception to this trend was a Japanese study which reported about a fifth of their participants being employed (Kobayashi, Murata, & Yoshinaga, 1992). In this study, 40% of the employed sample had IQ of 70 and above and 26% had moderate/severe ranges of ID. This figure stood in contrast to Rumsey and colleagues (1985) study which reported a competitive employment rate of about 29% for a sample with a higher proportion of adults with higher IQ levels. Rumsey and colleagues (1985) also highlighted in their study that parents were influential in determining whether their adult child found employment. The impact of parents is larger when considering that a small proportion of adults with ASD (between 1 and 3%) are employed in family businesses (Howlin et al., 2004; Kobayashi et al., 1992). Taylor and Seltzer (2010b) also examined the impact of a diagnosis of intellectual disability and indicated that whilst there were fewer adults with comorbid ASD and ID in college (2% as opposed to 47.1%) and competitive employment (4.1% versus 11.8%), the number of young adults with no ID diagnosis who were unengaged in day activities were four times as high as compared to those with an ID diagnosis (8.2% as opposed to 23.5%).

Table 2. Summary of studies examining social role attainments of adults with ASD

Author & Year **Location**	**Participants (Gender)** **Age (Range)** **Control group**	**Education outcomes**	**Living arrangements**	**Employment outcomes**	**Community Participation**	**Overall outcomes (Criteria)**
Beadle-Brown, Murphy, Wing, Gould, Shah & Holmes (2002) South London, UK	N = 144 (93M, 47F) Age = 20.9 yrs (13 to 30 yrs) No control group	SEN school = 35% Hospital = 18% Mainstream = 1% Probation = 1%	Residential units = 6% Home = 6%	Employment (sheltered/ open) = 4% Day centers = 29%		
Bilstedt, Gillberg, & Gillberg (2005) Gothenburg, Sweden	N = 120 (84M, 36F) AD = 78 (61M, 17F) PDD = 42 (23M, 19F). Age = 25.5 yrs (17-40 yrs) No non-ASD control group		Independent = 4			AD vs PDD gps Independent = 4/3% Good = 0/0% Fair = 8 vs 9% Restricted but acceptable = 16/6% Poor = 23/17% V Poor = 52/69% Gillberg & Steffenburg (1987)
Chung, Luk, & Lee (1990) Hong Kong	Autism = 66 (58M, 8F) Control = 96 Age = Not reported	Special schools – 57.6% Normal schools –				Good – 31.7% Fair – 47.6% Poor – 17.5%

	Non-ASD clinical sample control group	21.2% At home – 12.1% Training centre – 4.5% Unknown – 4.5%,				Very poor – 3.2% Lotter (1978)
DeMyer, Barton, DeMyer, Norton, Allen, & Steele (1973) Indiana, US	N = 105 (85M, 35F) Age = 12 yrs 3 autism gps and non-autistic psychiatric control	> 2 yrs schooling – 70% Placement in age appropriate classroom – 10%	Institutions – 42% Parent or foster homes – 58%	Paid job – 0% Work program in institution – 59%		
Eaves & Ho (2008) British Columbia, Canada	N = 48 (37M, 11F) Age = Not reported No control group	Regular elementary schools with special educational support – 100%	Independent = 8.3% Parents = 56% Supervised arrangements = 35%	Employment experienced – 56% (mostly in volunteer, sheltered or part time work, averaging 5 h a week)	Difficulties with day to day life – 54% Take public transport – 43%	Very poor – 0% Poor – 46% Fair – 32% Good – 17% Very Good – 4% Eaves & Ho (2008)
Eisenberg, L. (1956) Maryland, US	N = 63 (50M, 13F) Age = 15 yrs (9-25 yrs) No control group		Residential settings – 54% Homes with biological or foster parents – 46%			Poor – 73% Fair – 22.2% Good – 4.8% Eisenberg (1956)
Gillberg & Steffenburg (1987) Göteborg, Sweden	N = 46 Infantile autism = 23 Other childhood psychosis (some PDD) = 23 Age = 16-23 yrs		Self supporting – 4% Biological or foster parent(s) – 61% Institutions – 35%			IA vs Other Good = 4/4% Fair = 13/13% Restricted but acceptable = 35/9% Poor = 35/48% Very poor = 9/22% Dead = 4%
Howlin, Goode, Hutton, & Rutter (2004) London, UK	N = 68 (61 M, 7 F) Age = 29.3 yrs (all above 21) PIQ > 50 No control group	No formal qualifications – 78%	Independent with parent support – 4.4% Semi-sheltered hostel – 5.9% Home with parents – 38.2% Residential setting with some independence – 17.6%	Unsupported employment – 11.6% Self-employed – 1.5% Voluntary low pay – 1.5% Sheltered – 16.2% Family based – 2.9%		Very good – 11.7% Good – 10.3% Fair – 19.1% Poor – 45.6% V Poor – 11.7%

			Specialist autism placement – 20.6% Long stay hospital – 11.8%			
Kobayashi, Murata, & Yoshinaga (1992) Kyushu & Yamaguchi, Japan	N = 201 Age = 21.5 yrs No control group	Ordinary or special class in primary school – 80% University or junior college students – 3% Special technical students – 2.5%	Among 43 employed, Independent apt = 2 Group home = 1 With parents = 40	Employed – 20.8% Family biz – 1% Special unit – 38% Sheltered workshop – 13.7% Home – 9.1% Daycare – 8.6% Hospital – 2%	Good chances for social independence – 27.4%	V good – 10.7% Good – 16.2% Fair – 26.9% Poor – 22.8% V poor – 23.4% Kobayashi et al (1992)
Lotter, V. (1974) Middlesex, UK	Autistic = 29 Control = 21	Excluded from schools – 69% Years of schooling 10+ yrs – 27.6% 7-9 yrs – 17.2% 2-5 yrs – 20.7% 0-2 yrs – 13.8% None – 20.7%		Employment – 3.4%		Good – 14% Fair – 24% Poor – 14% Very Poor – 48% Rutter & Lockyer (1967)
Rumsey, Rapoport, & Sceery (1985) National recruitment, US	N = 14 (9 with HFA) Age = 28 yrs (18-39 yrs) No control group	High school – 35.7% Sped – 42.9% 8th Gr – 7.1% 1 yr JC – 7.1% Assoc deg – 7.1%	Independent – 7.1% Parents – 64.3% Supervised apartment – 14.3% Group home – 7.1% State hospital – 7.1%	Sheltered workshop – 21.4% Competitive – 28.6% Unemployed – 14.3% Job training – 21.4% Special employment – 7.1% Day program – 7.1%		
Rutter, Greenfield, & Lockyer (1967) London, UK	Psychotic gp = 63 (age = 15.6 yrs) Control gp = 61 (age = 16.5 yrs)	Psychotic gp: > 2 years of regular schooling – 44.4% School – 2.6% Special school – 2.6% Training	Psychotic gp: Long stay hospitals – 52.6% Unengaged at home – 18.4%	Psychotic gp: Paid jobs – 5.3% Village trust – 7.9%		Psychotic gp: Normal = 1.6% Good = 12.7% Fair = 25% Poor = 13% Very poor =

		centre – 10.5% centre Well-below expectations for their age & IQ			48%
Krauss, Seltzer, & Jacobson (2005) Wisconsin & Massachusetts, US	N = 133 (age = 31.9 years) No control group		Parents – 37% Residential – 63% Females with parents – 40.8%		
Seltzer, Krauss, Shattuck, Orsmond, Swe, & Lord (2003) Wisconsin & Massachusetts, US	N = 405 Adolescents = 251 (age = 15.7 yrs) Adults = 154 (age = 31.57 yrs) No control group		Parents – 64.9% Residential – 35.1%		
Shattuck, Seltzer, Greenberg, Orsmond, Bolt, Kring, Lounds, & Lord (2007) Wisconsin & Massachusetts, US	N = 241 Age = 22 yrs (10-52 yrs) No control group		Parents - 66.4% Community – 16.6% Semi-indep – 5.4% Insti/hosp – 9.5% Indep – 1.7%		
Taylor & Seltzer (2010b) Wisconsin & Massachusetts, US	N = 66 Age = Not stated (post-high school young adults) ID/Non-ID comparisons	Post high school degree = 2 vs 47.1%		Competitive employment = 4 vs 11.8% Supported employment = 12.2% vs 11.8% Adult day services = 73.5% vs 5.9% No regular activities = 8.2 vs 23.5%	

Living arrangements. Few adults (between 0 and 4%) with co-morbid ASD were reported to live independently (Bilstedt et al., 2005; DeMeyer et al., 1973; Eaves & Ho, 2008; Eisenberg, 1956; Gilberg & Steffenburg, 1987; Howlin et al., 2004; Kobayashi et al., 1992; Seltzer et al., 2003; Shattuck et al., 2007). Even so, those who live independently frequently do so with the support of parents (Bilstedt et al., 2005; Howlin et al., 2004). A large number (between 25 to 66%) live with their parents (DeMeyer et al., 1973; Eaves & Ho, 2008; Eisenberg, 1956; Gilberg & Steffenburg, 1987; Howlin et al., 2004; Kobayashi et al., 1992; Kruass, Seltzer, & Jacobson, 2005; Rumsey et al., 1985; Seltzer et al., 2003; Shattuck et al., 2007). Due to the variability in definitions employed across time and contexts, it was difficult to quantify the proportion living in hostels, hospitals, institutions, and other settings. However, there appeared to be a time trend towards more living at home or in hostels as opposed to hospital and institutions.

Community participation. One aspect frequently unreported in studies is the extent to which adults with co-morbid ASD have access to and participate within the community. Howlin and colleagues (2004) reported that a quarter of their sample had friendships that involved shared interests and activities. Lotter (1974) reported that half of the sample with _good' outcomes did not know how to access public transport but a more recent study (Eaves & Ho, 2008) reported that 47% of their sample could access public transport. Rumsey and colleagues (1984) reported that the social maturity of their participants was low in comparison to their IQs.

Overall social functioning. Some authors have attempted to provide a global measure of overall social functioning. Whilst this global rating is helpful in understanding the overall outcomes of adults with ASD, its broad nature makes interpretation between studies difficult as studies have differed in the domains being included and how they have going about describing the functioning of adults with ASD. In general, studies tended to operationalize overall social functioning in terms of the attainment of social roles and/or relationships and independence in daily living. The quality of social relationships with others have also been highlighted as an indicator being considered by all authors who reported overall social outcomes (Bilstedt et a., 2005; Chung et al., 1990; Eaves & Ho, 2008; Eisenberg, 1956; Gillberg & Steffenberg, 1987; Howlin et al., 2004; Lotter, 1974; Rutter et al., 1967). Educational or employment outcomes as well as independent living are also commonly measured in studies (Bilstedt et al., 2005; Chung et al., 1990; Gillberg & Steffenberg, 1987; Howlin et al., 2004; Kobayashi et al, 1992; Lotter, 1974; Rutter et al., 1967). In contrast, community participation was explicitly highlighted only in Eisenberg's (1956) study. The use of descriptors to indicate the severity of these domains also differ with some authors using a three-rating classification (e.g., Eisenberg, 1956), others using a four (Chung et al., 1990; Lotter, 1974; Rutter et al, 1967) or five (Bilstedt et al., 2005; Eaves & Ho, 2008; Gillberg & Steffenberg, 1987; Howlin et al, 2004; Kobayashi et al, 1992) rating classification. In general, the descriptors at the two extremes (i.e., good/very good and poor/very poor) are fairly similar across studies but there is some variation between the descriptors that represent the mid ranges (i.e., fair and restricted). With few exceptions (Chung et al., 1990; Eaves & Ho, 2008), the majority of adults with ASD were described to be poor or very poor (Bilstedt et al., 2005; Eisenberg, 1956; Gillberg & Steffenburg, 1987; Howlin et al., 2004; Lotter, 1974; Rutter et al., 1967).

Discussion

This literature review was limited in several ways. First, there was a high degree of heterogeneity among the samples employed by the different studies. This heterogeneity was expressed in terms of the age of participants, their diagnoses, their level of functioning, and the level of support. The diagnoses of the samples reported are not always clear given the evolving nature of the diagnostic criteria from childhood schizophrenia to the current ASD or pervasive developmental disorder. Furthermore, the diagnostic criteria of ASD have evolved across the years. Likewise, the level intellectual functioning of the samples reported varies with some studies reporting a higher proportion of participants with higher IQs (e.g., Howlin et al., 2004; Rumsey et al, 1985). This is potentially problematic especially within the light that IQ is one two frequently described indicators of prognosis for this population (Bailey, Phillips, & Rutter, 1996). However, the inclusion of participants with Asperger's syndrome and high-functioning autism are likely to, if at all, positively bias the findings. Next, this study reviewed published research from six countries representing three continents. This diversity of studies would almost certainly result in significant variations in policy and cultural differences that would have impacted upon the development of the samples being reported. With these limitations and diversity, it would not be surprising that a correspondingly broad variance of findings be reported. Moreover, the studies across contexts are likely to vary in the levels of early support (i.e., early intervention) and current support (e.g., supported employment, therapy). However, this literature review also revealed a surprisingly high level of concordance in findings in these studies that contribute to our understanding of adults with ASD.

First, adults with ASD continue to experience significant degrees of impairment in their core deficits. Whilst some adults experience some improvement in the core impairments, few cases of recovery, if any, from ASD were reported. However, this alleviation in symptomology was by no means universal and some reported a worsening of symptoms. This implies that the triad of impairments (Wing & Gould, 1979) continues to impact upon the lives of adults with ASD. A related finding is the correspondingly poor outcomes in social role attainment in the form of poor educational attainment in relation to IQ, low levels of employment and high reliance on sheltered workshops, most living with parents, and when reported, many have limited access to community.

Support for adults with ASD

Whilst the studies review do not explicitly address areas for intervention, their findings provide important leads to educational and intervention planning. The findings that adults with ASD continue to exhibit the core impairments in adolescence and adulthood have several implications. First, that programs preparing adolescents with ASD for adulthood need to include an explicit focus on supporting the core impairments with ASD (see Table 3 for some implications of the findings for practice). It would also be ideal to embed these supports within the day activities of adults with ASD, be it within day activity centres, sheltered workshops, or employment settings. Although it is beyond the scope of this paper to discuss the technologies that may serve this purpose, adults with ASD have been supported in the areas of communication and socialization through the use of environmental supports specially designed for individuals with ASD (Persson, 2000; Van Bourgondein et al., Schopler, 2003).

Given that the general social attainments of adults with ASD were identified in this study as poor with a high degree of reliance of among adults with ASD on residential living arrangements as well as sheltered and supported work environments, there is hence a need for special education programs to introduce a component explicitly preparing children and adolescents with ASD in special education programs to learn and transfer skills across the classroom to domestic, employment, and community settings. Moreover, transition of children and adults between environments and to the need placement require careful planning and support.

Table 3. Implications for education and intervention of adults with ASD

Finding	Practice Implications
Social impairment	Develop social skills (e.g., joint attention) Develop friendship acquisition and maintenance skills
Communication impairment	Explore augmentative/alternative communication modes Develop language skills Support development of pragmatic component of language
Repetitive behavior, interests, and activities	Environment management for atypical sensory reactions Using visual supports to manage insistence on sameness Positive behavior supports for managing challenging behavior
Poor employment outcomes	Matching of individual strengths and interests to employment Further training in pre-vocational/vocational skills Provide opportunities for application of learnt skills in employment contexts Continue development of transition programs Development of social enterprises as an alternative model of supported employment
Limited independence in home living	Further training in self-care/domestic living skills Training in independent leisure skills Provide opportunities for application of learnt skills in domestic contexts Collaboration with family members and other caregivers to apply learnt skills
Community participation	Further training in mobility and community skills Provide opportunities for application of learnt skills in community contexts Collaboration with family members and other caregivers to apply learnt skills
High degree of family support	Increased training for family members and other caregivers Increased collaboration with family members and other caregivers

A third phenomenon meriting discussion is the role of family support. The literature review also highlighted that many adults with ASD are unengaged and/or continue to live with their parents many years into their adulthood. One important implication is that that the family members, particularly parents, continue to shoulder a large proportion of the burden of care. Given that higher levels of autism symptoms is associated with higher levels of parenting stress (Tomanik, Harris, & Hawkins, 2004) and that parenting stress is in turn associated with an increase in challenging behaviors (Osborne & Reed, 2009), it is likely that some families supporting adults with ASD may find themselves caught in a vicious cycle. This finding of a disproportionately large burden of care on parents and family members imply that the effective support of adults with ASD necessitates the support of their family members and other caregivers within home environments and community. This support is critical for many parents who may experience increasing health problems was their child with ASD progresses into adulthood. The findings of the literature review suggests that this support to caregivers should have some component of helping adults with ASD develop and generalize their skills learnt in naturalistic settings, and in helping them to help their children with ASD access the community. Apart from providing family members with formal supports, it is also necessary to help family members build and access informal supports (Boyd, 2002).

Quality of life

Measuring quality of life involves an understanding of the extent to which individuals have valued life experiences across a variety of domains, both universal as well as those unique to the individuals (Schalock, 2005). Aspects of quality of life commonly studied include emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights (Schalock et al., 2005). This literature review highlights the dearth of research focusing on the quality of life of adults with ASD. Inferences that may be drawn from the literature review are that adults with ASD have very limited opportunities and interests/skills in developing interpersonal relationships, have limited independent means of pursuing financial activities for ensuring material well being, and limited independent participation in social inclusion activities. These suggest that adults, based on objective measures, have a poor quality of life. However, more research is needed. Investigations into the quality of life of these individuals, especially in relation to that of their peers with intellectual disabilities, are needed. Investigations may include areas such as subject well being (i.e., whether these individuals are happy), self-determination (e.g., ability to make choices for their own life), physical well-being, as well as community acceptance and participation.

Directions for future research

Whilst this literature review has contributed to the knowledge of the support of adults with ASD, it has also highlighted significant gaps in research. First, despite the understanding of outcomes, there are still significant gaps in studies documenting the impact of early intervention and special education. On a similar vein, there are gaps in the understanding of the effect of inclusion as well as the impact of specific education/intervention approaches on adult outcomes. There is need for prospective studies to address these issues.

Another issue pertains to the finding that outcomes in studies are typically defined in terms of the degree of core impairments, social relationships, or social role attainments. However, it has also been suggested that the broader concept of quality of life of adults with co-morbid ASD be considered (Ruble & Dalrymple, 1996). The International Classification of Functioning, Health, and Disability (World Health Organization, 2001) has been proposed as one such method of organizing support and for understanding progress (Simeonsson, Lollar, Hollowell, & Adams, 2006).

Finally, the studies reflect mostly findings from the North American continent, and Europe. However, ASD is an international phenomenon. The impact of broader contextual elements (e.g., culture, social mores) remains uninvestigated although the report by Kobayashi and colleagues (1992) suggest that differences could be expected in some instances.

Conclusion

Whilst it is clear that ASD is a complex condition with impairments that persist into adulthood leading to poor social role attainments such as employment, living arrangements, and community participation, the results of this literature review suggest that the effects are not confined to the individual but also to the family and beyond. It follows that a sustained and holistic approach to support be adopted. Whilst there is corpus of knowledge regarding the outcomes of adults with ASD is growing, this literature review also highlights the gaps that exist in the body of research literature such as the impact of educational approaches, the quality of life, and the impact of the broader cultural environment, questions that merit attention in future studies. Alongside intervention studies that need to be conducted, this review also highlights directions for future research such as the quality of life.

References

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders, Fourth Edition, Text Revision (DSM-IV-TR)*. Washington, DC: Author.

Bailey, A., Phillips, W., & Rutter, M. (1996). Autism: Towards an integration of clinical, genetic, neuropsychological, and neurobiological perspectives. *Journal of Child Psychology and Psychiatry, 37*, 80-126.

Beadle-Brown, J., Murphy, G., Wing, L., Gould, J., Shah, A., & Holmes, N. (2002). Changes in social impairment for people with intellectual disabilities: A follow-up of the Camberwell cohort. *Journal of Autism and Developmental Disorders, 32,* 195–206.

Bilstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: Population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders, 35*, 351-360.

Bilstedt, E., Gillberg, C., & Gillberg, C. (2007). Autism in adults: Symptom patterns and early childhood predictors. Use of the DISCO in a community sample followed from childhood. *Journal of Child Psychology and Psychiatry, 48*, 1102-1110.

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17,* 208-215.

Brown, R. I., & Brown, I. (2005). The application of quality of life. *Journal of Intellectual Disability Research, 49*, 718-727.

Chakrabarti, S., & Fombonne, E. (2001). Pervasive developmental disorders in preschool children. *Journal of the American Medical Association, 285*, 3093-3099.

Chakrabarti, S., & Fombonne, E. (2005). Pervasive developmental disorders in preschool children: Confirmation of high prevalence. *American Journal of Psychiatry, 162*, 1133-1141.

Chung, S. Y., Luk, S. L., & Lee, P. W. H. (1990). A follow-up study of infantile autism in Hong Kong. *Journal of Autism and Developmental Disorders, 20*, 221-232.

DeMeyer, M., Barton, S., DeMeyer, W., Norton, J., Allen, J., & Steele, R. (1973). Prognosis in autism: A follow-up study. *Journal of Autism and Childhood Schizophrenia, 3*, 199-246.

Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*, 739-747.

Eisenberg, L. (1956). The autistic child in adolescence. *American Journal of Psychiatry, 112*, 607–612.

Gillberg, C., & Steffenburg, S. (1987). Outcome and prognostic factors in infantile autism and similar conditions: A population-based study of 46 cases followed through puberty. *Journal of Autism and Developmental Disorders, 17,* 272–288.

Howlin, P. (2005). Outcomes in autism spectrum disorders. In F. R. Volkmar (Ed.), *Handbook of pervasive developmental disorders: Assessment, interventions, and policy* (3rd ed.) (pp. 201-220). New York: Wiley.

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, 45*, 212-229.

Knapp, M., Romeo, R., & Beecham, J. (2007). *The economic consequences of autism in the UK*. Retrieved from www.learningdisabilities.org.uk.

Kobayashi, R., Murata, T., & Yashinaga, K. (1992). A follow-up study of 201 children with autism in Kyushu and Yamaguchi, Japan. *Journal of Autism and Developmental Disorders, 22*, 395–411.

Krauss, M. W., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family settings: Positive and negative aspects of residential status. *Journal of Intellectual Disability Research, 49*, 111-124.

Lotter, V. (1974). Social adjustment and placement of autistic children in Middlesex: A follow-up study. *Journal of Autism and Childhood Schizophrenia, 4,* 11–32.

Murphy, G. H., Beadle-Brown, J., Wing, L., Gould, J., Shah, A., & Holmes, N. (2005). Chronicity of challenging behaviors in people with severe intellectual disabilities and/or autism: A total population survey. *Journal of Autism and Developmental Disorders, 35*, 405-418.

Oliver, C., Murphy, G., & Corbett, J. A. (1987). Self-injurious behaviour in people with a mental handicap: A total population survey. *Journal of Mental Deficiency Research, 31,* 147– 162.

Osborne, L. A., & Reed, P. (2009). The relationship between parenting stress and behavior problems of children with autism spectrum disorders. *Exceptional Children, 76*, 54-73.

Persson, B. (2000). Brief report: A longitudinal study of quality of life and independence among adult men with autism. *Journal of Autism and Developmental Disorders, 30*, 61-66.

Ruble, L. A., & Dalrymple, N. J. (1996). An alternative view of outcome in autism. *Focus on Autism and Other Developmental Disabilities, 11*, 3-12.

Rumsey, J.M., Rapoport, J.L., & Sceery, W.R. (1985). Autistic children as adults: Psychiatric social and behavioral outcomes. *Journal of the American Academy of Child Psychiatry, 24*, 465–473.

Rutter, M., Greenfeld, D., & Lockyer, L. (1967). A five to fifteen year follow-up of infantile psychosis: II. Social and behavioural outcome. *British Journal of Psychiatry,113,* 1183–1189.

Schalock, R. L. (2005). Introduction and overview. *Journal of Intellectual Disability Research, 49*, 695-698.

Schalock, R. L., Verdugo, M. A., Jenaro, C., Wang, M., Wehmeyer, M., Xu, J., & Lachapelle, Y. (2005). A cross-cultural study of core quality of life domains and indicators. *American Journal on Mental Retardation, 110,* 298-311.

Seltzer, M. M., Krauss, M. W., Shattuck, P. T., Orsmond, G., Swe, A., & Lord, C. (2003). The symptoms of autism spectrum disorders in an adolescence and adulthood. *Journal of Autism and Developmental Disorders, 33*, 565-581.

Seltzer, M. M., Shattuck, P. T., Abbeduto, L., & Greenberg, J. S. (2004). Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews, 10*, 234-247.

Shattuck, P. T., Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., Bolt, D., Kring, S., et al. (2007). Change in autism symptoms and maladaptive behaviors in adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 37*, 1735-1747.

Sigafoos, J., Arthur, M., & O'Reilly, M. F. (2003). *Challenging behavior and developmental disability*. London: Whurr.

Simeonsson, R. J., Lollar, D., Hollowell, J., & Adams, M. (2000). Revision of the International Classification of Impairments, Disabilities, and Handicaps: Developmental issues. *Journal of Clinical Epidemiology, 53*, 113-124.

Stromme, P., & Diseth, T. H. (2000). Prevalence of psychiatric diagnoses in children with mental retardation: Data from a population-based study. *Developmental Medicine and Child Neurology, 42,* 266–270.

Taylor, J. L., & Seltzer, M. M. (2010a). Changes in the autism behavioral phenotype during the transition to adulthood, *Journal of Autism and Developmental Disorders.* doi 10.1007/s10803-010-1005-z

Taylor, J. L., & Seltzer, M. M. (2010b). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders.* doi 10.1007/s10803-010-1070-3

Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviors exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability, 29*, 16-26.

Van Bourgondein, M. E., Reichle, N., & Schopler, E. (2003). Effects of a model treatment approach on adults with autism. *Journal of Autism and Developmental Disorders, 33*, 131-140.

Wing, L. & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children: Epidemiology and classification. *Journal of Autism and Developmental Disorders, 9*, 11-29.

Wing, L., & Potter, D. (2002). The epidemiology of autism spectrum disorders: Is the prevalence rising? *Mental Retardation and Developmental Disabilities Research Review, 8*, 151-161.

World Health Organization. (2001). *International classification of functioning, disability, and health*. Geneva: WHO, 2001.