

# Into the Unknown: Aging with Autism Spectrum Disorders

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## Abstract

Research investigation of older adults with autism spectrum disorders (ASD) noticeably lags behind studies of children and younger adults with ASD. This article reviews the current literature regarding a range of quality of life outcomes of aging adults with ASD. Studies that have addressed life expectancy, comorbid physical and mental health issues, ASD symptomatology, and social, residential, and vocational outcomes are reviewed. Research challenges in identifying older cohorts of adults with ASD are also discussed, and notable areas of concern are highlighted. Overall, aging with ASD does present challenges, but there is also evidence that positive outcomes are attainable. The article concludes with brief recommendations on how to optimize the aging process for individuals with ASD.

**Key Words:** *older adults; health; quality of life; age-related changes; autism*

According to the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition, text revision (DSM-IV-TR; American Psychiatric Association, 2000), autism spectrum disorders (ASD) are a group of neurodevelopmental disorders whose diagnostic features include a markedly impaired development of reciprocal social interaction, impairment of communication skills (both verbal and nonverbal), and repetitive, stereotyped, and restricted interests. The onset of these diagnostic features manifests before an individual is 3 years old. The Centers for Disease Control and Prevention (2009; CDC) reports 41% of individuals with ASD also have intellectual disability (ID) that can range from mild to profound. However, there are individuals with ASD with no ID who have intelligence quotients ranging from average to superior.

The most recent surveillance data collected in 2008 by the CDC's Autism and Developmental Disabilities Monitoring Network indicates that approximately 1 in 88 children has an autism spectrum disorder, a 78% increase in ASD prevalence from 2002 (CDC, 2010a). It remains a challenge to ascertain the extent to which unidentified environmental factors may be operating that may be contributing to this apparent

increase, or to what extent this prevalence increase is merely a reflection of greater awareness of ASD by the health professionals and the general public that has resulted in better surveillance, detection, and earlier diagnosis of ASD. The latter explanation that there is no apparent rise in prevalence, and that the main issue is lack of diagnosis in older cohorts, is supported by a recent epidemiological study of community-dwelling adults in the United Kingdom, which found a similar prevalence of 9.8 per 10,000, or approximately 1% across all age groups (Brugha et al., 2011). As the authors concluded, if prevalence of autism is truly increasing, then prevalence in the older age cohorts should have been significantly lower than the younger age groups.

Irrespective of whether actual prevalence is truly rising or not, the notable attention that ASDs have generally garnered in recent years has been met, justifiably, with various initiatives to prompt early detection and intervention strategies as a way to maximize an individual's abilities in the crucial early developmental stages of childhood. However, there is now a sizeable number of adults aging with ASD. In fact, the first child described by Dr. Leo Kanner (1943) in his seminal paper on autism, Donald Gray Triplett, is now

77 years of age. It is imperative that profiles and trajectories of lifespan outcomes specific to adults aging with ASD now be brought to the forefront of autism research. With the lifetime per capita incremental cost of autism estimated at \$3.2 million (Ganz, 2007), predominantly from lost productivity and adult care, focus on aging adults is imperative to inform support services and policymakers to optimize services.

The aging process, outcomes, and lifespan health concerns for aging individuals with intellectual and developmental disabilities (IDD), especially individuals with Down syndrome, and to a lesser extent, individuals with cerebral palsy, have received considerable research attention (e.g., Esbensen, 2010; Long & Kavarian, 2008; Zaffuto-Sforza, 2005) when compared with the literature concerning individuals with ASD. However, CDC prevalence rates for children with Down syndrome (approximately 1 in 1,000; Shin et al., 2009) and cerebral palsy (approximately 1 in 303; Yeargin-Allsopp et al., 2008) highlight that the lack of attention to adults with the primary diagnosis of ASD is perilously ignoring a segment of the population that requires lifetime services and support in larger numbers than those aging with either Down syndrome and cerebral palsy combined. Furthermore, there are several etiologies of intellectual disability that are associated with ASD: Rett syndrome (Wulffaert, Van Berckelaer-Onnes, & Scholte, 2009), Fragile X syndrome (Dölen & Bear, 2009), tuberous sclerosis (Baker, Piven, & Sato, 1998), Prader-Willi syndrome and Angelman syndrome (Veltman, Craig, & Bolton, 2005), Velo-cardio-facial syndrome (Antshel et al., 2007), and indeed, Down syndrome (Ghaziuddin, Tsai, & Ghaziuddin, 1992). Therefore, any research into the aging process and lifespan outcomes of aging in those with a primary diagnosis of ASD may have the potential translational applicability to those other etiologies of intellectual disability.

This article will review the current literature regarding research on outcomes of aging adults with ASD and will cover life expectancy and comorbidities, autism spectrum disorders symptomatology, and social, residential, and vocational outcomes. It will outline research challenges regarding the aging population with ASD. This article will then summarize notable areas of concern and will conclude with recommendations on how to optimize the aging process for individuals with ASD.

## Method

Articles for this review were compiled from an extensive literature search of PubMed, PsychInfo, Scopus, and CINAHL databases. Combinations of the following key words were used to ensure coverage of multiple domains: autism, autism spectrum disorders, adulthood, aging, employment, health, lifespan, life course, vocation, social, older adults, residential, quality of life, well-being. Given the expectation that extant literature was not extensive, there was no restriction placed on the date range for articles to be searched. In summarizing the literature for this review, emphasis was placed on studies that included middle-aged and older adults in their samples, except for studies used to contrast older adults with younger age groups. The articles included in this review were selected on the basis of their methodological rigor, recency, and in particular, for the salience of findings to inform the current status and future directions of research along with practical utility for potential intervention study designs. The more notable studies are highlighted and summarized in Table 1.

## Life Expectancy, Mortality, Physical, and Psychiatric Comorbidity

### Life Expectancy and Mortality

Shavelle and Strauss's (1998) population-based study to determine comparative mortality of persons with autism (but without severe physical disabilities or who were non-ambulatory), found that life expectancy was still reduced somewhat when comparing those with ASD to the general population. For example, life expectancy for individuals with ASD at age 5 (i.e., the number of additional years that 50% of that cohort will attain) was 62 years for males and 62.5 years in females, compared with the general population figures of 68.1 years for males, and 74.8 years for females. This is a disparity of 6.1 years (men) and 12.3 years (women). However, life expectancies at age 65 diminished this disparity (men with ASD = 12.3 years, non-ASD = 15.4 years; women with ASD = 16.0 years, non-ASD = 19.2 years). Thus, for both men and women with ASD at age 65, their life expectancy was just over 3 years shorter than the general population.

In terms of causes of mortality, several studies have found that deaths related to epilepsy or sudden unexpected (or unexplained) death in

Table 1  
*Summary of Notable Studies*

Author	Sample size	Age range	Diagnosis	Major finding(s)
<b>Life expectancy</b>				
Shavelle & Strauss, 1998: Population-based mortality study, 1980–1996	11,347 with ASD (excluded people with severe physical disabilities or non-ambulatory status)	Age groups from 5–9 through 70–75 years; 4% of sample was aged 35+	Previous clinical diagnosis, CDER (1978) and ICD-9-CM (1995) autism codes for CDDS	At age 65, life expectancy ~ 3 years shorter than for general population (for both males and females).
Shavelle, Strauss, & Pickett, 2001: Population-based mortality study, 1983–1997	13,111 with ASD (excluded etiology of Down syndrome, tuberous sclerosis, Rett syndrome, and non-ambulatory status)	Age range not specified, but included all individuals with ASD in CDDS	Previous clinical diagnosis as above (i.e., CDER & ICD-9-CM codes) for CDDS	Reduced life expectancy with increasing severity of intellectual disability; Notable increase in mortality due to seizures and accidental deaths from drowning, suffocation.
<b>Psychiatric comorbidity/Adaptive function</b>				
Totsika, Felce, Kerr, & Hastings, 2010: Cross-sectional study	819 adults with ID: 282 aged 50+ (87 with ASD) and 537 aged 19–49 years (194 with ASD)	19–90 years	ASD screening by research team (Disability Assessment Schedule; Holmes, Shah, & Wing, 1982).	For ages 50+ with ASD, 31.7% had psychiatric symptomatology compared with 49.7% in the younger group (19–49 years) with ASD.
Stuart-Hamilton & Morgan, 2011: Cross-sectional study	29 Adults with ASD and no ID; 14 with formal previous diagnosis; 15 no formal previous diagnosis	40s: no specific age range given	All participants completed the Autism-Spectrum Quotient (Baron-Cohen, Wheelwright, Skinner, Martin, Clubley, 2001)	48% reported having current treatment for depression/anxiety.
Matson, Rivet, Fodstad, Dempsey, & Boisjoli, 2009: Cross-sectional study	377 with ID; groups stratified by ID level, ASD, and presence of psychopathology	18–88 years	Previous clinical diagnosis using DSM-IV-TR criteria	Adaptive behavior skills higher in those with ID alone compared with those with ID plus ASD and those with ID plus ASD plus psychopathology.

(Table 1 continued)

Table 1  
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Author	Sample size	Age range	Diagnosis	Major finding(s)
<b>Changes in autism-related behaviors</b>				
Seltzer et al., 2003: Cross-sectional study	405 with ASD; groups stratified adolescents (10–21 years) adults (22–53 years)	10–53 years	Previous clinical diagnosis and research team administered ADI-R (Lord, Rutter, & LeCouteur, 1994)	Improvement from adolescence to adulthood, in terms of restrictive repetitive behaviors; Adolescents less impaired compared with adults in terms of reciprocal social interaction.
Shattuck et al., 2007: Cross-sectional, 4.5-year longitudinal study	241; groups stratified: 10–21 years, 22–30 years, 31 years and older	10–52 years	Previous clinical diagnosis and research team administered ADI-R (Lord et al., 1994)	Verbal communication, social reciprocity, and repetitive behaviors improved over 4.5-year period; no significant change in nonverbal communication. Individuals with ID had greater number of autism symptoms and maladaptive behaviors and improved less over time. Older group aged 31+ had fewer maladaptive behaviors compared with adolescents 10–21 and experienced more improvement over time.
Esbensen, Seltzer, Lam, & Bodfish, 2009: Cross-sectional study	712 with ASD	2–62 years	Previous clinical diagnosis	Restricted repetitive behaviors (including stereotyped behaviors, self-injurious behavior, compulsive behavior, ritualistic/sameness behavior, and restricted interests) less frequent and severe with increasing age.
<b>Sensory processing</b>				
Kern et al., 2006: Cross-sectional study	104 with ASD; age- and gender-matched controls without ASD	3–56 years	Previous clinical diagnosis and confirmation by research team with DSM-IV criteria (APA, 1994)	Auditory, visual, touch, and oral sensory processing differ significantly compared with age-matched controls. Differences reduce with increasing age.

(Table 1 continued)

Table 1  
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Author	Sample size	Age range	Diagnosis	Major finding(s)
<b>Social, vocational, and residential outcomes</b>				
Renty & Roeyers, 2006: Cross-sectional study	58 with ASD; IQ ranged from 70 to 139	18–53 years	Previous clinical diagnosis using DSM-IV-TR criteria (APA, 2000)	67.2% were single; the rest of the sample were either married/cohabitating (8.6%), in an intimate relationship (19.0%), or divorced (5.2%). 55.2% lived with parents, 25.9% supported or residential living, 10.3% lived independently, and 8.6% lived with a partner. 27.6% were competitively employed; 24.1% were unemployed; 18.9% were in sheltered/supported employment; 29.3% were students.
Stuart-Hamilton & Morgan, 2011: Cross-sectional study	29 adults with ASD and no ID; 14 with formal previous diagnosis (FD); 15 no formal previous diagnosis (NFD)	No age range; <i>M</i> ages: FD group = 48 years and NFD = 47 years	All included participants completed Autism-Spectrum Quotient screening (Baron-Cohen et al., 2001)	62% in a long-term relationship, 7% divorced/separated, and 31% had always been single. In the NFD group, the corresponding figures were 71%, 10%, and 19%. 57% of FD group had friends, 80% in the NFD group reported friends. Employment: full time, FD = 25%, NFD = 67%; part time, FD = 25%, NFD = 5%; unemployed and seeking work, FD = 19%, NFD = 0%; not seeking work/other, FD = 31%, NFD = 28%. 3% married, 56% had no friends. 4% lived independently, 6% lived in supported living, 39% lived with family, and 51% in other residential settings ranging from small group homes to larger institutional settings. 13% competitively employed, 38% supported or sheltered work settings, 4% voluntary work or worked with family, and 41% attended day/residential unit with no specific work. Composite outcome indicator (social/occupational/independent functioning): 12% rated very good, 10% rated good, 19% fair, 46% poor, and 12% very poor. Those with ID (IQ < 70) had poorest outcomes; those with IQs 70–99 and 100+ did not differ.
Howlin, Goode, Hutton, & Rutter, 2004: Cross-sectional and longitudinal study	68 adults with ASD; performance IQs of 50+ as a child; <i>M</i> = 80 and range = 51–137	21–48 years	Previous clinical diagnosis, confirmation by research team using Autism Diagnostic Interview (LeCouteur et al., 1989)	

(Table 1 continued)

Table 1  
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Author	Sample size	Age range	Diagnosis	Major finding(s)
Farley et al., 2009: Cross sectional and longitudinal study	41 with ASD and no ID; Full score IQs of 70 or above	22–46 years	Previous clinical diagnosis for epidemiological study and confirmation by research team using ADI-R (Lord et al., 1994) and Autism Diagnostic Observation Schedule—Generic (Lord et al., 2000)	Used Howlin et al.'s (2004) composite outcome indicator above: 24% very good, 24% good, 34% fair, 17% poor, 0% very poor.
Orsmond et al., 2004: Cross-sectional study	235 with ASD who co-resided with parents	10–47 years	Previous clinical diagnosis and confirmation by research team administered ADI-R (Lord et al., 1994)	Predictors of participation in social and recreational activities included less impairment in social skills, higher levels of internalizing behaviors, increased functional independence, greater maternal participation in activities, greater number of support services received, and inclusion in integrated settings during school-age years. Peer relationships were predicted by less impairment in social interaction skills and being in the adolescent age range group (10–21 years) rather than the adult age group (22–47 years).

*Note:* CDER = Client Development Evaluation Report; IDC-9-CM = *International Classification of Diseases, Ninth Revision, Clinical Modification* (National Center for Health Statistics and Centers for Disease Control and Prevention, 1995); CDDSS = California Department of Developmental Services; ADI-R = Autism Diagnostic Interview—Revised.

epilepsy (SUDEP) is disturbingly higher in people with ASD (Gillberg, Billstedt, Sundh, & Gillberg, 2010; Mouridsen, Brønnum-Hansen, Rich, & Isager, 2008; Pickett, Xiu, Tuchman, Dawson, & Lajonchere, 2011; Shavelle, Strauss, & Pickett, 2001). Using standardized mortality ratios (SMRs), defined as the ratio of observed number of deaths to expected number of deaths (Kahn & Sempos, 1989), Shavelle, Strauss, and Pickett's study identified the association between increasing level of intellectual disability and increased mortality risk. They noted a 22-times increase in the rate of SUDEPs in those with no or mild intellectual disability (NMID), and a 36.9-times increase in those with moderate to profound ID (MPID), when compared with the rates of SUDEP observed in the general population with epilepsy (Annegers & Coan, 1999; Ficker et al., 1998). Shavelle and colleagues also observed increased SMRs due to accidental deaths from drowning (3.9 NMID, 13.7 MPID), suffocation (5.7 NMID, 51.4 MPID), cancer (1.9 NMID, 2.9 MPID), respiratory diseases, predominantly pneumonia (1.3 NMID, 10.8 MPID), nervous and sensory diseases excluding epilepsy (4.8 NMID, 6.2 MPID), and circulatory diseases (2.3 NMID, 3.8 PMID). This study did exclude those who were non-ambulatory and those with concomitant etiologies of Down syndrome, cerebral palsy, tuberous sclerosis, or Rett syndrome. It should also be noted that research of this type is reliant on the accuracy of death certificates, and in Shavelle and colleagues' study, 8% of the death certificates actually listed either ASD or intellectual disability as the cause of death itself, with a further 8% that were unspecified. This loss of data is both regrettable and avoidable, but unfortunately, inaccurate death certificates appear to be a cause for concern in general mortality studies. To briefly illustrate this point, a recent study investigating the accuracy of 371 death certificates in a community-based sample from the general population found 48% containing errors (Cambridge & Cina, 2010).

Overall, life expectancy is reduced somewhat, although the level of intellectual disability can influence this figure, as reported in life expectancy studies of the general overall population with intellectual disability (Bittles et al., 2002). The foregoing data not only highlights concern regarding safety issues (e.g., accidental suffocation, drowning), but also highlights the need for careful lifespan surveillance and management of

epilepsy. In terms of the increased rates of death from nervous and sensory diseases, cancer, or circulatory diseases, the issue of whether there is an ASD-etiological derived predisposition to particular health issues, or whether a lack of appropriate health surveillance may be prompting later stage diagnosis, and thus poorer prognosis, is yet to be adequately determined.

### **Common Comorbid Physical Health Conditions**

There is an established, albeit pediatric-focused, literature that reports the increased likelihood of medical comorbidity for individuals with ASD (Gillberg & Billstedt, 2000; Gurney, McPheeters, & Davis, 2006). Not surprisingly, children with autism are noted to have significantly increased frequency of visits to physicians for preventive, nonemergency, and emergency care compared to children without ASD (Gurney, McPheeters, & Davis, 2006). High rates of epilepsy in children with ASD have been consistently reported within the range of 35%–46% (Canitano, Luchetti, & Zappella, 2005; Danielsson, Gillberg, Billstedt, & Olsson, 2005; Spence & Schneider, 2009). Chronic gastrointestinal disorders and food selectivity issues far exceed those of both typically developing children and with other IDD (Horvath & Perlman, 2002; Molloy & Manning-Courtney, 2003; Valicenti-McDermott et al., 2006). For example, Valicenti-McDermott et al. reported 70% of children with ASD had a history of gastrointestinal symptoms, compared with 42% of children with other developmental disabilities (DD), and 28% in children with typical development. Food selectivity was reported in 60% with ASD, 36% in children with other DD, and 22% in children with typical development. Compared with other children with DD (46%) and typically developing children (32%), 53% of children with ASD have been noted to experience chronic sleep problems (Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2008).

As these studies did not incorporate middle-aged and older adults in their samples, the chronicity of these conditions into older adulthood, as well as the age-related onset of other medical conditions, is unknown. Whether in combination or isolation, it is also noticeable that the above medical issues often have social ramifications beyond the physical health consequences they bring. These may include the

potential restriction of activities depending on the severity of epilepsy, restriction of food venues and choices, and experiencing daytime fatigue from poor sleep quality, which can affect educational/vocational activities. Furthermore, coping with these can often bring stressful situations and distress to other family members and caregivers as well as the individual with ASD.

### **Common Comorbid Mental Health Conditions**

The fact that psychiatric comorbidity is frequently experienced in individuals with ASD is now well documented. As many as 70%–75% of children and adults with autism are likely to have at least one mental health condition (Ghaziuddin & Zafar, 2008; Simonoff et al., 2008). Furthermore, in Simonoff et al.'s study, 41% of children with ASD were noted to have two or more. The most common issues include anxiety disorders and depression, obsessive compulsive disorders, attention deficit hyperactivity disorders, oppositional defiant disorders, and Tourette syndrome, all of which can be very problematic for many with ASD (Ghaziuddin & Zafar, 2008; Simonoff et al., 2008; Skokauskas & Gallagher, 2010). With regard to the presence of psychiatric symptomatology (reported as psychiatric caseness in this study) in older adults with ASD, a study compared a group of adults with ASD and ID aged 18–49 years with a group of adults aged 50-plus with ASD and ID (Totsika, Felce, Kerr, & Hastings, 2010). This study reported psychiatric caseness at 49.7% in the younger group, whereas the corresponding figure in the older group was 31.7%, a statistically significant difference. This study also found that in the older group aged 50-plus with both ID and ASD, 31.7% had psychiatric caseness compared with 23.3% of those aged 50-plus with ID. Although this difference did not reach statistical significance, it does indicate that individuals with autism are more prone to dual diagnosis compared with the population with ID without ASD. The impact of psychopathology and autism on adaptive functioning (i.e., daily activities that support personal and social independence; Doll, 1953), was investigated in a study by Matson, Rivet, Fodstad, Dempsey, and Boisjoli (2009). Their sample of 377 adults with ID aged from 18 to 88 years was drawn from one of two developmental centers. Four groups were compared, although the age ranges within the groups

were not stated. Adults with ID only were compared with those with ID and ASD, ID with ASD and comorbid psychopathology, and with another group with ID and comorbid psychopathology. Individuals with ID alone had the most adaptive skills, followed by the ID and ASD group. The lowest levels of adaptive functioning were found in both groups with comorbid psychopathology; however, they did not significantly differ from each other. The study emphasizes that individuals with both ASD and ID have reduced adaptive skills, and furthermore, the addition of psychopathology further compromises their ability for self-care and independence.

Stuart-Hamilton and Morgan (2011) conducted an online survey with 29 respondents in their 40s with ASD and no ID (*M* age = 47.7 years) and found that 48% reported being currently treated for anxiety/depression. Although this was a very small and convenience-based sample, the figure strongly supports the need for effective and continuous mental health screening and appropriate treatment for those with ASD across the lifespan, from those who have ASD with ID through those with ASD with superior intellectual ability.

Attention toward older adults with ASD in their mental health outcomes is needed, especially as there seems justifiable concern that older cohorts may have never received a formal diagnosis, and thus, treatment of mental illness may not be optimal (James, Mukaetova-Ladinska, Reichelt, Briel, & Scully, 2006; Brugha et al., 2011). Cooper (1997) asserted that older adults with ID are at greater risk, compared with the aging general population, of developing mental illness for several reasons. As Cooper described, aging adults will share the same risk factors as the general population, and along with age-related risk factors (e.g., loss and bereavements, development of chronic health issues), also will have the additional risk factors associated with having an ID itself (e.g., limited opportunities, stigma, lack of occupation and recreation, inability to fully exercise self-determination). The majority of older adults with ASD will share those same risk factors as those with ID. In terms of support needs, even though this nascent research indicates a reduction in prevalence of psychiatric issues with increasing age, replication is needed with larger sample sizes, to see whether this is a robust finding. There is also a need for investigation of whether specific psychiatric conditions decline more precipitously than others with increasing age. For example,

anecdotally, Dr. Temple Grandin, the well-known self-advocate with high-functioning ASD who is currently 64 years old, has described suffering with anxiety much less with increasing age (Perkins, 2010).

To summarize, the status of chronic medical and psychiatric comorbidities can either stabilize, improve, or deteriorate across the lifespan. With increasing age, in concert with the general population, aging individuals with autism will also be susceptible to common aging-related health conditions and diseases, including cardiovascular disease, cancer, diabetes, dementia, hypothyroidism, and osteoarthritis, yet empirical research regarding these conditions in those with ASD is not available. The likelihood of long-term medication use for epilepsy and mental health issues can result in an acceleration of osteopenia—the aging-related reduction in bone mass leading to increased risk for developing osteoporosis (Bolton et al., 2008; Boluk et al., 2004). This is a particular concern as seizure activity coupled with osteoporotic bones can lead to increased risk of fractures (Bolton et al., 2008) and to circumscribed physical functioning and immobility. The development of tardive dyskinesia from long-term use of psychotropic drugs is also a possibility. Older adulthood increases the probability of developing additional comorbid health conditions resulting in polypharmacy and increased risk of adverse drug reactions and toxicity. It is vital that medication regimens are regularly reviewed with adults with ASD to ensure that optimal therapeutic ranges are maintained and that the number of prescription drugs is minimized while still providing efficacious treatment of symptoms. Concern in general regarding the lack of adequate training of health professionals in the needs of the aging population with IDD has previously been noted (Perkins & Moran, 2010). Older adults with ASD will compose a sizeable subpopulation requiring careful attention for both their physical and psychological well-being.

### **Autism Spectrum Disorder Symptoms Across the Lifespan**

Jean-Paul Bovee, a self-advocate with ASD, eloquently asserted that “behavior is not static, nor is how autism is in our lives static” (2000, p. 251). Therefore, consideration of changes that can occur in the cardinal behavioral characteristics associated with ASD is warranted. Indeed, Bovee’s statement did subsequently receive empirical validation.

Generally, three possibilities can exist: There can be improvement (abatement of symptoms); there can be a plateauing; or there can be a decline. Investigation regarding the lifespan trajectories related to the three cardinal domains associated with ASD—(a) communication impairment, (b) impaired reciprocal social interactions, and (c) restrictive, repetitive behaviors—is comparatively recent. Seltzer et al. (2003) cross-sectionally compared adolescents and adults with ASD ( $N = 405$ , ages 10–53 years). Their study did support a pattern of improvement from adolescence to adulthood, in terms of restrictive repetitive behaviors, but adolescents were less impaired compared with adults in terms of reciprocal social interaction. Shattuck et al. (2007) tracked short-term change with both autism symptoms and maladaptive behaviors over a 4.5-year period, as well as cross-sectional comparisons by age groups ( $N = 241$ , ages 10–52 years). Shattuck et al. found that reduction in maladaptive behaviors continues across adulthood, and the rate of improvement may increase with increasing age; whereas, with regard to autism symptoms, there was a steady pattern of improvement across age cohorts for verbal communication, social reciprocity, and repetitive behaviors—and no change for nonverbal communication. Older sample members (aged 31-plus) had fewer maladaptive behaviors compared with adolescents (ages 10–21 years) and experienced more improvement over time. Their study also found that individuals with ID had a greater number of autism symptoms and maladaptive behaviors, and they improved less over time.

In a study that concentrated on the age-related differences in restricted repetitive behaviors ( $N = 712$ , ages 2–62 years), analyses revealed that repetitive restricted behaviors (including stereotyped behaviors, self-injurious behavior, compulsive behaviors, ritualistic/sameness behavior, and restricted interests) were less frequent and severe with increasing age (Esbensen, Seltzer, Lam, & Bodfish, 2009). Overall, a general pattern of improvement, more accurately described as abatement in severity of symptoms with increasing age, is noted for many with ASD, although ASD-related impairments do remain pervasive across the lifespan. However, for a small minority of adults, ASD is truly a childhood disorder. Seltzer, Shattuck, Abbeduto, and Greenberg (2004) observed, “[I]ndeed it is astonishing that as many as between 10–20% outgrow the diagnosis, as autism is arguably among the most

severe and pervasive of the developmental disorders” (p. 240). These studies profiling changes in autism symptoms have provided fascinating data but were limited by cross-sectional comparisons for age-related differences and relatively short longitudinal periods to determine age-related changes and had low representation of adults aged 50-plus. Further research to extend these trajectories well beyond those aged 50-plus is now needed to see whether the patterns identified continue in the same trajectories. It is pertinent to consider the potential mechanisms that can be contributing to positive changes in function. Three possible explanations will be briefly considered: changes manifesting from the physiological aging process, growing self-awareness, or mere exposure to a lifetime of experiences that result in developing better coping strategies.

### **Are Changes a Result of the Aging Process?**

Many ASD-related behaviors can occur in response to sensory processing difficulties, which are often the most common of the associated clinical difficulties in young children (Kern et al., 2001). A notable cross-sectional study compared differences in sensory processing difficulties (including auditory, visual, touch, and oral) across ages ( $N = 104$ , ages 3–56 years) to age- and gender-matched controls without ASD (Kern et al., 2006). Persons with ASD had significantly different sensory processing compared with controls. This study also compared those who are sensory seeking (i.e., having high threshold for response to stimuli; Watling, Deitz, & White, 2001) and could be considered hyposensitive to stimuli, with those who are sensory defensive (O’Neill & Jones, 1997) and have a low threshold for response to stimuli, that is, hypersensitive. It was found that, with increasing age, the autism group’s processing scores were becoming more similar to the control group. The autism group showed with both hypo- and hypersensitivity to auditory processing, and visual processing and hypersensitivity to touch were becoming similar to controls with increasing age. Only hyposensitivity to touch remained unchanged with increasing age. In the general population without autism, sensory changes usually start to manifest in the 40s to 50s, with reduction in acuity and discrimination occurring across the senses (Saxon,

Etten, & Perkins, 2010). A possibility is that some age-related changes in autism symptoms (e.g., reduction in frequency and severity in restricted behaviors, stereotypies) may be explained in some part by the age-related reduction in sensory sensitivities. Thus, previous triggers or sensory hypersensitivities are no longer salient, leading to positive changes in behavior.

### **Are Changes a Result of Greater Self-Awareness and Knowledge of Social Mores?**

Kanner’s (1973) observations and reasoning as to why some children with autism had more positive outcomes than adults should also be considered. Kanner reflected that “unlike most other autistic children, they became uneasily aware of their [own] peculiarities and began to make a conscious effort to do something about them” (p. 209). Indeed, self-awareness of “differentness” may be something that is initially developmentally delayed but may still manifest across the lifespan. Factors including increasing chronological age, having increased interactions within new social settings and circumstances, or achieving greater maturity with social interactions are possibilities that may increase one’s self-awareness and knowledge of social mores. It is during adolescence, in young adults without ASD, when one learns to analyze one’s own personality and that of others and will develop relationships based on preferred personality characteristics (Fischer & Ayoub, 1994). Cognitive development also allows individuals to recognize the multiple emotional complexities present in oneself and others (Rosenblum & Lewis, 2006). Self-awareness often becomes much more relevant at the time of puberty and adolescence, but there may be individuals with ASD who never develop such self-awareness, or it may be delayed several years beyond this usual adolescent time frame, perhaps even decades beyond. Furthermore, development of self-awareness to the point that it allows discrimination of “differentness” is another stage entirely, and the motivation to adapt behavior accordingly is another phase. Environmental factors (e.g., minimal access to inclusive postsecondary educational opportunities, lack of competitive employment, lack of independent modes of transportation) and social factors (e.g., restricted opportunities to forge friendships beyond family members, avoidance of new events/places)

may also unwittingly and inadvertently reinforce some maladaptive behaviors rather than provide the learning garnered by social modeling from new environments with peers without disabilities. Lack of appropriate levels of behavioral support services and acceptance of a person's current behavioral repertoire by caregivers can potentially hamper the development of self-awareness and socially appropriate behavior.

### **Are Changes a Reflection of Accumulated Knowledge From Experiences and Coping?**

It is interesting to consider that just as everyone continues to learn and benefit from experiencing situations across her or his lifetime, older adults with ASD will similarly be able to draw on previous experiences to help them cope with situations they have encountered before. Anecdotal, Grandin commented on her aging process in a recent interview (Perkins, 2010). In particular, regarding her sensory hypersensitivities, she stated that she did not feel that she was any less sensitive as she aged, but she had learned to cope with those hypersensitivities better over time. In another interview she was asked about the squeezing machine, her self-made calming device (Wallis, 2010). Grandin stated, "The thing about being autistic is that you gradually get better. You get less and less autistic-like, if you keep doing things and getting exposed to things that help you develop" (n.p.). Although recognizing that Grandin's experience may be an exceptional example with limited generalizability, it is still pertinent to note to what she attributes her positive outcomes.

Overall, in terms of autism-related behaviors, outcomes are variable: positive for some, and less so for others, and may rely on a combination of physiological (i.e., aging processes), psychological changes (i.e., self-awareness), environmental exposure (i.e., inclusive activities), or knowledge gained from an accumulation of life experiences. Thus, although intervention for children and adolescents that aims to maximize skill development is for many very effective, we must not overlook older individuals with autism. Indeed, new windows of opportunity to readdress previous behavioral difficulties may arise with increasing age. Restrictions of social and vocational opportunities because of an individual's autism-related behaviors may actually be more amenable to positive behavioral supports than earlier in the

individual's life, especially if those renewed efforts occur in tangent with changing profiles of sensory sensitivities. It is evident that some of these factors can be modifiable, and thus make the aging process of adults aged 50-plus potentially a period of new skills acquisition, rather than maintenance or loss.

### **Social, Vocational, and Residential Outcomes**

Although physical, psychological, and autism-related changes are important to note, research regarding later life outcomes has started to elucidate other domains of adult functioning that are equally important in considering quality of life outcomes. One study by Renty and Roeyers (2006) investigated quality of life in high-functioning adults with ASD ( $N = 58$ , ages 18–53, IQ range = 70–139) and found that perceived social support was associated with increased quality of life, and higher unmet formal support needs were associated with decreased quality of life. In this sample, 55.2% lived with parents; 25.9% were in supported or residential living; 10.3% lived independently; and 8.6% lived with a partner. Employment/vocational categories were not mutually exclusive categories but did reveal that 27.6% were competitively employed; 24.1% were unemployed; 18.9% were in sheltered/supported employment; and 29.3% were students. With regard to relationships, 67.2% were single, and the rest of the sample were either married/cohabitating (8.6%), in an intimate relationship (19.0%), or divorced (5.2%).

Stuart-Hamilton and Morgan's (2011) online survey had 29 respondents in their forties with ASD and no ID. They reported the findings across two groups, that is, those with a formal diagnosis (FD) of ASD ( $N = 14$ ,  $M$  age = 48.5 years), and those who had received no formal diagnosis (NFD;  $N = 15$ ,  $M$  age = 46.8 years). They confirmed ASD in both groups by response to the Autism Spectrum Quotient screening instrument (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). In the FD group, 62% were in a long-term relationship; 7% were divorced/separated; and 31% had always been single. In the NFD group, the corresponding figures were 71%, 10%, and 19%, and there was no significant difference between the groups in terms of the percentages. However, the authors noted a significant difference between the FD group and

United Kingdom general population figures of 72%, 18%, and 10% (Smith, Tomassini, Smallwood, & Hawkins, 2005), but the NFD group was not statistically significant from the United Kingdom general population. Employment categories were full-time employment (FD = 25%, NFD = 67%), part-time employment (FD = 25%, NFD = 5%), unemployed/seeking work (FD = 19, NFD = 0%), and not seeking work/other (FD = 31, NFD = 28). Significantly, more of the NFD group were employed compared with the FD group, and interestingly, in the NFD group, no one was unemployed. Those not seeking work in either category were either in receipt of long-term disability benefits or full-time homemakers. The authors did note that the unemployment rate in the FD group was four times as high as the current United Kingdom average of 4.7% at that time. Regarding contact with social services in the NFD, 100% reported no contact; whereas, in the FD group, 50% had contact with social services, and 50% did not. Respondents were also asked if they had friends. In the FD group, 57% did report having friends, but 43% reported having none. In the NFD group, 80% reported friends, compared with 20% who did not.

What was notable in these two preceding studies of adults with ASD without ID are the drastically reduced employment prospects that place these adults at a fiscal disadvantage. This disadvantage will continue to accumulate across the lifespan, reducing the ability for an individual to be financially comfortable, reap the advantages of employer-provided benefits, and significantly eroding the capacity to save for retirement. Even before retirement age, financial disadvantages may have already had a severe impact on residential and transportation options, and the availability of disposable income to pursue hobbies, interests, and even vacations. Furthermore, living options are often reliant on family members, and lack of friendships and social isolation are obviously problematic.

Howlin, Goode, Hutton, and Rutter (2004) investigated adult outcomes in a sample comprising adults with ASD with performance (nonverbal) IQs above 50 ( $N = 68$ ; ages 21–48 years, performance IQ  $M = 80$  and range = 51–137), with the rationale that those with IQs below 50 are unlikely to achieve high levels of independence. They found 13% were competitively employed; 38% were employed in supported/sheltered work settings; 4% undertook voluntary

work or worked with their families; and 41% were in a day/residential unit with no specific work. In terms of relationships, 3% were married, and 56% had no friends or acquaintances. Only 4% lived independently; 6% lived in hostel-type supported living; 39% lived with their families; and 51% lived in residential settings ranging from small group homes to larger institutional settings.

Howlin et al. (2004) also devised a composite outcome score based on ratings and data for occupations, friendships, and independent living that ranged from very good to very poor. Only 12% were rated as having a very good overall outcome, 10% rated as good, 19% as fair; 46% rated poor, and 12% very poor. When stratified by performance IQ (below 70, 70–99, 100+), Howlin et al. observed that individuals with IQs below 70 had poorer outcomes. Those with performance IQs of 100-plus did not have significantly better outcomes than those in the 70–99 range. Thus, the presence of ID with ASD is associated with poorer adult outcome, but in those without ID, having superior levels of intelligence does not confer any additional advantage of improved outcome. Farley et al. (2009) also applied Howlin et al.'s method to calculate outcome scores for their study of individuals with ASD with full-score IQs of 70 or above ( $N = 41$ , ages 22.3–46.4 years). Their ratings were 24% for very good, 24% for good, 34% fair, 17% poor, and no participant received a rating of very poor. Clearly, when comparing Renty and Roeyers's (2006) data, Stuart-Hamilton and Morgan's data (2011), and Howlin et al.'s study, the impact of ID in addition to ASD on overall outcomes in the realm of employment, relationships, and independent living status, is clear. Another interesting observation made by Farley and colleagues was that a small number of participants (unfortunately, the exact number was not stated) had difficulties securing employment and independence because of comorbid anxiety.

Orsmond, Kraus, and Seltzer (2004) investigated individual characteristics and environmental factors that predict participation in social activities and relationships in a group of adolescents and adults with autism, who co-resided with their mothers ( $N = 235$ , ages 10–47). Participation in social and recreational activities was predicted by characteristics of less impairment in social skills, higher levels of internalizing behaviors, increased functional independence, along with environmental factors of greater maternal participation in

activities, greater number of services received, and inclusion in integrated settings during school-age years. However, peer relationships were predicted only by individual characteristics of less impairment in social interaction skills and being younger. Thus, mothers themselves have an impact on the social outcomes of their children as well as their access to support services and enrollment in an inclusive school—all of which suggest that mothers who are effective advocates for services and inclusion lay the vital foundation to maximize social outcomes in their children's postschool lives. Indeed, it is interesting to note the parallels that exist between Grandin and Triplett (Kanner, 1943). They are both examples of successfully aging adults with ASD; both came from families who refused institutionalization (Triplett lived briefly in an institution before his family demanded his return to their family home), insisted on inclusion in school and recreational activities, and encouraged community participation and employment/vocational activities (Donvan & Zucker, 2010; Grandin & Scariano, 1996). A major caveat was that both families were financially advantaged. This emphasizes the importance of continued access to appropriate support and resources across the lifespan. Encouragement of competitive, but more importantly, sustainable, employment to improve fiscal security is preferable. Age should not be a barrier to aging adults who seek new employment opportunities. Indeed, stable employment may become an easier objective to achieve in some older adults with ASD who have experienced abatement in ASD symptoms that may have restricted their employment prospects when they were younger. Improvement of employment/vocational opportunities and outcomes can also aid the development of social relationships that extend beyond those environments.

### **Research Challenges in Identifying Aging Adults**

In the foregoing review, the absence of studies that have investigated individuals who are truly aging is readily apparent. As described earlier, given that the life expectancy of those with ASD is only slightly decreased than those who are typically developing, the gap in our knowledge of aging adults with ASD is alarming. At present, it is difficult to imagine that there is adequate knowledge, preparation, and provision to fully support this population.

Unlike for the populations of adults aging with specific etiologies (e.g., older adults with Down syndrome, cerebral palsy, etc.), there are notable difficulties in accurately identifying the current extent of the aging population with ASD and accessing those individuals for research purposes. The major barrier is that there are likely to be older adults with ASD who have never formally received a diagnosis of autism (Arehart-Treichel, 2008; Heijnen-Kohl & van Alphen, 2009). Brugha et al's (2011) epidemiological study also concluded that adults with ASD living in the community tend to be undiagnosed and socially disadvantaged. Thus, the use of online-only recruitment strategies may systematically omit a sizeable population of community-dwelling adults with ASD (and their families) who do not access the Internet.

An easily identifiable population will be those known to formal service systems who have a diagnosis of ASD. Another population that is accessible for study would be those receiving support services and who are assessed by researchers as meeting diagnostic-screening criteria (from self or proxy reports or researcher assessment). However, there are likely to be some older adults with ASD who may have never received a formal diagnosis of ASD, and also never received formal support services, who require both targeted recruitment and diagnostic screening. These "hidden" individuals may be adults with ASD who have lived independently or with their spouse or primary caregiver for the entirety of their lives, who have benefited from strong informal support networks, employment/financial stability, and thus never needed formal support services. Indeed, these very individuals may represent exemplars of leading fully inclusive lives. However, individuals who have received decades of able assistance from informal supports provided primarily by a caregiver within their own families are also a cause for concern. Destined to outlive their caregiving parents, older adults with ASD may become vulnerable when those primary caregivers die or are no longer able to provide care, and alternatives or sibling caregivers are not available. In such cases, either individuals enter the formal support system for the first time in their lives (with the inherent adaptation that that requires) or are hidden and overlooked until such time that a major crisis ensues. Knowledge derived from these hidden populations of aging adults with ASD is therefore valuable in informing

researchers regarding risk and protective factors that contribute to successful aging in those who do not use support services. It will also help identify those who may need to access such supports in the future.

Reported outcomes of older adults with ASD have to be considered within the context from which the sample is derived and the proportion of subpopulations that are actually represented. The population of individuals with ASD is a complex one and incredibly diverse. People with ASD can have profound ID through to superior IQs, have comorbid physical and mental health issues, and have differing communicative and adaptive abilities. Indeed, according to the American Psychiatric Association (APA) the diagnostic criteria of ASD will be modified in the forthcoming fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* due for publication in 2013 (APA, 2011). APA proposes that there will one category of autism spectrum disorder, and the previous subcategories of autistic disorder, Asperger's disorder, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified will be eliminated (APA, 2011). The three current domains of markedly impaired development of reciprocal social interaction, impairment of communication skills (both verbal and nonverbal), and repetitive, stereotyped, and restricted interests will be collapsed into two: (a) deficits in social communication and social interaction across contexts and (b) restricted, repetitive patterns of behavior, interests, or activities (APA, 2011). According to the APA, subpopulations within ASD will be clearly delineated using clinical specifiers (e.g., severity, verbal abilities) and associated features (e.g., known genetic disorders, epilepsy, ID). This level of diagnostic specificity can only enhance the ability of future researchers to study more homogeneous groups. Indeed, the majority of studies reviewed herein had already recognized differential outcomes due to these clinical specifiers and features. Thus, comparison from current to future research findings will still be possible despite future diagnostic modifications.

Careful selection of samples to address the specific research question is paramount. Generalizability of outcomes to the larger population of older adults with ASD should be balanced with the need to investigate the subpopulations of adults with ASD and the benefit the research will have in formulating practice and policy. One

could argue that the identification of those with greater support needs should naturally take precedence to form the basis of targeted interventions/programs. However, those currently unknown, but who may lose their informal support structure, are also in dire need of having their circumstances studied for policymakers and planners to have accurate and reliable data for addressing future levels of support needed. Furthermore, on the positive side, researchers could also identify examples of successful aging of older "hidden" adults with autism as a basis to inform us of the factors that contribute most to experiencing a quality of life that is desirable and replicable. Given that optimal levels of funding for formal support services are currently a challenge in many countries, and services are increasingly stretched and unable to meet demand, the balance and blending of formal to informal support utilized by those successfully aging with ASD could be most insightful as well as persuasive knowledge for advocacy uses.

## Discussion

### Notable Areas of Concern

It is readily acknowledged that much of the literature reviewed herein captured an aging population but not the true aged population, especially when one considers the youngest gerontologically defined age-range categories started with populations aged 65-plus. The impact of aging processes and aging-related outcomes for individuals with ASD remains relatively unknown. The emerging literature indicates that ASD behavioral characteristics appear changeable across the lifespan, and comorbidities, including epilepsy and ID, and mental health issues, including anxiety and depression, can reduce quality of life. Social isolation, restriction in both vocational/employment opportunities, and residential options have all been noted. Although some individuals with ASD will lead their life without formal supports, many will not. These individuals will need the lifelong assistance of their families and support services. Currently, many aging families and support services are simply unprepared for this aging population. Also of note are those who have not accessed the formal support system but will need to as their families age beyond their capability to continue to provide care.

Aging-in-place, defined by the Centers for Disease Control and Prevention as “the ability to live in one’s own home and community safely, independently, and comfortably, regardless of age, income, or ability level” (2010b), has long been the preferred philosophy to ensure that an older adult can remain in a family home despite changes in need. Those already known to the service system have the advantage of aging in place, whereas older adults new to the system may have very different options, including residence in assisted living facilities or nursing homes that are unfamiliar with providing care to older adults with IDD. Thus, it is time to ensure that all types of geriatric care be fully inclusive of older individuals with IDD, including those with ASD. Philosophical differences and sensitivities about older adults with IDD utilizing assisted living facilities and nursing homes remain, as many consider them to be a return to institutional settings that so many fought hard to leave. However, full inclusion demands that older adults with ASD have access to the same range of residential opportunities and possibilities that the older general population does, and it would ultimately be beneficial in improving the ability of residential and nursing facilities to care for those newly introduced to the service system. This would be especially relevant in areas where alternative residential options within the developmental disability support services are limited or subject to a waiting list. Older age cohorts of the general population have spent many years lacking familiarity with individuals with lifelong IDD due to the segregation that occurred from institutionalization. Younger cohorts are much more familiar with individuals with IDD because of increased inclusion in schools and colleges, increased community-based residence, and community participation and integration. The attention toward competitive employment further bolsters such familiarity. This continued integration across the lifespan will naturally occur with the integration of individuals with IDD into the complete range of senior/retirement activities and other aging contexts.

### **Optimizing the Aging Process**

The gerontological ideal of “successful aging” as described by Rowe and Kahn (1987, 1997, 1998) included low risk of disease, low risk of disease-related disability, maintaining cognitive and physical function, and having active engagement

in life. These goals are attainable, but aging with ASD does present additional challenges. Factors that can challenge positive outcomes are either modifiable or are unmodifiable. Unmodifiable factors such as presence of ID, epilepsy, and presence of lifelong comorbid physical and psychiatric health issues are likely to affect lifespan outcomes and interfere with social and vocational outcomes as well as the ability to live independently. However, there are factors that can be modified to optimize the chances of successfully aging with ASD.

Optimizing the aging process should include careful health surveillance and screenings for preventive health (e.g., cancer screenings, oral health), effective management of lifelong chronic comorbid physical (e.g., epilepsy) and psychiatric issues (e.g., anxiety), along with the newly emerging health issues in older adulthood. As long-term medication usage is likely for epilepsy and mental health issues, appropriate monitoring of medication for maintaining efficacy, while avoiding toxicity and polypharmacy with increasing age, is also crucial. As reviewed earlier, behavioral characteristics associated with ASD can improve with increasing age. Therefore, it is also essential to promote lifelong learning, education, employment (and retirement), and social opportunities with increasing age or that involve perhaps revisiting activities/environments that were declined or avoided in previous years. The potential for independent living should also be revisited and promoted across the lifespan. Fiscal and residential plans in future years should also be considered especially for those who are living with aging family members.

The preparation for transition into adulthood (in terms of education, employment, health care provision) is currently a prominent initiative. However, the transitions that older individuals can experience in terms of loss of primary caregivers, transfer to alternative residential provision, preparations for a fulfilling retirement, and so forth are equally important to consider. Unfortunately, later age transitions are not universally triggered at the same chronological age as youth transitions are and are subject to individuals’ unique circumstances. Therefore, it is important to address the need for future planning and assessment for all involved to ensure such transitions are made as seamlessly as possible.

Research specifically addressing the health, social, vocational, and fiscal profiles of older

adults is now critical. In future years, there will be an advantage of greater numbers that have been formally diagnosed with ASD, which will assist the readily identifiable population to the research community. The time has come to reassess the balance of research activity devoted to individuals with ASD across the lifespan. As life expectancy in those with ASD is only slightly reduced, the decades of time spent in middle to older adulthood far exceeds that spent in childhood and adolescence. Therefore, our level of empirical knowledge throughout the lifespan should be more proportionate.

Research-based education for the community at large, along with for family members, professionals, stakeholders, and policymakers, needs to be a higher priority to prepare and bolster the development of quality natural and paid supports to meet the increasing demand of the current and future aging population. Unfortunately, the fact remains that aging with ASD still remains a journey into the relative unknown.

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