

## The Challenge and Promise of Autism Spectrum Disorders in Adulthood and Aging: A Systematic Review of the Literature (1990–2013)

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**Abstract:** In the past five years, there has been a noticeable increase in the number of publications addressing the issues of autism spectrum disorders (ASDs) in the domain of adulthood and aging. However this increase still represents an extremely small proportion of the overall literature which is predominantly focused on autism in the childhood and adolescence stages of development. The purpose of this paper is to present results from a systematic literature review covering the timeframe of 1990 to 2013 (including advance online publications). Five data bases were queried at the intersection of *ASD* in the domain of *adulthood and aging*. Using “ASD” and “adulthood and aging” as the two primary foci, we had several objectives: (1) to conduct an exhaustive and comprehensive review of the literature; (2) to determine emergent sub-themes from the comprehensive review of publications; (3) to identify the top exemplar articles per emergent theme; (4) to establish an emergent theme that had the greatest number of publications; and (5) to document three journals that most frequently publish articles exploring ASDs, adulthood and aging. This review is different than previous reviews in that: (a) it emphasizes intergenerational factors; (b) it stresses multidisciplinary perspectives; (c) it is life- course oriented; and (d) we review the promise and potential of neurodiversity and highlight the abilities and capabilities possible for individuals with ASDs into adulthood and aging.

**Keywords:** autism spectrum disorder, adulthood, aging, Asperger, ageing, autism, pervasive developmental disorder

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## Aphorisms—Autism Spectrum Disorders and Adulthood and Aging

*Autism is one of the most prevalent and severe disorders evident in children and adults.<sup>1</sup>*

*Unfortunately, only a few longitudinal studies have followed children with autism into adulthood. The studies that do exist suggest that only a small number of the people diagnosed with autism during the 1980s, before the criteria broadened to include higher-functioning people, have been able to live independently.<sup>2</sup>*

*The aging of the population in western countries, the increasing rate of diagnosis of ASDs, and the burgeoning use of services by persons with ASDs make the need to learn more about aging and autism a high priority.<sup>3</sup>*

*The number of older people with autism will steadily increase in the foreseeable future and we hope that research intended to both understand and meet their changing needs across the lifespan will increase apace.<sup>4</sup>*

*This [ASD] is a lifelong disorder.<sup>5</sup>*

*The time span of adulthood is greater than that of childhood and adolescence combined ... as such the adult ASD population comprises and will continue to comprise the majority of the ASD population.<sup>6</sup>*

*We would like to raise the question as to whether it is appropriate for a patient to receive a diagnosis of AS [Aspergers Syndrome] in old age. Indeed, it could be argued that if people have reached 65+ with relatively few problems, it is inappropriate to start labeling them now. However, on the contrary, we argue that there is a great need even for the elderly people to receive an appropriate diagnosis of AS, because this may ensure that they do not receive an unsuitable intervention—whether that be medication or a psychological regimen.<sup>7</sup>*

*Although misunderstanding, social isolation, unemployment, worsening mental health, financial hardship and reduced life chances are still harsh realities for adults with ASD, the post-industrial service society expects them to self-direct their decisions regarding education, training and employment so that they could become flexible participants in a very volatile and unstable labour market.<sup>8</sup>*

*Too often, employers don't realize what autistics are capable of, and assign them repetitive, almost menial tasks. But I believe that most are willing and capable of making sophisticated contributions to society, if they have the right environment. Sometimes the hardest part is finding the right job,—but organizations are now arising to address the problem.<sup>9</sup>*

*Even though some autism symptoms seem to decrease with age, elderly with autism will not reach normal levels of social functioning.<sup>10</sup>*

*Autism is used as a counterexample to empathy and inter-subjectivity but also as evidence of the limitless potential and neurodiversity of the human mind.<sup>11</sup>*

*The greatest challenge facing people with AS {Asperger's Syndrome} is not necessarily their primary symptoms related to AS, or even their comorbid symptoms, but rather finding knowledgeable supports and services in their communities.<sup>12</sup>*

*The ASDs are heterogeneous conditions in which 2 people individuals diagnosed as having the disorder do not necessarily share a single symptom.<sup>13</sup>*

*Individuals with autism spectrum disorders (ASD) spend their majority of lives as adults ...<sup>14</sup>*

*Society's overwhelming proclivity for depicting autism as a disability of childhood poses a formidable barrier to the dignity and well-being of autistic people of all ages.<sup>15</sup>*

*Because autism is fundamentally discursive, it cannot exist outside of, or prior to, rhetoric. Rhetoric is, and always has been, integral to what autism means, what it is, and therefore (critically), what could or should be desirable, appropriate, or dominant ways of living within, understanding, interacting with, or responding to autism's shifting ontology at any given historical moment.<sup>16</sup>*

*This march toward greater specialization, combined with the pressing need for expertise in science, technology, engineering and mathematics, so-called STEM workers, suggests that the prospects for autistic workers will be on the rise in the coming decades.<sup>17</sup>*

## Preface

When conducting a systematic literature review most scholars inevitably encounter a magic “hit,” a seemingly perfect find, a hoped-for gold-standard result, and a real signal in all that “noise.” In other words, an article with a title that literally stands out as the perfect match within the fine-tuned search of parameters, keywords, and advanced search operators on the topic of their investigative work. When conducting this systematic review of the topic of autism, adulthood and aging, the journal article titled, “Gerontological Autism: Terms of Accountability in the Cultural Study of the Category of the Fourth Age” by Haim Hazan<sup>18</sup> is one such enigmatic discovery. The title of this “perfect” article leapt from the electronic inventory and begged to be automatically added to a growing list of key articles collected, analyzed and categorized. But despite the provocative label of “gerontological autism,” Hazan’s



article is less an examination of autism as a condition in the aging experience and more a philosophical piece on the cultural attitudes toward the oldest old (those in the “Fourth Age”). Hazan used autism as a descriptive term to indicate the supposed “cross-cohort incommunicability” in our postmodern era that reflects a “cultural autism” toward the elderly, given their supposed invisibility and separation from mainstream society. In other words, those in extreme old age are in an “extra-cultural” condition placing them apart from the rest of humanity.

Hazan’s critique and cultural study of the Fourth Age is provocative because of the use of the word “autism” (via the work of Hacking).<sup>19</sup> He describes the experiences of those in later life—because both the oldest old and those with ASDs are similar enough but not in all existential dimensions. The experience was like being “an anthropologist on Mars” (attributed to Temple Grandin via the work of Sacks)<sup>20</sup> or like an “alien in the land of humans.” But this metaphor for “gerontological autism” needs further philosophical examination and is worthy of further clarification.

Our interest explored in this paper is autism spectrum disorder (ASD) as an adulthood condition and part of the aging experience; but not necessarily a declaration that in most cultures to be very old is the same as being an autistic (or labeled as autistic). Even though our paper has more to do with scientific studies than epistemological debates, we were curious as to how *autism* in aging has been “discovered” and ironically published in journals about aging issues as a way of describing the failure of developing an intergenerational language to understand the life-world of “extreme old-age.” According to Hazan’s perspective this *failure* is minimally the breakdown in communication and social connections—which may be an attribute of ASDs, but not necessarily—between the oldest cohorts and the rest of society.

We were interested in conducting a comprehensive systematic review of the literature found up to the revision of this manuscript, March 22, 2013, at the intersect of aging and ASD issues. It was fascinating to encounter the use of the term “autism” to describe not only a lifelong neurodevelopmental disorder present in the domain of adulthood and aging, but as a way of describing and capturing the fragmentation of the life course near its terminus (or as Gilleard and Higgs<sup>21</sup> would refer to the “Fourth Age”

as a time of “aging without agency”). It includes the distancing of the extremely old from the rest of us, but who still share the same humanity—and the seemingly obligatory trajectory of senescence. But there is more. The beauty of the serendipity in the search process is that it renders further connections. Reviewing Hazan’s complex paper led to an article by Ian Hacking<sup>19</sup> “Humans, Aliens and Autism.” We recommended those not familiar with the varied landscape of autism read it. By sharing ten reservations, qualifications, and cautions about the disorder—the condition—Hacking offers a different understanding of the common knowledge of autism. We take this as a strong template in that the experience of aging and all of its nuances is still a matter of both scientific and humanistic inquiry. More direct to the goal of this paper, in his astute commentary, Hacking states “What we now call autism began as infantile autism, but never forget autism is for life.” When placed in context of what it means to be human, we recommend the philosophical renderings of the meaning and significance of autism—*across the life course*—should be considered.<sup>19,22–25</sup>

## Introduction

The phenotyping, diagnostics, and understanding of autism in adulthood and aging can be considered the discovery of new territory slowly being mapped and catalogued. Yet, the known terrain is still incomplete and the research horizons as challenging as *hic sunt dracones*. But progress is underway. While there is much research to be done, the landscape is being charted and points of orientation plotted. The goal of our literature review is to be comprehensive and inclusive, instead of restricting the parameters and constraining the search process. We offer an indication that there has been a modest increase in the amount of literature in this domain in our time frame of interest. We seek an eclectic understanding of the scholarship on autism, autism in adulthood and aging, and find affinity with guideposts and heuristic structures that cluster the extant literature into a helpful typology. While we do not claim to exhaust the search of every publication conducted in this domain, we are confident we present the most up-to-date exemplar publications capturing the spirit of theory, methodology, and practices of the various constructed subthemes. These subthemes provide a relevant structure and working



matrix to the array of diverse publications thus far. Also presented are unique and inclusive perspectives emphasizing intergenerational factors, life-course orientation (from young adulthood through old age), and a strengths-based component offering a complementary perspective to the traditional “disability” and “disorder” (or deficit) conceptual models and research outcomes. For example, the presentation and description by Brugha et al<sup>26</sup> captures the main sentiment of the traditional model and reviewed ASDs in the context of the health sciences.

Autism spectrum disorders (ASDs) are developmental disorders characterized by impairment of reciprocal social interaction, social communication and social imagination, often in the presence of restricted repetitive behaviors, with negative impacts on learning and independence in adulthood, affecting individuals with abilities ranging from the profoundly learning disabled to the intellectual superior, of whom some may also suffer from other co-morbid psychiatric disorders. (p. 647)

With this comprehensive description as a reference point, a benchmark of understanding, we recognize the notion of “spectrum” is just that—where classification and conditions warrant a quantitative approach of health status along a continuum rather than a binary or categorical diagnosis.<sup>27</sup> In other words in addition to the three core deficits, the classification and characteristics of *autism spectrum disorders* which capture an array of conditions, represents a continuum of social communication challenges, and where *heterogeneity* is a key descriptor for genetic factors and for the phenotypic presentation.<sup>13,28,29</sup> The heterogeneity in the autism phenotype has many investigators referring to a broad array of deficits as “the autisms”,<sup>28</sup> although the classification system in the new DSM-5 (May, 2013) seeks to consolidate several ASD subtypes into one entity.<sup>30–33,188</sup>

We recognize the need to focus on the impairments and the physical and mental health disorders associated with autism; but the epistemology should not be limited or guided by epidemiology or nosology. In the scholarship, there is room for “positive biology”,<sup>34</sup> “positive psychology”,<sup>35</sup> and even “positive or humanistic neurology”.<sup>36</sup> This paradigm shift should be used to investigate and understand the landscape for all individuals on the autism spectrum and examine the varied dimensions of neurodiversity.<sup>24,25,37–43</sup> Some propose a distinctly “quantitative approach” to understand-

ing ASD such that autism is not seen as a disease or a developmental qualitative disorder, but as a behavioral extreme in individual variation deserving of rich and supportive mentoring services that facilitate creativity and prosperity for individuals with ASDs.<sup>44</sup>

There are most certainly challenges with ASDs for the individual in adolescence and adulthood;<sup>45,46</sup> the family,<sup>47–55</sup> in the context of our national legal and policy system;<sup>56</sup> in the context of ethics and cultural beliefs;<sup>57</sup> and for our communities in an aging society.<sup>8,58</sup> But there is hope for meaningful interventions and support systems and the promise of a fulfilling life with dignity, productivity, and purpose.<sup>14,59,60</sup>

While the concept of aging with autism issues is still emerging and empirical findings building, it is important to recognize knowledge has been heavily skewed toward the early childhood years where a plethora of research is more evident and interventions are deemed more effective.<sup>61</sup> Others have proposed there is a “infantilization of autism” such that public awareness and media attention are dominated by the depiction of autism as a child-bound disability that creates barriers to understanding autism as a life-long challenge.<sup>15</sup> Some say that the focus on the childhood years is also where fund-raising and awareness raising has gained the most traction. For example, in a *New York Times* story about his 42-year-old younger brother, Noah, who is diagnosed with autism,<sup>63</sup> Karl Greenfield describes how he struggled with his lifelong impact as a sibling<sup>62</sup> and offers the insight that many will “grow old with autism.” Many of these individuals, typically older than age 22, have “aged out” of the educational system and there is often little in the way of resources and services for those who exit the secondary school system and age into adulthood with autism spectrum challenges.<sup>64</sup> Furthermore, Greenfield<sup>63</sup> indicates for those individuals with autism who cannot find employment, continue on in education, or find sheltered workshops there are not many options. He notes

If the current CDC [US Centers for Disease and Prevention] estimation of prevalence is correct, then there will be an awful lot of adult autistics who need lifetime support and care. Noah’s life has been a grim study in how scarce those resources are. Without them, his behavior has regressed.



“Aging out” (beyond educational and social services) and then *growing old* with autism is still a missing piece of the larger puzzle set. “Aging out” at 22 years old (see video documentary *Autism: Coming of Age*, a WGBY Public Television Documentary) is an expression obviously relative to those who work with youth in special education. From a gerontological perspective this journey is seen as “into aging and onward”—*for the long haul*. The ultimate goal of our systematic literature review is to fill knowledge gaps while also serving as a catalyst for more awareness, more education, and more interventions addressing the challenges and the promise of ASDs. Scholarship should not focus on autism in childhood or as a medical issue limited to geriatrics, but as a multidisciplinary perspective of the entire life course and of various domains of scholarly inquiry.<sup>11,65</sup> In other words, autism does not have an age limit nor does one field or a single profession have a monopoly on understanding autism. It is important to investigate the autism experience *through the life course* with an interest in scientific and humanistic dimensions.<sup>22,24,25,51,53,55,60,66</sup> Searching the literature with this perspective in mind additional questions arose which need to be addressed: (1) How do individuals with ASD prepare for adulthood?<sup>67,68</sup> (2) What happens to people with ASDs in midlife and beyond?<sup>69</sup> (3) Do ASDs have a distinct and separate profile in childhood versus adulthood and aging? (4) Are there human development biological and phenotypic expressions of autism to differentiate autism in childhood and youth years from the experiences of maturation and senescence? (5) Are potential biomarkers different? (6) Should treatments, services, and programs for adults with ASD be organized and delivered in a different manner than for children and youth?<sup>14</sup> (7) Is it possible to recover from autism, and if so, how?<sup>70</sup> and (8) Are there differences between aging individuals with high-functioning autism (HFA) compared to individuals without HFA?<sup>71</sup>

Some of these questions are addressed in a study by Geurts and Vissers.<sup>10</sup> They examined the lives of older adults with HFA and found mixed results and that the differential impact of autism may depend on the specific cognitive domain being examined. They suggest knowledge based on childhood and adulthood autism studies cannot be translated directly to elderly with autism because deficits are different depending

on age of the individual with autism. Geurts and Vissers conclude that while the aging trajectory for people with HFA is typical in most cognitive domains, it is also atypical and divergent from normal patterns in other domains. They saw both a “double jeopardy effect” for visual memory (aging + autism = accelerated decrease in cognitive functioning) and a “safeguarding effect” (individuals with HFA have acquired compensatory strategies to cope with their cognitive challenges as they get older). Geurts and Vissers also raise many more questions needing to be answered as research continues to emerge and unfold. These are only some of the key questions which call for more scientific inquiry of autism in an aging society. But of more concern is the overall lack of knowledge in the domain of gerontology and geriatrics for multidisciplinary issues of autism.

Thus far, the issues of autism associated with adulthood, aging and older people “have generated little interest among researchers, which is an unfortunate oversight.” Much is left to investigate. There is both good news—*the increase in scholarship*—and bad news—*the increase is just the beginning*.<sup>22</sup> We hope that by using a heuristic analysis structure to present our systematic literature review findings, we will bring more attention and awareness to the topic and inspire future research.

### For this section, we recommended the following citations as the most relevant and current

Barker ET, Hartley SL, Seltzer MM, Floyd FJ, Greenberg JS, Orsmond GI. Trajectories of emotional well-being in mothers of adolescents and adults with autism. *Developmental Psychology*. 2011;47(2): 551–61. doi:10.1037/a0021268.<sup>47</sup>

Dicker S, Bennett E. Engulfed by the spectrum: The impact of autism spectrum disorders on law and policy. *Valparaiso University Law Review*. 2011;45(2):415–56.<sup>56</sup>

Geurts HM, Vissers ME. Elderly with autism: Executive functions and memory. *Journal of Autism and Developmental Disorders*. 2012;42(5):665–75. doi:10.1007/s10803-011-1291-0.<sup>10</sup>

Grandin T. *Thinking in Pictures (Expanded, Tie-In Edition): My Life With Autism*. New York: Vintage; 2010.<sup>37</sup>



Greenfeld KT. Growing old with autism. *New York Times Op-Ed*. May 23, 2009b. Retrieved at: <http://www.nytimes.com/2009/05/24/opinion/24greenfeld.html?scp=7&sq=karl%20Greenfeld&st=cse><sup>63</sup>

Harmon A. Autistic and seeking a place in an adult world. *New York Times*. Sep 17, 2011. Retrieved at: <http://www.nytimes.com/2011/09/18/us/autistic-and-seeking-a-place-in-an-adult-world.html?pagewanted=all><sup>59</sup>

Neely J, Amatea ES, Echevarria-Doan S, Tannen T. Working with families living with autism: Potential contributions of marriage and family. *Journal of Marriage and Family Therapy*. 2012;38(s1):211–26. doi:10.1111/j.1752-0606.2011.00265.x.<sup>51</sup>

Norton R. *Aging Out: The Sad Story of the Hodgins Family*. Mar 8, 2012. Retrieved at: <http://blog.sfgate.com/rnorton/2012/03/07/aging-out-the-sad-story-of-the-hodgins-family>.<sup>64</sup>

Robison JE. *Be Different: Adventures of a Free-Range Aspergian with Practical Advice for Aspergians, Misfits, Families And Teachers*. New York: Crown Archetype; 2011.<sup>39</sup>

Rydzewska E. Destination unknown? Transition to adulthood for people with autism spectrum disorders. *British Journal of Special Education*. 2012;39(2):87–93. doi:10.1111/j.1467-8578.2012.00536.x.<sup>8</sup>

Smith LE, Greenberg JS, Seltzer MM. Social support and well-being at mid-life among mothers of adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2011;42(9):1818–26. doi:10.1007/s10803-011-1420-9.<sup>53</sup>

Solomon O. Sense and the senses: Anthropology and the study of autism. *Annual Review of Anthropology*. 2010;39:241–59. doi:10.1146/annurev.anthro.012809.105012.<sup>11</sup>

Tammet D. *Embracing the Wide Sky: A Tour Across the Horizons of the Mind*. New York: Free Press; 2009.<sup>43</sup>

White SE, McMorris C, Weiss JA, Lunsky Y. The experience of crisis in families of individuals with autism spectrum disorder across the lifespan. *Journal of Child and Family Studies*. 2012;21(3):457–65. doi:10.1007/s10826-011-9499-3.<sup>55</sup>

## Process and Procedure for the Systematic Literature Review

This paper is a systematic literature review that includes sources from the year 1990 to 2013 and online-first

publications found in five databases at the intersect of *ASD* in the domain of *adulthood and aging*. Using “ASD” and “adulthood and aging” as the two primary foci, we had several objectives: (1) Conduct an ideally exhaustive, comprehensive review of the literature to derive a cumulative count of relevant publications; (2) Create an inventory of the top exemplar publications; (3) Determine if higher order themes emerged in the comprehensive review of publications; (4) Identify the top exemplar articles per emergent theme; (5) Establish which emergent theme that had the greatest number of publications; and (6) Document the top three journals that most frequently publish articles exploring ASDs and adulthood and aging. The literature was systematically reviewed for relevant peer-reviewed journals, books, and book chapters to achieve these objectives. To generate a list of articles (as of March 22, 2013) systematic searches were done in five electronic databases: AgeLine, PsychINFO, PubMed, Web of Science and ProQuest. Various forms and combinations of the terms *autism*, *autism spectrum disorder*, *Asperger syndrome*, *pervasive developmental disorder*, *adult*, *adulthood*, *meta*, *systematic review*, and *aging* were used. From the database searches, 416 sources published after 1990 and found before March 22, 2013 were identified and integrated into this paper. To determine the relevance of each source or article the abstract was read. If the abstract information was insufficient the article was read in full. Study reference lists meeting the inclusion criteria were reviewed to discover additional studies for inclusion. Relevant books were identified through published scholarly journal book reviews, published journal article references, Google Scholar, and through the Amazon.com search tool. Our research strategy was also supplemented by inspecting the reference lists of included study articles. To meet the study inclusion criteria at least one of the study participants had to be aged 18 years and older diagnosed with and ASD, autism syndrome (AS), or HFA and published or online between January 1990 and March 22, 2013. Studies only providing data on animal subjects were excluded.

## Autism Spectrum Disorders in Adulthood and Aging: The Major Review Publications

In this section we highlight the most significant publications thus far in the domain of autism, adulthood



and aging. They offer both depth and breadth to the topic and create a referential benchmark to show how this literature review is different from previous publications.

In their peer-reviewed article “Outcomes in Adults with Autism Spectrum Disorders: A Historical Perspective” published in *Autism*, Henninger and Taylor<sup>72</sup> examine the ways in which researchers define successful adult outcomes for individuals with ASDs. Their review includes publications from the first systematic follow-up reports (about mid-1990’s) to year 2011 (year of their review publications). They divide the historical timeframe into three eras and conclude the First Era studies used vague and unreliable outcome scales. Second Era studies, done in the last decade, mark a focus on more rigorous and empirical measures of individuals with ASDs on independence in residential placement, employment, and relationships. In the more recent Third Era, studies were more likely to consider Person-in-Environment (PIE) issues offering a more dynamic and broader framework for measuring outcome measures. Although Henninger and Taylor note the percentage of adults with ASD and poor outcomes has stayed about the same over time they offer there is hope for more optimistic future findings. We argue that studies on emergent adulthood experiences should take into account both PIE factors, which incorporate both subjective and objective indices of independence, and functional abilities. Additionally, they propose an interesting life course stage “emergent adulthood” as a new human developmental phase between adolescence and adulthood. Identification of this life course stage could alter perspectives of developmental tasks strongly connected to “successful outcomes” in traditional studies.

In a similar thread, the publication of Bishop-Fitzgerald, Minshew, and Eack<sup>14</sup> represents a systematic review of psychosocial interventions for adults with autism spectrum disorders. Although they reviewed 1,217 studies, only 13 met their inclusion criteria. They found that the effects of psychosocial interventions were largely positive, but the quantity and quality of studies is limited. We recommend this article as it frames the demographic challenges ahead when placing the current estimates for ASD prevalence (1 in every 88 children) and that approximately 70% of identified individuals with ASD are under 14.

Bishop-Fitzgerald, Minshew, and Eack noted, “This cohort of children is rapidly approaching adulthood and will need effective treatment and services once they age out of entitlement services provided within and through the United States special education system.”

The 2011 article “Autism Spectrum Disorders in Older Adults: Toward Defining a Research Agenda,” published in *The Journal of the American Geriatrics Society*, is a major contribution to the literature in the autism adulthood and aging domain. On behalf of the Autism-in-Older Adults Working Group, Piven and Rabins<sup>3</sup> capture the work and effort of a larger interdisciplinary group that met in March 2010 to review current knowledge, identify gaps in knowledge, define research directions to help individuals with ASD, inform the healthcare system, and prepare society to meet the needs of this growing population.<sup>73</sup> The article is not a review publication per se but much of the extant research relating to key health and medical sciences community issues is examined. Piven and Rabins also examine ASD issues across the life span in the dimensions of prevalence, manifestations, effect on quality of life, course of ASDs, associated medical and psychiatric features, interventions, and long-term care. They state prior to the convening of the working group only one systematic study had been published examining autism issues for adults aged 50 and older. Based upon the lack of research and gaps of knowledge, the authors articulate the following future research priorities: (1) Develop diagnostic criteria and instruments to diagnosis and assess the needs of older adults with ASDs; (2) Conduct cross-sectional descriptive phenomenology studies in adults, including current symptoms and behaviors, neuropsychiatric features, associated medical conditions, and descriptions of available service and support networks; (3) Conduct longitudinal studies on life span trajectories; (4) Conduct neurobiological studies examining whether findings (eg, those from genetic and imaging studies) in young individuals with ASDs are present in older persons with ASDs, and examine the interaction between aging, associated disease, and autistic symptoms in the brain of autistic individuals as they age; (5) Conduct studies on the psychosocial, behavioral, educational, and pharmacological interventions in older individuals with ASDs; and (6) Develop mechanisms to support research train-



ing on aging with ASDs. Piven and Rabins accurately identify key intervention and autism policy issues for aging adults versus young adults. For example, they believe the literature offering evidence of efficacy in interventions for ASDs in children and adolescents raises the question of whether similar interventions would benefit middle-aged and older adults; especially those whose condition has not been previously recognized, diagnosed or treated. They also propose different interventions might be more effective for different age groups. Furthermore, they propose older individuals with ASDs, whose social and care needs have been met by family members, could lose all their support with the death or incapacity of their parents or siblings.<sup>52</sup> Many issues yet to be addressed need to be researched.

In a more recent article titled “Brief Report: The Medical Care of Adults with Autism Spectrum Disorders—Identifying the Needs,”<sup>73</sup> Bruder, Kerins, Mazzarella, Sims and Stein sustain the biomedical themes proposed by themes proposed by Piven and Rabins.<sup>3</sup> Surprisingly, however, Bruder et al<sup>73</sup> do not mention or cite the Piven and Rabins review in their publication. This may be due to the gap in publication sequence but the connections and concordance of conclusions are similar. From their survey, Bruder et al<sup>73</sup> reveal only a few physicians provide medical care for adults with ASD. Importantly, results from the same survey show the majority of the physicians report lack of training in the care of adults with ASD and desire more education and training in this area.

The publication “Aging in Autism Spectrum Disorders: A Mini-Review” follows the protocol of the journal *Gerontology*. Happé and Charlton’s<sup>74</sup> research reflects the small amount of published research they encountered in their search process. Their conclusion was that “very little is known about old age in autism” (p. 73). Although Happé and Charlton note search term parameters for their review article, it was not clear what time frame they used for their inclusion criteria (ie, year of publication). Nevertheless, Happé and Charlton’s search results yielded three subcategories of publications: case studies reporting older individuals with ASD, discussion papers raising questions about aging and/or the diagnosis of ASD in older age, and papers reporting empirical data from surveys or studies of older individuals with ASD. The main strength of the Happé and Charlton

paper is the narrative and data comparison for relevant research on ‘neurotypical’ aging in core domains of autistic impairment: social cognition, executive function, cognitive style, and memory.<sup>75</sup> For example, the authors discuss the aging process effects on “theory of mind” and speculate about the age-related decline in social cognition. They postulate whether social cognition would worsen in adults with ASD, but note some high-functioning individuals (eg, Temple Grandin) may show improving understanding of socio-cognitive situations, possibly due to increasing compensation and adaptive abilities. Happé and Charlton also propose cognitive reserve, compensation, quality of life, loneliness, and physical health as areas for future research. Finally, they suggest studies of aging in autism will be important not only to plan appropriate services but also to shed light on the full developmental trajectory of this neurodevelopmental condition, and perhaps provide clues to neuropathology and etiology.

The team of Mukaetova-Ladinska, Perry, Baron, and Povey<sup>76</sup> published their review paper in the *International Journal of Geriatric Psychiatry*. It represents an effort similar to the Piven and Rabins<sup>3</sup> publication. Their team met in Newcastle University, UK on October 29, 2009 and wrote on behalf of a research group wanting to address the question of aging in people with ASDs and focus on those with a disability. In terms of the number of publications on ASD according to age, Mukaetova-Ladinska et al<sup>76</sup> provide the best comparison in the literature up to the point of our systematic review. They conducted a PubMed search for relevant literature between 1946 and January 2011. Their key findings were: (1) There are no data regarding aging in people with ASD; (2) Prevalence rates, clinical symptomology and medical and mental health needs, as well as social needs, need to be determined for older individuals with ASD; (3) There is a need to design appropriate tools for diagnosing older people with ASD; and (4) Understanding brain aging in people with ASD will facilitate novel therapeutic interventions for this population and also knowledge regarding the molecular mechanism of aging.<sup>77</sup>

In their article published in *Research in Autism Spectrum Disorders*, Edwards, Watkins, Lotfizadeh, and Poling<sup>4</sup> presented the findings of their review of 146 intervention research studies on autism in the





top four journals. They discovered most of the 2063 study participants were between 2 and 8 years of age and only 1.7% (five participants) were 20 years or older. The mean participant was age 6.89 and 85.8% of the participants were male. Edwards et al<sup>4</sup> conclude autism intervention researchers largely overlook older people.

In her paper “How Does Visual Thinking Work in the Mind of a Person with Autism? A Personal Account” published in *Philosophical Transactions of The Royal Society B*, Temple Grandin<sup>78</sup> includes a list of major publications addressing autism in adulthood and aging. She offers a myriad of ways in which “thinking” can take place for individuals on the spectrum and proposes three principal autism thinking types: (1) photo-realistic visual thinkers (that Grandin identifies with); (2) pattern-thinking (music and math minds); and (3) word (fact) thinkers. Her primary concern is that as individuals with Asperger’s or HFA progress through school and college they especially may not be supported or mentored toward specific careers and occupational tracks. Grandin shares her autobiographical and retrospective nuances of developmental changes and adaptations for an individual with autism through the college-years and into mature adulthood.<sup>79</sup> As a result, they may be poorly equipped to realize both functional and fulfilling lives into the adulthood and the aging years.<sup>80,81</sup> In relation to the topic of this paper it important to note that Temple Grandin<sup>82</sup> turned 65 in August 2012. Based upon her life experiences and opportunities, she believes there is much creativity and talent to be harnessed in individuals with HFA and Asperger syndrome (AS).

The paper “Adults with Autism Spectrum Disorders” by Patricia Howlin and Philippa Moss<sup>83</sup> is one of many “review” cluster articles in the journal *The Canadian Journal of Psychiatry* with a guest editorial titled “Autism in Adult Life” by Eric Fombonne.<sup>84</sup> Howlin and Moss emphasize and restate previous review article themes. They argue that many adults with ASDs are significantly disadvantaged in issues of employment, social relationships, physical and mental health, and quality of life. They state most research focuses on young adults, but little is known about people with ASD as they reach mid-life and beyond into later life.<sup>85</sup> To ensure a better future and quality of life for individuals with ASD,

Howlin and Moss offer several recommendations, eg, systematic follow-up studies from childhood over the lifespan.

In the same *Canadian Journal of Psychiatry* special issue Shattuck et al, review 23 studies on the topic of services for adults with an ASD. One of the main conclusions of their article “Adults with Autism Spectrum Disorders” is that the evidence base of ASD services for adults is underdeveloped and relatively little is known. We highly recommend readers review this article.

In 2011, Levy and Perry published their article<sup>66</sup> “Outcomes in Adolescents and Adults with Autism: A Review of the Literature” in *Research in Autism Spectrum Disorder*. They offer an excellent review of the literature on outcomes for adolescence and adults with autism. They conclude outcomes in adolescence and adulthood are dependent on many factors eg, autism severity, cognitive functioning, language development, additional psychopathology, and access to intervention programs and services. However, they also argue that the majority of studies thus are small samples of predominantly higher functioning individuals.

Holwerda, van der Klink, Groothoff, and Brouwer examine factors that facilitate or hinder the ability of people with autism to work in their article<sup>87</sup> “Predictors for Work Participation in Individuals with an Autism Spectrum Disorder: A Systematic Review published in the *Journal of Occupational Rehabilitation*. They found individuals who successfully work need adequate intervention and services geared to help them adjust to societal psychosocial demands. Holwerda, van der Klink, Groothoff, and Brouwer<sup>87</sup> also conclude high quality studies predicting successful employment participation are lacking.

In their chapter “Adults with Autism Spectrum Disorders” in the book *International Handbook of Autism and Pervasive Developmental Disorders*, Mahan and Kozlowski<sup>6</sup> provide an extensive overview of key ASD domains in the literature. These domains include treatment techniques used among adults with ASD, prognosis, living placements, transition from high school, employment options and supports, specific models providing multiple services, and training programs focusing on relationships and sexuality.

Although the publication is targeted to specialists in communication disorders, Smith<sup>88</sup> has written a very valuable overview of aging and autism issues



in her publication, *Perspectives on Gerontology*. Smith<sup>88</sup> conducts a review of the literature, identifies potential needs for individuals with ASD as they age, and addresses some of the challenges that will affect professionals working in geriatric settings as this population (those with ASD) ages.

Poon<sup>89</sup> conducted a systematic review of 18 peer-reviewed research articles reporting on the outcomes of adults with ASD. Poon<sup>89</sup> focused the review on publications about adults with higher support needs, and thus studies that focused solely on high functioning autism or Asperger's syndrome were omitted. Poon<sup>89</sup> found that adults with ASD continue to experience significant degrees of impairment in the core deficits and experience poor outcomes in social role attainment. We included this publication in this section because of the international focus and publication outlet, but Poon<sup>89</sup> indicated the review reflected findings mainly from the North American continent, and Europe.

Perkins and Berkman reviews the current literature related to quality of life outcomes of aging adults with ASD.<sup>90</sup> Specific areas for their review include: life expectancy, comorbid physical and mental health issues, ASD symptomatology, and social, residential, and vocational outcomes. They concluded from their review that aging with ASD presents challenges, but there is also evidence that positive outcomes are attainable.

The last publication we highlight in this section is the 2012 book by Grandin,<sup>82</sup> *Different . . . Not Less: Inspiring Stories of Achievement and Successful Employment from Adults with Autism, Asperger's, and ADHD* [Attention Deficit Hyperactivity Disorder]. Although not scientific in nature the book reviews older individuals now diagnosed with ASDs. Their stories present a review of their lives and describe life as an older person with ASD. Even though their stories explain their challenges their stories can be inspirational to anyone who identifies with life challenges in general.

We recommend these fourteen peer reviewed journal publications and three book as exemplars that highlight and emphasize the issues of adulthood, aging, and autism. Researchers for each publication demonstrate the need for an increase in the knowledge and understanding of autism issues across the life course and to determine if these issues are different from those associated with autism in childhood

and adolescence. Collectively, they offer a deeper and comprehensive view of the factors known thus far but also show how much is unknown regarding the experience of ASDs beyond childhood and adolescence.

This systematic literature review contributes to the landscape of aging scholarship by reaching beyond the limitations inherent with each of the previous publications on autism, adulthood, and aging. It is more inclusive of research topics and categories emerging in the field. For example, this review is different from the Piven and Rabins<sup>3</sup> article because their focus was primarily on older adults and within the optic of medical science, in particular geriatrics, whereas our review is gerontologically focused, multidisciplinary and utilizes a life-course approach to cover topics from emergent adulthood through old age. Similar to Pivens and Rabins, the Mukaetova-Ladinski et al<sup>76</sup> article is also geriatric-focused and has a distinct neuropsychiatric emphasis. The Happé and Charlton<sup>74</sup> review was comprehensive but was published in a European-based journal *Gerontology: International Journal of Experimental, Clinical, Behavioural, and Technological Gerontology*. Thus far adulthood and aging research has primarily been done in Europe and the United Kingdom. Our review advances the field of knowledge by primarily targeting a North American audience. Finally this review expands the scope of database searches beyond PsychINFO and previously limited key words searches (eg, "autism" and "interventions") that were the focus of the Edwards et al,<sup>4</sup> study.

### The preeminent publications we recommend for this section are

Bishop-Fitzpatrick L, Minshew NJ, Eack S. A systematic review of psychosocial interventions for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2012. doi:10.1007/s10803-012-1615-8.<sup>14</sup>

Edwards TL, Watkins EE, Lotfizadeh AD, Poling A. Intervention research to benefit people with autism: How old are the participants? *Research in Autism Spectrum Disorders*. 2012;6(3):996–9. doi:10.1016/j.rasd.2011.11.002.<sup>4</sup>

Grandin T. How does visual thinking work in the mind of a person with autism? A personal account. *Philosophical Transactions of the Royal Society B*. 2009;364(1522):1437–42. doi:10.1098/rstb.2008.0297.<sup>78</sup>



Grandin T. *Different ... Not Less: Inspiring Stories of Achievement and Successful Employment From Adults with Autism, Asperger's, and ADHD*. Arlington, TX: Future Horizons Inc; 2012.<sup>82</sup>

Grandin T, Duffy K. *Developing Talents: Careers For Individuals with Asperger Syndrome and High-Functioning Autism*. Shawnee Mission, KS: Autism Asperger Publishing Co; 2008.<sup>365</sup>

Happé F, Charlton RA. Aging in autism spectrum disorders: A mini-review. *Gerontology*. 2012;58(1):70–8. doi:10.1159/000329720.<sup>74</sup>

Henninger NA, Taylor JL. Outcomes in adults with autism spectrum disorders: A historical perspective. *Autism*. 2012. doi:10.1177/1362361312441266.<sup>72</sup>

Holwerda A, van der Klink JJ, Groothoff JW, Brouwer S. Predictors for work participation in individuals with an autism spectrum disorder: A systematic review. *Journal of Occupational Rehabilitation*. 2012;22(3):333–52. doi:10.1007/s10926-011-9347-8.<sup>87</sup>

Howlin P, Moss P. In: Review-Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*. 2012;57(5):275–83.<sup>83</sup>

Levy A, Perry A. Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders*. 2011;5(4):1271–82. doi:10.1016/j.rasd.2011.01.023.<sup>66</sup>

Mahan S, Kozlowski A. Adults with autism Spectrum disorders. In: Matson JL, Sturney P, editors, *International Handbook of Autism and Pervasive Developmental Disorders* (Autism and Child Psychopathology Series) (Part 3), pp. 521–38. Springer: New York; 2011.<sup>6</sup>

Mukaetova-Ladinska EB, Perry E, Baron M, Povey C, Autism Ageing Writing Group. Ageing in people with autistic spectrum disorder. *International Journal of Geriatric Psychiatry*. 2012;27(2):109–18. doi:10.1002/gps.2711.<sup>76</sup>

Perkins EA, Berkman KA. Into the unknown: Aging with autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities*. 2012;117(6):478–96.<sup>90</sup>

Piven J, Rabins P; on behalf of the Autism-in-Older Adults Working Group. Autism spectrum disorders in older adults: Toward defining a research agenda. *Journal of the American Geriatrics Society*. 2011;59(11):2151–5. doi:10.1111/j.1532-5415.2011.03632.x.<sup>3</sup>

Poon KK. Supporting adults with autism spectrum disorders: Lessons from six decades of international research. *International Journal of Special Education*. 2012;27(3):1–14. Retrieved from: <http://www.internationaljournalofspecialeducation.com/><sup>89</sup>

Shattuck PT, Roux AM, Hudson LE, Taylor JL, Maenner MJ, Trani JF. Services for adults with an autism spectrum disorder. *Canadian Journal of Psychiatry*. 2011;57(5):284–91.

Smith PA. Aging in autism. *Perspectives on Gerontology*. 2012;17(2):69–75. doi:10.1044/gero17.26.9.<sup>88</sup>

## The Knowing of Autism Spectrum Disorders: Diagnosis, Prognosis, and Nosology

ASDs are complex neurodevelopmental disabilities with significant impairments in important functional skills such as communication and socialization. In the past decade, the topic of ASDs has exponentially increased in both the popular media and in academic publications. One example is the comprehensive coverage in the special issue of the prestigious and premier publication on scientific discovery, *Nature*<sup>91</sup> on the topic of the “mind’s tangled web.” This article is available in printed and Web-based collections. We recommend the public and professional care providers read it. Almost a year later, *Nature* (November 2, 2012) published another set of articles on autism<sup>92</sup> covering a variety of topics, including the domain of adulthood.<sup>22</sup>

ASD symptom presentation and severity is heterogeneous and varies throughout human development.<sup>93</sup> In the literature there are many operational definitions of ASDs. The dominant and *de facto* definition and established measuring process, especially for clinicians, is in the DSM-IV-TR Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition, Text Revision) and The International Classification of Diseases, Ninth Edition, Clinical Modification (ICD-9-CM) systems.<sup>94</sup> Using the traditional or received view definition in the *absence* of intellectual disability (ID) individuals having an IQ of 70 or higher are diagnosed with “high-functioning” autism spectrum disorder (HFASD).<sup>95</sup> However the spectrum from mild impairment to severe impairment is wide. Within the HFASD classification an individual is identified with a specific ASD diagnosis: Asperger disorder, (or syndrome),<sup>7,96–98</sup> autistic disorder, or pervasive developmental disorder—not otherwise specified (PDD-NOS).<sup>95</sup>



In the time frame of the publication of this paper, the debate and dialogue around the changes and modifications (<http://www.dsm5.org/Pages/Default.aspx>) to the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, scheduled for publication in May 2013, will still undoubtedly be unfolding, especially as it relates to preliminary draft revisions concerning ASDs<sup>99</sup> for information on the ICD-10 diagnostic criteria,<sup>31,32,100,101</sup> and<sup>33</sup> for perspectives on the forthcoming (DSM-5). For example, a proposal by the DSM-5 Neurodevelopmental Work Group and other researchers<sup>102–104</sup> recommend a new category called *autism spectrum disorder (ASD)* that would incorporate several previously separate diagnoses, including autistic disorder, Asperger disorder, childhood disintegrative disorder and PDD-NOS (APA, 2012).<sup>105</sup> This proposal represents a significant change to the current DSM-IV-TR classification. The supposed goal of the DSM-5 is to eliminate categorical disorder diagnoses within the PDD classification and recognize autisms from mild to severe with the diagnosis “ASD.”<sup>30,1,94,106,107</sup> Researchers who have already begun to test the validity of the new ASD DSM-5 criteria claim a more robust sensitivity and specificity of diagnostic assessments<sup>108,109</sup> and support stricter DSM-5 criteria.<sup>110</sup> Other researchers argue AS and HFA can be differentiated.<sup>111</sup> In the interim, the larger autism support ecosystem of parents, teachers, clinicians, therapists, physicians, and health care and social work professionals await the final nosology. On December 1, 2012, the American Psychiatric Association (APA) Board of Trustees approved the final diagnostic criteria for the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* (see <http://www.psych.org/practice/dsm/dsm5>). In terms of inclusion and exclusion much is at stake for individuals of all ages on the “spectrum.”

As one reviews the selected literature on the evolution of the DSM-5, the focus is primarily on the importance of diagnosing autism in children and youth. Thus far, diagnosing with this as a primary goal, early detection has facilitated targeted and effective interventions.<sup>112</sup> Hofvander et al<sup>113</sup> state in the context of adulthood and aging issues, the newly revised DSM-5 will have an impact in terms of prevalence, indicators, inclusion, intervention strategies, and policy implications. The research team of van Niekirk et al<sup>114</sup>

argues that the proposed DSM-5 diagnostic criteria will help facilitate the diagnosis of ASD in elderly people. But again, the current knowledge on the topic of adulthood, aging and ASD is limited. Both the diagnosis and the prognosis of adulthood and aging with an ASD has been a significant missing dimension for both the landscape of an aging society and for the individual aging experience.<sup>66</sup> Mahjouri and Lord<sup>32</sup> propose that more research is needed about adults with ASD to better understand current patterns of behavior, as this will improve the ability to make a diagnosis in the absence of reports of early history.

In addition to the behavioral definitions of autism, Dicker and Bennett,<sup>56</sup> document that in the US legal system the courts rely exclusively on the “Individuals with Disabilities Education Act” (IDEA) definition; a definition focusing on educational performance that does not typically rely on the DSM criteria.

Of all the definitions we found Lord and Jones<sup>7100</sup> was the most informative and succinct: “Autism spectrum disorders is a summary term for an *as-yet-not-understood* combination of social-communication deficits and repetitive and restricted behaviors and interests that interact together to form a pattern that appears to be more than the sum of its parts.”

## Recommended publications for this section

Fisch G. Nosology and epidemiology in autism: Classification counts. *American Journal of Medical Genetics Part C (Seminars in Medical Genetics)*. 2012;160C(2):91–103. doi:10.1002/ajmg.c.31325.<sup>147</sup>

Geurts HM, Jansen MD. A retrospective chart study: The pathway to a diagnosis for adults referred for ASD assessment. *Autism*. 2011;16(3):299–305. doi:10.1177/1362361311421775.<sup>96</sup>

Gillespie-Lynch K, Sepeta L, Wang Y, et al. Early childhood predictors of the social competence of adults with autism. *Journal of Autism and Developmental Disorders*. 2012;42(2):161–74. doi:10.1007/s10803-011-1222-0.<sup>135</sup>

Levy A, Perry A. Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders*. 2011;5(4):1271–82. doi:10.1016/j.rasd.2011.01.023.<sup>66</sup>

Lord C, Jones R. Annual research review: Re-thinking the classification of autism spectrum disorders. *Journal of Child Psychology and Psychiatry*.



2012;53(5):490–509. doi:10.1111/j.1469-7610.2012.02547.x.<sup>100</sup>

Matson JL, Wilkins J. Nosology and diagnosis of Asperger's syndrome. *Research in Autism Spectrum Disorders*. 2008;2(2):288–300. doi:10.1016/j.rasd.2007.07.003.<sup>318</sup>

Roy M, Dillo W, Emrich H, Ohlmeier M. Asperger's syndrome in adulthood. *Deutsches Arzteblatt International*. 2009;106(5):59–64. doi:10.3238/arztebl.2009.0059.<sup>98</sup>

Seltzer MM, Krauss MW, Shattuck PT, Orsmond G, Swe A, Lord C. The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*. 2003;33(6):565–81. doi:10.1023/B:JADD.0000005995.02453.0b.<sup>129</sup>

Seltzer MM, Shattuck PT, Abbeduto L, Greenberg JS. Trajectory of development in adolescents and adults with autism. *Mental Retardation and Developmental Disabilities Research Reviews*. 2004;10(4):234–47. doi:10.1002/mrdd.20038.<sup>134</sup>

Tantum D, Girgis S. Recognition and treatment of Asperger syndrome in the community. *British Medical Journal*. 2009;39(1):41–62. doi:10.1093/bmb/ldp006.<sup>104</sup>

van Alphen SP, Oude Voshaar RC. Screening of autism spectrum disorders in the elderly: A contribution to a psychometric approach. *International Psychogeriatrics*. 2012;24:1187–8. doi:10.1017/S1041610212000166.<sup>165</sup>

van Niekerk ME, Groen W, Vissers CT, van Driel-de Jong D, Kan CC, Oude Voshaar RC. Diagnosing autism spectrum disorders in elderly people. *International Psychogeriatrics*. 2011;23(05):700–10. doi:10.1017/S1041610210002152.<sup>114</sup>

## The Epidemiology of Autism: Incidence, Prevalence, and the Counting of Autism

The challenge of explaining the “apparent” rise in autism rates is complicated and fraught with varying interpretations and explanations.<sup>115–125</sup> For example, Mazumdar et al<sup>121</sup> found a causal relationship between neighborhood-level diagnostic resources and spatial patterns of autism incidence (in other words, “contextual drivers of increased prevalence”) but they did not rule out the possibility of environmental issues that may have influenced autism risk.

Rutter claimed that the true incidence of autism spectrum disorders is likely to be within the range of 30–60 cases per 10,000 which he noted as a ‘huge increase’<sup>126</sup> over the original estimate 40 years ago of 4 per 10,000. He further proposed that the increase in the incidence of autism is largely a consequence of improved ascertainment and a considerable broadening of the diagnostic concept. He did indicate that a “true risk” due to some, as yet to be identified, environmental risk factor could not be ruled out,<sup>126</sup> but in a commentary response to King and Bearman's<sup>118</sup> publication, Rutter<sup>127</sup> answered his own question: *Has there been a true rise in incidence?* with “In my view, we simply do not know” (p. 1238).

Insel responded to the recent numbers of autism prevalence (1 in 88 children, 1 in 54 boys) from the latest Centers for Disease Control and Prevention report (CDC, 2012) by asking the insightful question: *Are more children affected or more detected?*<sup>128</sup> Insel further elaborated on his own question in this fashion,

Total population epidemiological studies suggest much or all of the increase is due to better and wider detection. Studies of administrative and services data suggest that better detection cannot fully explain the profound and continuing increase. Are we seeing more affected or more detected? The question is vitally important, but there is not one, simple answer just as autism is not a single, simple disorder.

Signs of ASD typically appear before age three and persist throughout the lifespan.<sup>129</sup> Many children with ASDs also have intellectual disabilities (ID) and approximately 70% have a lifelong disability requiring substantial social and educational support.<sup>46,130,131</sup> While some individuals with ASD develop typical functional skills, many display a broad range of ongoing intellectual, behavioral, social, and emotional limitations.<sup>132</sup>

Seltzer et al indicate for most persons,<sup>129</sup> ASDs are lifelong disabilities<sup>133</sup> and as individuals move through the life course more targeted and *developmentally appropriate* strategies are needed.<sup>134</sup> In studies of adults with ASD, the degree of function, symptoms, and outcomes are highly variable indicating function in individuals can improve, deteriorate, or remain stable during the life course.<sup>7,66,96,129,135</sup> Outcomes are dependent are many factors such as autism severity, cognitive functioning, language development, additional psychopathology, and access to services and programs.



The increased prevalence of ASD is documented as a global concern.<sup>119,136,137,327</sup> The global prevalence ratio for ASDs is estimated to be 1:160.<sup>136</sup>

In the US, ASD is considered one of the fastest growing developmental disabilities.<sup>137</sup> It is estimated approximately 1.5 million individuals in the US have an ASD diagnosis. The most current estimates from Centers for Disease Control and Prevention (CDC) indicate 1 in 88 children are currently diagnosed with an ASD.<sup>138</sup> This represents a 78% national increase from 2002–2008. On March 20, 2013, the CDC via the National Center for Health Statistics indicated that the prevalence of diagnosed ASD in 2011–2012 was estimated to be 2.00% for children aged 6–17. This prevalence estimate (1 in 50) is significantly higher than the estimate for children in that age group in 2007 (see Blumberg, Bramlett, Kogan et al in Recommended Publications list). Interestingly, there is evidence autism spectrum conditions may be more prevalent in specific geographic regions, especially in “information-technology” rich areas where the connection between “systemizing” and autism is vectored through familial associations.<sup>140</sup>

There are several proposed reasons why the prevalence rate has increased so dramatically, including shifts in provider diagnostic patterns, diagnostic substitution, increased awareness, changes in administrative diagnostic criteria, and/or program eligibility requirements.<sup>112</sup> While the number of children diagnosed with ASD is increasing rapidly, the number of adults with ASD is less clear and less reliably measured.<sup>132</sup> From their 2009 study Brugha et al<sup>141</sup> estimate approximately 1% of the adult population in the United Kingdom is diagnosed with an ASD while more recently Brugha, Cooper, McManus, Purdon, Smith, Scott, Tyrer<sup>26</sup> reported 1.1%. More importantly, Brugha et al<sup>141</sup> have indicated that there is no evidence of a statistically significant reduction in prevalence of ASDs as a function of age. They found prevalence was greatest in men, in those living in social housing, and in those with the lowest educational qualifications Brugha et al<sup>141</sup> concluded that,

Overall, our findings suggest that prevalence is neither rising nor falling significantly. This favors the interpretation that methods of ascertainment have changed in more recent surveys of children compared with the earliest surveys in which the rates reported were considerably lower. Our data suggest that the causes of

autism appear to be temporally constant and that recent apparent rises in rates of diagnosis must therefore reflect better survey case finding rather than some new environmental toxin (p. 464).

Numerous researchers have shown the prevalence rates for older individuals with ASD is underestimated, underreported, and underdiagnosed.<sup>114,143</sup> Chow et al<sup>142</sup> conclude the number of diagnosed older individuals may actually to be smaller because narrower definitions were more likely used at the time of the diagnosis.

Due to the demonstrated and anticipated increased in the prevalence of ASD and the demographics of an aging society, there are concerns the convergence of both trends will dramatically impact social and health care systems.<sup>3,144</sup> In 2006, the US Census Bureau projected a doubling of the US population aged 65 and older by 2030. Based upon the current life expectancy of school-aged children with ASD, there will be approximately 700,000 individuals aged 65 and older with ASDs in the next 20 years.<sup>3</sup> As it stands currently, Brugha et al<sup>141</sup> succinctly state the problem: “Adults with ASD living in the community are socially disadvantaged and tend to be unrecognized.”

## Recommended publications

Blumberg SJ, Bramlett, MD, Kogan, MD, et al. Changes in prevalence of parent-reported autism spectrum disorder in school-aged US children: 2007 to 2001–2012. National health statistics reports; no. 65. Hyattsville, MD: National Center for Health Statistics. March 20, 2013. Retrieved at <http://www.cdc.gov/nchs>.

Brugha TS, McManus S, Bankart J, et al. Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*. 2011;68(5):459–66. doi:10.1001/archgenpsychiatry.2011.38.<sup>141</sup>

Brugha TS, Cooper SA, McManus S, et al. Estimating the prevalence of autism spectrum conditions in adults: Extending the 2007 adult psychiatric morbidity survey. *The Health and Social Care Information Centre (NHS)*. Retrieved at: <http://www.ic.nhs.uk>, Sep 26, 2012.<sup>26</sup>

Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders: Autism and developmental disabilities monitoring network,



United States, 2006. *Morbidity and Mortality Weekly Report (MMWR), Surveillance Summaries*. Dec 18, 2009;58(SS10):1–10.

Elasbbagh M, Divan G, Koh Y-J, et al. Global prevalence of autism and other pervasive developmental disorders. *Autism Research*. 2012;5(3):160–79. doi:10.1002/aur.239.<sup>136</sup>

Gerhardt PF, Lanier I. Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy*. 2011;41(1):37–45. doi:10.1007/s10879-010-9160-2.<sup>232</sup>

Lord C. Epidemiology: How common is autism? *Nature*. 2011;74(7350):166–8. doi:10.1038/474166a.<sup>119</sup>

Newschaffer CJ, Croen LA, Daniles J, et al. The epidemiology of autism spectrum disorders. *Annual Review of Public Health*. 2007;28:235–58. doi:10.1146/annurev.publhealth.28.021406.144007.<sup>123</sup>

Pinbrough-Zimmerman J, Bakaian A, Fombonne E, Bilder D, Taylor J, McMahon W. Changes in the administrative prevalence of autism spectrum disorders: Contribution of special education and health from 2002–2008. *Journal of Autism and Developmental Disorders*. 2012;42:521–30. doi:10.1007/s10803-011-1265-2.<sup>112</sup>

Rutter M. Incidence of autism spectrum disorders: changes over time and their meaning. *Acta Paediatrica*. 2004;94:2–15. doi:10.1111/j.1651-2227.2005.tb01779.x.

Rutter M. Aetiology of autism: Findings and questions. *Journal of Intellectual Disability Research*. 2005;49:231–8.<sup>126</sup>

Roelfsema M, Hoekstra R, Allison C, et al. Are autism spectrum conditions more prevalent in an information-technology region? A school-based study of three regions in The Netherlands. *Journal of Autism and Developmental Disorders*. 2012;42(5):734–9. doi:10.1007/s10803-011-1302-1.<sup>140</sup>

vanNiekerc ME, Groen. W, Vissers CT, vanDriel-de Jong D, Kan CC, Oude Voshaar RC. Diagnosing autism spectrum disorders in elderly people. *International Psychogeriatrics*. 2011;23(05):700–10. doi:10.1017/S1041610210002152.<sup>114</sup>

Weintraub K. The prevalence puzzle: Autism counts. *Nature*. 2011;479:22–4. doi:10.1038/479022a.<sup>124</sup>

## Methodology and Measurement

Murphy et al argue that the current standard route to clinically diagnosis ASDs is costly and time-

consuming resulting in an enormous economic consequence.<sup>27</sup> They state that past ASD symptoms relayed through retrospective accounts are bound to be problematic because it not only relies on the availability of an informant but also on their reliability. To improve diagnosing, they present MRI scans using Support Vector Machine (SVM) software as a means to diagnose based upon physical evidence and not relying upon behavioral assessments only. Brain anatomy can be used to accurately distinguish adults with autism other neurodevelopmental disorders such as ADHD. However while Murphy et al,<sup>27</sup> call for increased use of MRI scans Philip et al<sup>145</sup> conducted a systematic review and meta analysis of 146 articles in the use of fMRI investigation of ASD. They conclude developmental changes in brain activation occur differently in individuals with ASD versus individuals without ASDs.<sup>146</sup> Paradoxically, Philip et al<sup>145</sup> found a general bias *towards* imaging adults rather than younger cohorts. They explain the demanding nature of participating in fMRI experiments make it difficult for younger children to participate in the scanner environment. Nevertheless, they argue for longitudinal studies on ASDs beginning in early childhood using fMRI to determine the etiology of ASDs. They also suggest both behavioral and imaging data appear to indicate people with ASD develop alternative and compensatory processing styles and strategies that would likely confound findings in adult populations.

In the absence of an ASD gold standard biomarker and in addition to a lack of consensus on the definition of ASD, screening for and assessing ASD in adulthood is difficult. Behavioral evaluations may be influenced by the “apparent manifestation of criteria” currently used to define the disorder.<sup>147</sup> ASD diagnosis is based on the presence of an identified set or spectrum of behaviors affecting individuals in different ways. Common characteristics of people with ASD include restricted narrow interests, repetitive behaviors, and profound impairments in reciprocal social interactions.<sup>100,148</sup> Lombardo and Baron-Cohen<sup>149</sup> highlight the communication deficit, the social cognition deficit, and the self-referential deficit as key theoretical factors in association with social impairments.

Only a few studies have been published identifying the psychometrics that could be used to help diagnose autism and AS in adults—and the elderly.<sup>7,150–153</sup> According to, Brugha et al<sup>26</sup> as of March 1, 2012 there



were no tested methods for conducting epidemiological studies for individuals with ASDs in the adult general population. Instead the recognition and diagnosis depended on information about the pattern of behavior and skills observed.<sup>154</sup> Nevertheless it is important to include current assessment and screening methods in our review.

Recognizing the need for a “red flag” tool to help frontline professionals make a decision for a full diagnostic assessment for ASD, Allison, Auyeung, and Baron-Cohen<sup>150</sup> report the psychometrics and positive results for their 10-item Autism Spectrum Quotient (AQ-10, adult version) (see also Hoekstra et al,<sup>153</sup> for a description of the AQ-Short). In a longitudinal study by Billstedt, Gillberg, and Gillberg<sup>155</sup> the semi-structured Diagnostic Interview for Social and Communication Disorders (DISCO) scale was used to gather data. After following a sample of individuals since childhood, they found many of the adults still reported social interaction problems. They also note behavioral impairments were much more variable in adulthood. Billstedt et al<sup>155</sup> conclude that certain childhood measures could prospectively predict adult social interaction style, communication type, and pattern of self-chosen activities.

In their study, Brugha et al<sup>156</sup> provide information on the validity on two survey methods: the Autism Diagnostic Observation Schedule module-4 (ADOS-4) and the 20-item Autism Spectrum Disorder Quotient (AQ-20). They also discuss the use of the “informant-based” DISCO scale and the Autism Diagnostic Interview-Revised (ADI-R). The ADI-R has also been used in a population of Latino adolescents and adults with autism.<sup>157</sup>

Nygren et al propose that even though the ADI-R supposedly represents the “gold standard” to diagnosis classic autism,<sup>158</sup> it doesn’t cover the broader phenotype symptoms in the DISCO scale (version 10) and could be used to assess more areas of development and has diagnostic algorithms for all of the commonly used clinical categories of ASD. Their results suggest limited use of the AQ-20 as a screening tool in general population surveys. They argue for further research to improve screening methods for the general populations. Yet, given those caveats, Brugha et al<sup>26</sup> suggest that until a better screening tool can be developed, the AQ-20 remains the only fully evaluated self-report measure of ASD that can be used in adult surveys.<sup>159</sup>

When examining outcomes for adults with ASD, Kamio, Inada, and Koyama<sup>160</sup> propose more studies should include measures of quality of life.<sup>161</sup> Kamio et al<sup>160</sup> use the 26-item scale WHOQOL-BREF in their study of adults with HFASDs. Ritvo et al<sup>162</sup> report on the use of the Ritvo Autism Asperger Diagnostic Scale (RAADS) but claim the scale did not distinguish between autism and AS. Holdnack, Goldstein, and Drozdick<sup>163</sup> evaluated cognitive functioning in adolescents and adults diagnosed with autism or AS using the Wechsler Adult Intelligence Scale-Fourth Edition (WAIS-IV) and the Advanced Clinical Solutions Social Perception subtest.

Matson, Hess, Mahan, Fodstad, and Neal conducted a study to determine which items from the Autism Spectrum Disorders-Diagnostic for Adult (ASD-DA) categorize adults with ASD with varying degrees of autism.<sup>164</sup> They found the items most likely to distinguish individuals with ASD were in the socialization domain. Importantly, Matson et al<sup>164</sup> also discovered *adults* with ASD were more likely to be male and non-verbal. They state that using caregiver reports proved to be an accurate method to determine ASD within an adult AD population with IDs. Yet, Matson et al<sup>164</sup> also propose there is considerable overlap between ASD and ID and the more severe the ID becomes the more difficult it is to diagnose ASD. A Netherlands research team<sup>114</sup> found that some screening instruments for older adults with ASD were reliable. However, they recommend a thorough patient history corroborated and supplemented by a close relative or caregiver, who has known the patient for at least ten years, still remains the most important diagnostic tool.<sup>165</sup>

Even with “gold standard” tools such as the ADI-R (Autism Diagnostic Interview-Revised) and the ADOS clinicians need to be trained on the procedures and processes of using of using these scales. Important to understand is that the ADI and ADOS assessments were mainly designed to measure autism symptoms in childhood—not in adults.<sup>166</sup> Bastiaansen et al<sup>166</sup> suggest there is no established tradition to diagnose ASD in adults. They further note it is very challenging to disentangle social and communicative problems associated with ASD from the often complicated clinical picture in adulthood. Furthermore, the symptoms and diagnosis may change over the course of life.<sup>96</sup> As individuals age,





diagnosing becomes more complicated and in older adults it is often difficult to get a developmental history.<sup>167</sup>

We end this section with succinct statements from Bishop and Seltzer<sup>159</sup> who suggest multiple avenues for future research to discover strategies for obtaining valid self-reports of the symptoms of adults with ASD,

For some individuals, self-report provides a valid method for ascertaining information about ASD-related impairment, and may serve as the only means of gathering information about certain symptoms that are not necessarily visible to others (eg, sensory preferences). For other individuals, such as those with limited insight into their difficulties, self-report may not be an appropriate way to establish or confirm an ASD diagnosis, or to index a person's level of ASD symptomatology. However, adults with ASD have a perspective that is important to consider in both assessment and treatment, and there is a clearly a need to develop self-report measures that can be used in individuals with different levels of ability (p. 2362).

## Recommended publications

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Bishop SL Seltzer MM. Self-reported autism symptoms in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorder*. 2012;42:2354–63. doi:10.1007/s10803-012-14.<sup>159</sup>

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James IA, Mukaetova-Ladinska E, Reichelt FK, Briel R, Scully A. Diagnosing Aspergers syndrome in the elderly: A series of case presentations. *International Journal of Geriatric Psychiatry*. 2006;21(10):951–60. doi:10.1002/gps.1588.<sup>7</sup>

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Philip R, Dauvermann M, Whalley H, Baynham K, Lawrie S, Stanfield A. A systematic review and meta-analysis of the fMRI investigation of autism spectrum disorders. *Neuroscience and Biobehavioral Review*. 2012;36:901–42. doi:10.1016/j.neubiorev.2011.10.008.<sup>145</sup>

Ritvo RA, Ritvo E, Guthrie D, Yuwiler A, Ritvo M, Weisbender L. A scale to assist the diagnosis of autism and Asperger's disorder in adults (RAADS): A pilot study. *Journal of Autism and Developmental Disorders*. 2008;38(2):213–23. doi:10.1007/s10803-007-0380-6.<sup>162</sup>

## The Etiology of Autism (Environmental and Biological Factors)

The etiology of autism is a topic of controversial debate.<sup>168</sup> For some researchers, the focus is entirely on brain anatomy, genetics or the biological bases of autism.<sup>169</sup> For others, the goal is to identify the cause(s) of autism to understand the complex interplay between environment and gene regulation.<sup>168</sup> While recognizing that autism is a complex disorder,<sup>116</sup> Russo<sup>170</sup> has proposed that both genetic and epigenetic factors be fully



investigated (and supported with funding) in order to fully understand autism spectrum disorders.<sup>123,171</sup>

Hallmayer et al in a study of genetic heritability and shared environmental factors among twin pairs with autism concluded that environmental factors common to twins explain about 55% of the liability to autism. Hallmayer et al<sup>172</sup> propose that nongenetic risk factors that may index environmental influences include parental age, low birth weight, multiple births, and maternal infections during pregnancy. Pardo, Vargas, and Zimmerman<sup>173</sup> have proposed that environmental factors (eg, neurotoxins, infections, maternal infections) in presence of genetic susceptibility and the immunogenetic background of the host influence the development of abnormalities in cortical organization and neuronal circuitry and neuroinflammatory changes responsible for the generation of autistic symptoms.<sup>174</sup>

Although there is increasing research investigating ASD biological bases,<sup>175</sup> there are still unresolved scientific, social, and ethical issues needing to be explored.<sup>176</sup> Amaral<sup>175</sup> indicates several pitfalls and roadblocks to discovering a singular etiology for ASD and every biological parameter assayed in individuals with ASD is associated with “enormous” heterogeneity. The prevailing notion of *heterogeneity* is a common descriptor for both the phenotypic and the genetic profile of ASD due to the pivotal interactions between gene, brain, and behavior throughout development.<sup>177</sup> Pelphrey, et al<sup>177</sup> argue the goal is to “constrain the heterogeneity” and look for a more focused and limited group of core indicators when they stated

We argue the reciprocal relationship between brain disruption and atypical social development drives homogeneity in the syndrome’s presentation even in the presence of enormous phenotypic and genotypic presentation (p. 633).

This acknowledgment of the potential homogeneity is hypothetically found as an interactive dynamic of Person-in-Environment (PIE), or more specifically neural structures and brain systems interacting with social environments. ASD is theoretically couched in a core issue and features such as reciprocal dysfunctional social interaction.<sup>177</sup> We find this perspective a refreshing approach. Similar to the case in the biological domain, observed findings of *reduced* long-range functional connectivity in adults

with ASD could be the *result* of the ASD. Regarding the developmental and life course context for ASD phenotypic expression Pelphrey et al,<sup>177</sup> succinctly state,

If individuals with an ASD lack the necessary, early developing mechanisms for social engagement that ensure normative social development, then opportunities for social interaction are inherently reduced, particularly experiences sought out by the individual (p. 632).

Again, this approach highlights the reciprocity and the importance of PIE interaction effects, especially over a period of time. This is essential when in understanding ASD in the context in the aging experience.

The exact determination for the role of genetic factors that affect liability for autism spectrum disorders are emergent in ongoing research and in the literature. The relative contribution of genes and environment is “contentious.”<sup>178</sup> Klei et al<sup>178</sup> proposed that the genetic architecture of ASD has many components: additive, non-additive and de novo genetic effects, as well as gene-gene and gene-environment interactions. In their study, Klei et al<sup>178</sup> conclude that a substantial portion of ASD liability arises from inherited variation acting additively and a myriad of common genetic variants of very small effect impacts ASD liability.

From their multicenter MRI study results Ecker et al<sup>179</sup> propose autism is a syndrome and should not be labeled a disorder. They argue autism is best characterized by an atypical neural “connectivity” and that adults with ASDs have distributed differences in brain anatomy and connectivity associated with specific autistic features and traits. More specifically Ecker et al<sup>180</sup> found that adults with ASD had significant differences in cortical thickness and cortical volume, which primarily affected the frontal and temporal lobes. Although there is evidence regarding reduced “long-range” connectivity between the frontal cortex and other brain regions in individuals with ASD;<sup>28,181</sup> there is also evidence of impaired local connectivity in several regions of the brain.<sup>182</sup> However Vissers et al<sup>182</sup> call for more refinement of the theory of “connectivity” and how such patterns relate to behavioral characteristics of ASD. Through autopsy, Weidenheim, Escobar, and Rapin<sup>183</sup> examined the brain neuropathology of a 63-year-old male diagnosed with ASD of Asperger subtype. They offer a unique profile and a detailed



account of neuropathology for autism in an older adult. Weidenheim et al<sup>183</sup> conclude in this one case the behavioral data and the pathological findings are consistent with an early neurodevelopmental process affecting multiple neuroanatomic networks, but they did not discover any distinguishable morphologic signature that was detectable with routine (and current) neuropathologic technology. For a similar case study and using high-resolution magnetic resonance imaging of a 63-year-old male autistic savant with prodigious artistic skills, see the publication by Corrigan et al.<sup>184</sup>

Researchers recognize age-related changes in ASD may result from dynamic processes in brain structure and function across the lifespan.<sup>28,103</sup> Given the high heritability of ASDs, Peca, Ting, and Feng<sup>185</sup> propose a strong case for the influence of genetics in the etiology of ASDs; up to 90% in monozygotic twins when taking into account the conjunction with the prominence of ASDs in genetic syndromes. Campbell and Wang<sup>186</sup> found in their study that college students aspiring to be science, mathematics, and engineering majors were more likely than other students to report a sibling with ASDs. Other researchers offer evidence for a strong overlap between the genetic and epigenetic risk architecture in autism.<sup>187</sup> While genes alone do not entirely explain the complex etiology of autism spectrum disorders,<sup>170,188</sup> genetic factors play a major role in the “etiologic panorama”.<sup>30,189,190</sup> Researchers propose there is a familial linkage between neuropsychiatric disorders eg, ASDs and intellectual interests. Sullivan et al,<sup>191</sup> suggest ASD, schizophrenia, and bipolar disorder share common etiologic factors and a family history of schizophrenia and bipolar disorder are risk factors for ASD.

More males than females are diagnosed with ASD.<sup>192</sup> But some argue that the repetitive stereotyped behavior characteristics and difficulties at school identified in the DSM are less pronounced in the female phenotype and may lead to “under-recognition” of females with ASDs.<sup>193</sup> Some researchers<sup>194,195</sup> propose an “extreme male brain,” or variant of male intelligence, theory of autism. This perspective is extended in other research that indicates that the non-social cognitive domain is modulated by sex differences on the autism spectrum, although the social-cognitive domain is equally impaired in male and female adults with autism spectrum conditions.<sup>196</sup> Baron-Cohen<sup>197</sup> has suggested at a recent WIRED

conference (London, UK) that “autism is linked to minds that are wired for science”.<sup>198</sup> Other researchers suggest that Baron-Cohen’s work is an example of “rhetorical gendering autism”.<sup>199</sup> Others propose that ASD may constitute a gender defiant disorder.<sup>200</sup> In other words, they indicate an increased androgyny in adults with ASD. In contrast Lai et al<sup>143</sup> conclude that in male adults the discrepancy between empathizing and systemizing is related to distinct individual brain structure differences. Men, with a stronger drive to systemize rather than empathize, have increasingly larger midline cingulate and prefrontal structures, whereas those with a stronger drive to empathize than to systemize have an increasingly larger ventral basal ganglia and hypothalamus. However, researchers offer critical arguments against the “empathizing-systemizing” theory and the gender associations with affinities to STEM (science, technology, engineering, mathematics) fields.<sup>201</sup>

A recent study by Dickstein et al has found that ASD affects the brain activity of children and adults differently (see Dickstein et al in Recommended publications list). Autism is typically marked by brain overgrowth in the earliest ages but not at older ages when *decreases* in structural volumes and neuron numbers are observed.<sup>202,203</sup> More specifically, the team of Via, Radua, Cardoner, Happe, and Mataix-Cols,<sup>103</sup> found individuals with ASDs have robust decreases in gray matter volume in the bilateral amygdala-hippocampus complex and bilateral precuneus parts of the brain. Doyle-Thomas et al,<sup>204</sup> examined cortical thickness in individuals with ASD between the ages of 7 and 39 years and conclude social impairment is associated with atypical brain morphology in ASD participants. Specifically they found relative to controls, the ASD group had reduced cortical thinning across age. Trajectories of brain development in ASD are dynamic and many findings in young children differ from those seen in older adults.<sup>3</sup> Specifically with regards to ASDs in older adults Geurts and Vissers<sup>10</sup> conducted a unique study with a sample of 23 older adults ranging in age from 51–83. From their robust findings they conclude that in particular domains elderly with HFA have subtle neuropsychological deficits and the developmental trajectories that are different than elderly without HFA. Geurts and Vissers also state that knowledge of ASDs based on childhood and adulthood studies



cannot be directly translated to older adults with ASDs. Autism deficits are different depending on the age of the individual.

In one study, Hallahan et al<sup>205</sup> found adults with ASDs did not differ in brain, head size, or volume of ventricular cerebrospinal fluid (CSF), but adults with ASD did differ in cerebellar volume and an increase in peripheral CSF. In their review of the existing literature Murphy et al<sup>27</sup> note there is preliminary evidence that adults with ASD have abnormalities in the development of specific white matter tracts in the brain and these differences continue into and change in adulthood. From their studies, many researchers also propose that overall brain volume in adults with ASD does not differ from controls, but there are regional differences in gray and white matter.<sup>93,186,206,207</sup>

Raznahan et al indicate cortical dysmaturation,<sup>207</sup> specifically cortical thickness, in ASDs is not restricted to childhood but extends across the lifespan and this cortical dysmaturation is focal and localized in specific regions. It is most pronounced in areas of the brain relating to social cognition. Using a cross-sectional research design Prigge et al<sup>208</sup> examined corpus callosum growth from a developmental perspective across a 30-year age range and found increased variability in total corpus callosum area in males with autism. Dinstein, Heeger, Lorenzi, Minshew, Malach and Behrmann<sup>209</sup> found differences between high-functioning adults with autism (versus controls) on evoked cortical responses and suggest that this may represent a fundamental physiological alteration of neural processing in autism.

In another study McKay et al<sup>210</sup> used fMRI tasks in adults with ASDs and typically developed (TD) controls. They discovered individuals with ASDs utilize a different pathway in the brain to process information (neural processing streams) compared to TD individuals. McKay et al<sup>210</sup> also found these differences may occur due to early dysfunctional connectivity in the brains of individuals with ASD, but that some compensation due to re-wiring of the brain was possible, especially in high functioning adults.

To identify age-related gene expression differences and possible correlates of abnormal functioning in this disorder Chow et al<sup>142</sup> examined postmortem DNA and mRNA patterns in the prefrontal cortex in young children versus adults with autism. They found the key pathways associated with autism are different

in younger than in older individuals. For example, the adult autistic brain shows evidence of neuron loss, reduced or arrested growth, cortical thinning, and possible degeneration. Chow et al<sup>142</sup> also propose their evidence shows that in the prefrontal cortex important gene expression abnormalities change with age. Such changes might be related to findings in other studies that report a shift in morphology and function in the adult autistic brain. Courchesne et al<sup>202</sup> propose studies of the older autistic brain may not address original causes but are essential to discovering how best to help the older aging autistic person.

In the domain of neurobiology and autism, the potential role of dysfunctional mirror neurons (ie, broken mirror hypothesis) and the role of de novo mutations<sup>211</sup> have received an increasing amount of attention. The number of publications on this topic have increased dramatically in the last decade, but the definitive role of mirror neurons, or the mirror neuron system, as an underlying causal factor in ASDs, is still subject to debate and findings from research have been controversial, mixed and not clear in all cases.<sup>212,213</sup> For example, previous researchers suggest ASD impairments are due to mirror neuron dysfunction and may decrease with age. But Enticott et al<sup>214</sup> conclude while mirror neuron activity is associated with social impairments there was no indication that the impairments due to mirror neuron impairment decrease with age.

Researchers also indicate age may be a critical factor determining inferior frontal gyrus (IFG) activity. In a group of individuals with autism IFG increased but not in a control group.<sup>215</sup> Bastiaansen et al<sup>215</sup> suggest that by age 30, individuals with ASD no longer differed from typically developing individuals. Also, the neural “noise” in the IFG decreases with age in individuals with ASDs and may indicate improved functioning in the mirror neuron system.

At the neuroanatomical and biochemical brain levels, an interesting study by Domes, Heinrichs, Michel, Berger, and Herpertz<sup>216</sup> examined the use of oxytocin as a factor in the pathogenesis of autism. They propose oxytocin could be used to treat autism symptoms eg, social engagement and “mind reading.” But according to Murphy, Beecham, Craig, and Ecker<sup>27</sup> we know relatively little about the biology of ASD in adulthood, and/or whether the neurodevelopmental abnormalities detected early in life persist,



change, predict outcome, or can be used to help identify autism later in life.

Researchers postulate the biological age of parents could be a factor in children born with ASDs. A number of population studies show that children with ASD are more likely born to older parents.<sup>217–220</sup> Interestingly, other researchers emphasize the role of gender in prenatal factors proposing the advanced age of the father is more significant than the advanced age of the mother.<sup>189,221</sup> This then begs the question, why is the underlying mechanism for paternal age a factor? Researchers hypothesize the offspring of older fathers have an increased risk of neurodevelopmental disorders such as schizophrenia and autism by generation of *de novo* copy number variations (CNVs) in the male germline.<sup>222,223</sup> But not all researchers are in agreement with the paternal age and ASD connection. For example King, Fountain, Dakhllallah, and Bearman<sup>224</sup> propose that the advanced maternal age rather than paternal age, may pose a greater risk. In a cohort study Parner et al,<sup>225</sup> identified an association between parental age and ASD, but the combined underlying mechanisms through which paternal and maternal age impact ASD risk do not seem to act synergistically. Eriksson et al,<sup>189</sup> also propose that in clinical and research settings, the familial background should be taken into account with an approach examining the broader phenotype of ASD. Other studies have considered familial factors beyond “first-degree” relatives. For example, Golding, Steer, and Pembrey<sup>226</sup> questioned if the age of the grandparent at the time of the parent’s birth was a possible factor for a child to be born with an ASD. They found children with ASDs were more likely born to parents whose maternal grandmother was older when the parent was born. Another study by Frans et al found that advanced grandpaternal age was associated with increased risk of autism (see Frans et al in Recommended publications list).

## Recommended publications

Amaral DG. The promise and the pitfalls of autism research: An introductory note for new autism researchers. *Brain Research*. 2011;1380:3–9. doi:10.1016/j.brainres.2010.11.077.<sup>175</sup>

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- Vissers M, Cohen M, Geurts H. Brain connectivity and high functioning autism: A promising path of research that needs refined models, methodological convergence, and stronger behavioral links. *Neuroscience and Biobehavioral Reviews*. 2012;36(1):604–25. doi:10.1016/j.neubiorev.2011.09.003.<sup>182</sup>
- Wallace G, Dankner N, Kenworthy L, Giedd J, Martin A. Age-related temporal and parietal cortical thinning in autism spectrum disorders. *Brain: A Journal of Neurology*. 2010;133(12):3745–54. doi:10.1093/brain/awq279.<sup>203</sup>



Whiteley P, Todd L, Carr K, Shattock P. Gender ratios in autism, Asperger syndrome and autism spectrum disorder, *Autism Insights*. 2010;2:17–24. doi:10.4137/AUI.S3938.<sup>192</sup>

## Young Adults, College Students, and Transition into Adulthood

We highly recommend to readers that they begin with the report, *Interventions for Adolescents and Young Adults with Autism Spectrum Disorders*, which was prepared for the Agency of Health Care and Quality (AHRQ) by Taylor, Dove, Veenstra-VanderWeele, Sathe, McPheeters, Jerome, and Warren.<sup>227</sup> The goal of their report was to examine the effects of available interventions on adolescents and young adults with ASD, focusing on the following outcomes: core symptoms of ASD; medical and mental health comorbidities; functional behaviors and independence; the transition to adulthood; and family outcomes. The report by Taylor et al<sup>228</sup> is comprehensive and scholarly, but their findings indicate that there is a dramatic lack of evidence on best approaches to therapies for adolescents and young adults with autism spectrum disorders.<sup>54</sup>

Farley et al stress the importance of treating autism disorders as a lifetime diagnosis,<sup>229</sup> and it appears that the life stage of adolescence and emergent adulthood in the life course is a critical period for persons with ASD.<sup>79,228,230</sup> Taylor and Seltzer<sup>231</sup> found that although symptoms of autism and maladaptive behaviors generally improved while young adults were in the secondary school system, improvement slowed significantly after leaving high school, and this was even more dramatic for young adults who did not have IDs. They attribute the significant slowing in improvement to those young adults without comorbid ID to difficulties in finding educational and occupational activities after the high school exit.

In a recent study Shattuck, Narendorf, Cooper, et al<sup>86</sup> found youth with ASDs have poor postsecondary employment and education outcomes, especially in the first two years after high school. In a 2009 article, Taylor indicates that as youth exit high school and transition to adulthood, they may lose many of the entitlement services they received while in the school system. And for young adults transitioning to independent living, integrated employment, and community participation the research clearly indicates there

is a significant gap in the support services beyond the school-college years.<sup>232–234</sup> Thus “life-skills training” may take on a greater importance.<sup>235–237</sup> This critical finding is corroborated by more recent studies both internationally<sup>8,233</sup> and from the collective work of a research group from Washington University in St. Louis, MO.<sup>86</sup> For example Shattuck, Wagner, Narendorf, Sterzing, and Hensley<sup>238</sup> found rates of disengagement are high after exiting high school and disparities by race and socio-economic status indicate a need for targeted outreach and services. Those from lower-income families and those with greater functional impairments are at heightened risk for poor outcomes. Taylor and Seltzer<sup>239</sup> state that the years after high school exit are a time of increased risk especially for those with ASDs, without IDs, and whose families are under-resourced. Taylor and Seltzer<sup>231</sup> suggest the current service system may be inadequate to accommodate the needs of youth with ASD who do not have IDs in the transition to adulthood.<sup>240</sup> More specifically Chiang, Cheung, Hickson, Xiang, and Tsai<sup>80</sup> focused their study on the examination of the policy and legal issues (eg, IDEA) addressing the transitional processes such as individual education plans from secondary educational levels into postsecondary educational levels and into the adult years of life. They indicate that when students with disabilities are well prepared for the transition from high school to adulthood, the odds they will have positive adult outcomes increases, including improved outcomes in occupational fulfillment and ultimately quality of life. However, many students with autism do not receive appropriate transition services, are underemployed and many adults with autism remain without any supportive services. However, these findings can be interpreted when using another perspective. For example, some researchers have examined the transition to adulthood and the role of self-determination in the framework of critical theory and larger cultural norms and have questioned the purpose and function the social service and educational industry processes that claim to serve people with disabilities.<sup>241</sup> Smith and Routel<sup>241</sup> propose that the transition from special education services to supports received in community settings has been “commodified and reified, controlled by educational and human service professionals, meeting the needs of the industries that they represent and capitalism in general” and as a result people with



disabilities and their families are left segregated and isolated.

Although current interventions might improve outcomes in young individuals with ASDs who receive treatment, many adults have not been identified or treated and are likely to need alternative sources of support when they are no longer able to live with their parents. Because individuals with ASDs also have low rates of marriage and parenthood, reliance on children or spouses in the absence of parents will not meet their needs. There are limited studies examining alternative housing and residential support for adults with ASD.<sup>242,243</sup> In the United Kingdom (UK) Felce and Perry<sup>244</sup> investigated differences in congregate and non-congregate groups for adults with ASD and determined there were few advantages to diagnostic grouping of individuals with ASD. Chiang and Chen<sup>245</sup> used a complexity model and technology to develop a life-long learning disorder program for adults with ASD in interdependent homes.

Gerhardt and Lanier conducted a review of the literature on outcomes for adults with ASD and discovered the vast majority of adults diagnosed with spectrum disorders are either unemployed or underemployed resulting in many adults with autism without supportive services.<sup>232</sup> In contrast Billstedt, I. Gillberg, and C. Gillberg<sup>246</sup> found the majority of young adults with autism had a better than expected level of “quality of life” but they remain but they remained dependent on parents/caregivers for support in educational, accommodation and occupational situations.<sup>155</sup>

From their studies Chiang et al<sup>80</sup> report approximately 57% of high school “leavers” with ASD did not pursue postsecondary education. They also found that the majority of adults with autism do not have a bachelor’s degree or a paid job. For those who did pursue postsecondary education, parental expectations for post-secondary education ranked very high and critically important as a predicative factor for success.<sup>80</sup>

Henninger and Taylor conclude that in nearly all of the studies they reviewed published from mid-1990s to 2011 show that the majority of adults with ASD have poor outcomes.<sup>72</sup> However they argue more recent studies integrating evolving concepts (eg, emergent adulthood, PIE issues, etc.) could have an impact on what is being measured and perhaps lead to a more optimistic picture of outcomes for adults with autism.

From their review of several studies Palmen et al<sup>247</sup> conclude there is a fair amount of evidence indicating behavioral interventions can improve adaptive skills in young adults with high-functioning ASD. Research on effective treatment models such as residential programs is limited. Bourgondien, Reichle, and Schopler<sup>248</sup> indicate the TEACCH model was related to a decrease in behavior difficulties, but in their treatment program they found no difference in the acquisition of skills.

Independent functioning is an important issue for people with HFASDs and who have difficulty in developing reciprocal friendships, obtaining paid employment, engaging in recreational activities, and living independently.<sup>247</sup> One promising indication of potential success for those adults with HFA (high-functioning autism) is the role of adequate social support which should be initiated early as possible in the individual’s lifetime.<sup>247</sup> Palmen et al<sup>249</sup> also call for more methodological rigor in future studies especially with the aim to find ways to improve independent functioning. Kreiger et al<sup>249</sup> discovered adults with AS who understand their own needs is a key indicator of success in the labor market, but disclosure was rare and social stigma was still present.

White, Ollendick, and Bray examined the symptoms and needs of college students with HFASD and determined the prevalence of HFASD in a university sample.<sup>95</sup> They found the rate for college students *similar* to the CDC rate of eight year olds diagnosed with ASDs, 1:110. However White et al<sup>95</sup> propose there might be a number of college students, who would meet HFASD diagnostic criteria and included in the prevalence rate, but began their college careers undiagnosed. They also found HFASD symptoms were correlated with other mental health problems, such as social anxiety, dissatisfaction with college, and overall discouragement with life. Nevill and White<sup>81</sup> recommended universities should make efforts to prevent social isolation of students with ASD by educating students about ASD and supports to ease college transition.<sup>79</sup>

According to Schall and McDonough,<sup>250</sup> in the past there has been a paucity of research on the characteristics and needs of youth and young adults with ASD but the amount of literature on this topic has increased. In their systematic review of the literature Taylor, McPhetters et al<sup>228</sup> found few studies





have been conducted assessing vocational interventions for adolescents and young adults with ASD. They also claim there is very little evidence for specific vocational treatment approaches for individuals as they transition to adulthood.<sup>86</sup> Shattuck et al<sup>86</sup> propose future research is needed to explore how to improve the transition to postsecondary activities before high school exit. This perspective not only targets educational and employment potential, but would also help individuals sustain their ability to optimize daily living skills from adolescence into adulthood.<sup>71,251</sup>

What promises to be a valuable research tool and have direct application value was the creation of a comprehensive index of employment, vocational, and educational activities for adults with ASD developed through detailed examination these activities collected from nearly 350 adults over a 12-year period. Taylor and Seltzer<sup>252</sup> claim this index improves the ability to examine trajectories of development during adulthood, as well as measure the impact of interventions and services aimed at promoting independence.

## Recommended publications

Altgassen M, Koban N, Kliegel M. Do adults with autism spectrum disorders compensate in naturalistic prospective memory tasks? *Journal of Autism and Developmental Disorders*. 2012;42(10):2141–51. doi:10.1007/s10803-012-1466-3.<sup>71</sup>

Baker J. *Preparing for Life: The Complete Guide for Transitioning to Adulthood for Those with Autism and Asperger's Syndrome*. Arlington, TX: Future Horizons, Inc; 2006.<sup>235</sup>

Billstedt E, Gillberg IC, Gillberg C. Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism*. 2011;15(1):7–20. doi:10.1177/1362361309346066.<sup>246</sup>

Chiang HM, Cheung YK, Hickson L, Xiang R, Tsai LY. Predictive factors of participation in postsecondary education for high school leavers with autism. *Journal of Autism and Developmental Disorders*. 2012;42(5):685–96. doi:10.1007/s10803-011-1297-7.<sup>80</sup>

Farley MA, McMahon WM, Fombonne E, et al. Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research*. 2009;2(2):109–18.<sup>229</sup>

Gerhardt PF, Lanier I. Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy*. 2011;41(1):37–45. doi:10.1007/s10879-010-9160-2.<sup>232</sup>

Ling-Yi L, Shu-Ning Y, Ya-Tsu Y. A study of activities of daily living and employment in adults with autism spectrum disorders in Taiwan. *International Journal of Rehabilitation Research*. 2012;35(2):109–15. doi:10.1097/MRR.0b013e32835108b1.<sup>233</sup>

Palmen A, Didden R, Lang R. A systematic review of behavioral intervention research on adaptive skill building in high-functioning young adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*. 2012;6(2):602–17. doi:10.1016/j.rasd.2011.10.001.<sup>247</sup>

Schall C, McDonough J. Autism spectrum disorders in adolescence and early adulthood: Characteristics and issues. *Journal of Vocational Rehabilitation*. 2010;32(2):81–8. doi:10.3233/JVR-2010-0503.<sup>250</sup>

Shattuck PT, Narendorf SC, Cooper B, Sterzing P, Wagner M, Taylor JL. Postsecondary education and employment among youth with autism spectrum disorder. *Pediatrics*. 2012. doi:10.1542/peds.2011-2864.<sup>86</sup>

Shattuck PT, Roux AM, Hudson LE, Taylor JL, Maenner MJ, Trani JF. Services for adults with an autism spectrum disorder. *Canadian Journal of Psychiatry*. 2011;57(5):284–91.

Shattuck PT, Wagner M, Narendorf S, Sterzing P, Hensley M. Post high school service use among young adults with autism spectrum disorder. *Archives of Pediatric and Adolescent Medicine*. 2011;165(2):141–6. doi:10.1001/archpediatrics.2010.279.<sup>238</sup>

Taylor JL, Seltzer MM. Changes in the mother-child relationship during the transition to adulthood for youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2011a;41(10):1397–410. doi:10.1007/s10803-010-1166-9.<sup>239</sup>

Taylor JL, Seltzer MM. Employment and postsecondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*. 2011b;41(5):566–74. doi:10.1007/s10803-010-1070-3.<sup>231</sup>

Taylor JL, Dove D, Veenstra-VanderWeele J, et al. Interventions for adolescents and young adults with autism spectrum disorders. *Comparative*



*Effective Review No. 65. AHRQ Publication No. 12-EHC063-EF.* Rockville, MD: Agency for Healthcare Research and Quality. 2012. Retrieved from: <http://www.effectivehealthcare.ahrq.gov/reports/final.cfm>.<sup>227</sup>

White SW, Ollendick TH, Bray BC. College students on the spectrum: Prevalence and associated problems. *Autism*. 2011;15(6):683–701. doi:10.1177/1362361310393363.<sup>95</sup>

## Older Parents and Family Issues

Hines, Balandin, and Togher document that having an adult son or daughter with autism has an enduring influence on the lives of older parents.<sup>253</sup> Older parents face a delicate balancing act of maintaining the stability of their sons or daughters, while attempting to find fulfillment in their own lives.

Communication issues between older parents and their adult children with ASDs, who often have communication deficits, are long lasting and the quality of communication can be both a source of strain and gratification.<sup>253</sup> Many older parents describe their son or daughter as a “real person” but their true nature trapped within, buried under autism instead of their child being autism. However, older parents saw the symptoms of autism as being irremediable. Hines et al<sup>253</sup> conclude in the face of their child’s challenging behaviors older parents blame an objectified autism separate from their offspring’s true self. This allows parents to preserve positive perceptions of their adult son or daughter.

Smith, Greenberg, and Seltzer recommend future interventions take a family systems approach to help older parents recognize and reduce their exposure to negative support.<sup>53</sup> Sources of negative support include many who are critical, demanding or both in a close social network that results in a significant emotional toll for mothers.<sup>50</sup> Smith et al<sup>53</sup> identify social support as a critical factor to promote positive maternal well-being for middle-aged mothers caring for youth or adults with ASDs. In another study Smith, Greenberg, and Mailick<sup>54</sup> propose that multi-family group psychoeducation is a potentially powerful intervention model for reducing family distress during the transition to adulthood.

Rattaz et al investigated parent’s satisfaction with special education and care services for their child (the age of autistic persons in this study ranged from 4 to 53) with ASD and they discovered a higher

degree of dissatisfaction in parents of adolescents than in parents of children or adults.<sup>230</sup>

In a previous review of the literature Piven and Rabins<sup>3</sup> suggested few adults with ASD live alone and many live with their families, particularly their parents. However many older parents experience high levels of caregiver burden and these levels equate with those caring for individuals with very serious medical conditions.<sup>254</sup> Wong et al<sup>255</sup> found that both global and everyday stressors contributed to awakening cortisol levels for midlife and aging mothers of individuals with ASD. Finally, families of children with ASD face significant economic burden, and in terms of parental labor market losses, the impact is substantial.<sup>48</sup>

## Recommended publications

Cidav Z, Marcus SC, Mandell DS. Implications for childhood autism for parental employment and earnings. *Pediatrics*. 2012;129(4):617–23. doi:10.1542/peds.2011-2700.<sup>48</sup>

Hines M, Balandin S, Togher L. Buried by autism: Older parents’ perceptions of autism. *Autism*. 2012;16(1):15–26. doi:10.1177/1362361311416678.<sup>253</sup>

Piven J, Rabins P; on behalf of the Autism-in-Older Adults Working Group. Autism spectrum disorders in older adults: Toward defining a research agenda. *Journal of the American Geriatrics Society*. 2011;59(11):2151–5. doi:10.1111/j.1532-5415.2011.03632.x.<sup>3</sup>

Smith LE, Greenberg JS, Seltzer MM. Social support and well-being at mid-life among mothers of adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2011;42(9):1818–26. doi:10.1007/s10803-011-1420-9.<sup>53</sup>

Smith LE, Greenberg JS, Mailick MR. Adults with autism: Outcomes, family effects, and the multi-family group psychoeducation model. *Current Psychiatry Reports*. 2012;14:732–8. doi:10.1007/s11920-012-0328-1.<sup>54</sup>

Zweifel J, Covington S, Applegarth L. “Last-chance kids”: A good deal for older parents-but what about the children? *Sexuality, Reproduction and Menopause*. 2012;10(2). Retrieved at: <http://www.srm-ejournal.com/article.asp?AID=10433&UID><sup>220</sup>



## Grandparent Considerations

In the literature, the role of grandparents in the lives of youth and adults with ASD is a topic that is gaining increased attention,<sup>256,257</sup> including in a number of trade books<sup>258–260</sup> and resources by advocacy organizations;<sup>261,262</sup> Grandparents Autism Network—<http://www.ganinfo.org>). Today, most grandparents will be involved in the lives of a grandchild with ASDs for at least twenty years and possibly even forty years or more<sup>263</sup> increasing the likelihood the relationship with a significant grandparent is likely to continue into the grandchild's adulthood.<sup>29</sup> A grandparent who develops a strong supportive relationship with a grandchild with ASD in childhood will likely maintain the relationship into adulthood. This intergenerational overlap is consistent with general population statistics.

In her research on the changing dynamics of the grandparent-grandchild relationships Monserud<sup>264</sup> found adult grandchildren, who could not acquire adult roles, continued to remain dependent on caregivers and their relationships with their grandparents. Most often adult children with ASDs reside with parents, were not employed, remained single, were childless and more involved with their grandparents. Three percent of her sample was grandparents who provided the sole care for their adult grandchild with ASD.

One factor shown to positively affect the strength of the connection between adult grandchildren and their grandparents is a history of caregiving by grandparents during their grandchild's formative years.<sup>265</sup> In a retrospective examination of adults who were raised by their grandparents Dolbin-MacNab, Rodgers, and Traylor<sup>266</sup> report that instrumental and emotional support from grandparents provided individuals with ASDs with a sense of stability and unconditional love.

It is essential grandparents are recognized as fundamental figures in the lives and care of children and adults with ASD. Grandparents, who actively participate in their grandchild's diagnostic and treatment meetings with the multidisciplinary team of professionals required to facilitate supportive and educational services,<sup>191,267,268</sup> experience increased communication with all family members and are more inclined to be supportive and involved with their grandchildren.<sup>191</sup> In their study of technological workshops targeting children with ASDs Wright, D'Astous, Wright and Diener<sup>269</sup> discovered actively supportive grandparents

perceived their grandchildren learned technological skills, increased their social interactions with peers, family members and the grandparents themselves. Grandparents found hope for future educational and employment opportunities for their grandchildren. They also indicated the interests in the technological skills computer program they shared with their grandchildren facilitated communication opportunities with their grandchildren, with other grandparents of grandchildren with ASD, and with their adult sons and daughters (see also D'Astous et al in Recommended publications list). Likewise from their studies of grandparents with grandchildren with disabilities,<sup>270</sup> Lee and Gardner express the unconditional love and support grandparents provide also helps grandchildren in adulthood.

Although data on the number of custodial grandparents of adult grandchildren with ASD is unknown, frequently grandparents are a source of both emotional and physical support for their grandchildren and their families.<sup>256,268,269,271</sup> For custodial grandparent of a grandchild with an ASD the greatest concern is for grandchild's needs and support when the grandparent is no longer capable of providing the care. The grandparent's aging and health problems may necessitate making legal arrangements and emergency plans for placement needs and services. Graetz<sup>49</sup> interviewed families of 26 adults with ASD regarding their social and psychological needs in caring for their family member. He found overwhelmingly most caregivers felt services available for families supporting an adult with ASD were inadequate.

## Recommended publications

Autism Speaks. *A Grandparent's Guide to Autism: Autism Speaks Family Support Kit*. 2011. Retrieved at: <http://www.autismspeaks.org><sup>261</sup>

D'Astous, V, Wright, S, Wright, C, Diener, M. Grandparents of grandchildren with autism spectrum disorders: Influences on engagement. *Journal of Intergenerational Relationships*. 2013;11(2).

Graetz JE. Autism grows up: Opportunities for adults with autism. *Disability and Society*. 2010;21(1):33–47. doi:10.1080/09687590903363324.<sup>49</sup>

Grubb S. *Grandparenting a Child with Autism: The Joy and Frustration and Growth of Living with Autism*. Minneapolis, MN: Quill House Publications; 2012.<sup>258</sup>

Hillman J. Grandparents of children with autism: A review with recommendations for education,



practice, and policy. *Educational Gerontology*. 2007; 33(6):513–27. doi:10.1080/03601270701328425.<sup>256</sup>

Krumins J. *Autism and the Grandparent Connection: Practical Ways to Understand and Help Your Grandchild with Autism Spectrum Disorder*. Peterborough, ON, Canada; 2010.<sup>259</sup>

Margetts JK, LeCouteur A, Croom S. Families in a state of flux: The experience of grandparents in autism spectrum disorder. *Child: Care, Health and Development*. 2006;32(5):565–74. doi:10.1111/j.1365-2214.2006.00671.x.<sup>268</sup>

Mucklow N. *Grandparent's Guide to Autism Spectrum Disorders: Making the Most of the Time at Nana's House*. Overland Park, KS: AAPC Publishing; 2012.<sup>260</sup>

Sullivan A, Winograd G, Verkuilen J, Fish MC. Children on the autism spectrum: Grandmother involvement and family functioning. *Journal of Applied Research in Intellectual Disabilities*. 2012;25(5):485–95. doi:10.1111/j.1468-3148.2012.00695.x.<sup>257</sup>

Woodbridge S, Buys L, Miller E. 'My grandchild has a disability': Impact on grandparenting identity, role and relationships. *Journal of Aging Studies*. 2011;25(4):355–63. doi:10.1016/j.jaging.2011.01.002.<sup>267</sup>

Wright S, D'Astous V, Wright C, Diener M. Grandparents of grandchildren with autism spectrum disorder (ASD): Strengthening relationships through technology activities. *International Journal of Aging and Human Development*. 2012;75(2):169–84. doi:10.2190/AG.75.2.d.<sup>269</sup>

## Long-Term Care Challenges

The increasing life expectancy of the general population and the diminishing disparity in the life expectancy of people with developmental disabilities compounds the crisis of long-term care issues. Wick and Zanni<sup>272</sup> argue long-term care practitioners need to prepare to care for individuals diagnosed with autism in the 1980s, who are now reaching old age and will need extended care facilities. A recent Institute of Medicine report concludes the US workforce will not be prepared to care for the anticipated increase in the number of older adults in the entire population. The report highlights the need for physicians and nurses and, importantly, the much larger demand for direct care workers, who provide 70% to 80% of the daily hands-on care for disabled older adults.

Exacerbating the need to care for older adults is the lack of evidence that existing models of care can meet the needs of older adults with ASDs. Additionally, the current long-term care workforce is not trained to address the unique complexities of caring for individuals with ASDs. For example, symptom profiles common in older adults, such as late-life decline in sensory abilities (eg, hearing and vision), may affect individuals with ASD, who typically have preexisting sensory abnormalities. Additionally, routine is important for individuals with ASDs. However, nursing home care may not be sensitive to this. Disrupted routine can result in extreme agitation and adversely affect others. These examples and a wealth of others, well known to those familiar with behaviors characteristic of ASD, suggest the potential need for novel models of care and intervention strategies for these individuals.

## Recommended publications

Cadman T, Eklund H, Howley D, et al. Caregiver burden as people with autism spectrum disorder and attention-deficit/hyperactivity disorder transition into adolescence and adulthood in the United Kingdom. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2012;51(9):879–88. doi:10.1016/j.jaac.2012.06.017.<sup>254</sup>

Cimera RE, Wehman P, West M, Burgess S. Do sheltered workshops enhance employment outcomes for adults with autism spectrum disorder? *Autism*. 2012;16(1):87–94. doi:10.1177/1362361311408129.<sup>332</sup>

Felce D, Perry J. Diagnostic grouping among adults with intellectual disabilities and autistic spectrum disorders in staffed housing. *Journal of Intellectual Disability Research*. 2011. doi:10.1111/j.1365-2788.2011.01496.x.<sup>244</sup>

McGill P, Poytner J. High cost residential placements for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*. 2012. doi:10.1111/j.1468-3148.2012.00689.x.<sup>242</sup>

Robertson J, Emerson E. *A Systematic Review of the Comparative Benefits and Costs of Models of Providing Residential and Vocational Supports to Adults with Autistic Spectrum Disorder*. Report for the National Autistic Society, Institute for Health Research, Lancaster University; 2006.<sup>243</sup>

Wick JY, Zanni GR. Autism and aging: Hardly out of the woods. *Consultant Pharmacist*. 2009;24(9): 648–50, 653–60. doi:10.4140/TCP.n.2009.648.<sup>272</sup>



## Miscellaneous Topics-e.g., Sexuality, Marital Satisfaction, Sensory Issues

We found miscellaneous topics relevant to the domain of autism, adulthood and aging that do not fall into the major themes of this paper. For example, there are publications relating to AS and the criminal justice system<sup>273</sup> and the prevalence of autism spectrum disorders in an incarcerated population.<sup>274</sup> Garcia-Villamizar and Dattilo<sup>275,276</sup> found evidence that participating in recreational activities positively influenced the stress and quality of life of adults with ASDs. However, research on the association between leisure and quality of life for adults with ASD is lacking.

Gilmour, Schalomon, and Smith examine the sexual attitudes and behaviors of adults with high-functioning ASDs.<sup>277</sup> When comparing adults with ASD and non-ASD participants, they report there were no significant differences in interest in sex, sexual behaviors, or comprehension of sexual language. Gilmour et al<sup>277</sup> recommend caregivers, family members, and friends of individuals with ASD need to be aware the majority of individuals with ASD have sexual interests and behaviours.<sup>278</sup> This finding was also corroborated by the data in a publication by Byers, Nichols, Voyer, and Reilly<sup>279</sup> who found similar results that ran counter to social stereotypes that portray individuals with disabilities, including individuals with higher functioning autism or Asperger's Syndrome, as asexual and/or having sexual behavior problems. Byers et al<sup>279</sup> found that adults with ASD were quite knowledgeable about areas of sexuality that can affect sexual functioning and the participants reported engaging in both solitary and partnered sexual activity on a regular basis.

In their sample of married couples with one spouse diagnosed with an ASD, Lau and Peterson<sup>280</sup> found that although marital satisfaction was high, the respondents who had AS were predominantly avoidant in romantic relationships. They also found having a child with AS reduced parental satisfaction but not marital satisfaction.

On the topic of physical perceptions, Tavassoli and Baron-Cohen<sup>281</sup> indicate adults with ASD showed normal detection and adaptation to olfactory stimuli. In another study Tavassoli and Baron-Cohen<sup>282</sup> found with the exception of salty tastes, adults with ASD less accurately identified tastes overall when compared to

control groups. Many adults with AS perceive audiovisual speech in a manner qualitatively different than typically developed individuals.<sup>273</sup> Saalasti et al<sup>283</sup> believe individuals with AS have deficient integration processes involving the motor system. Researchers hypothesize these challenges contribute to the difficulties in face-to-face communication. Many audiovisual cues are audiovisual—not only in speech perception, but also in turn-taking and understanding intentions through emotional expression. On a different but related topic Barnes and Baron-Cohen<sup>284</sup> found in the context of storytelling ability adults with ASD were less likely to situate information. In other words by focusing on local details versus global details, they have difficulty incorporating the “big picture” into their story.

## Recommended publications

Aston MC. *What Men with Asperger Syndrome Want To Know About Women, Dating and Relationships*. London, UK: Jessica Kingsley Publishers;2012.<sup>278</sup>

Browning A, Caulfield L. The prevalence of treatment of people with Asperger's syndrome in the criminal justice system. *Criminology and Criminal Justice*. 2011;11(2):165–80. doi:10.1177/1748895811398455.<sup>273</sup>

Garcia-Villamizar D, Dattilo J. Effects of a leisure programme on quality of life and stress of individuals with ASD. *Journal of Intellectual Disability Research*. 2010;54(7):611–9.<sup>275</sup>

Garcia-Villamizar D, Dattilo J. Social and clinical effects of a leisure program on adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*. 2012;5(1):246–53. doi:10.1016/j.rasd.2010.04.006.<sup>276</sup>

Gilmour L, Schalomon PM, Smith V. Sexuality in a community-based sample of adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*. 2012;6(1):313–8. doi:10.1016/j.rasd.2011.06.003.<sup>277</sup>

Lau W, Peterson CC. Adults and children with Asperger syndrome: Exploring adult attachment style, marital satisfaction and satisfaction with parenthood. *Research in Autism Spectrum Disorders*. 2011;5:392–9. doi:10.1016/j.rasd.2010.06.001.<sup>280</sup>

Saalasti SKM, Jari K, Tiippana K, Laine-Hernandez M, Wendt von L, Mikko S. Audiovisual speech perception and eye gaze behavior of adults with Asperger Syndrome. *Journal of Autism and Developmental Disorders*. 2012;42(8):1606–15. doi:10.1007/s10803-011-1400-0.<sup>283</sup>



Tavassoli T, Baron-Cohen S. Olfactory detection thresholds and adaptation in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2012a;42(6):905–9. doi:10.1007/s10803-011-1321-y.<sup>281</sup>

Tavassoli T, Baron-Cohen S. Taste identification in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2012b. doi:10.1007/s10803-001-1377-8.<sup>282</sup>

Weidenheim KM, Escobar A, Rapin I. Brief report: Life history and neuropathology of a gifted man with Asperger syndrome. *Journal of Autism and Developmental Disorders*. 2012;42(3):460–7. doi:10.1007/s10803-011-1259-0.<sup>183</sup>

## Trade and Text Books

The inventories of Jessica Kingsley Publishers (UK) and Future Horizons (US) are well known for their long established publications on autism. In this section, we highlight books from these inventories that are critical for professionals interested in autism, adulthood and aging issues. We identified the books through the use of search strategies within Google Books and Amazon.com listings.

As many health care professionals will attest, there is a scarcity of literature that specifically addresses adults with autism.<sup>144</sup> In his book *Adults with Autism: A Guide to Theory and Practice*, Hugh Morgan<sup>285</sup> sets out to fill this gap by providing practical help and guidance for those caring for the growing population of adults with autism. Even though it is 16 years old, it is still a noteworthy publication and presents a UK perspective. Aside from the work of Hugh Morgan, there are several invited contributors. Throughout the first several chapters, contributors probe issues of theory and practice from both local and international perspectives. Subsequent chapters analyze the implications arising from thought and behavior inflexibility with an emphasis on the management of transitions and bereavement. Later chapters explore themes such as models for practice in employment, further education, pharmacological and educational approaches to mental health problems, epilepsy, and challenging behaviors. This work concludes with a chapter that develops many themes of this text as the basis for a medical training program. It is an essential guide for all who care about the well-being of adults with autism. Also explored in this book are the potential challenges in caring for

adult individuals with autism and that autistic traits can be powerful assets.

Professionals who work with young adults will get hard-to-find information on how specific social, behavioral, and cognitive characteristics of people with autism that affect their transition to adulthood. Wehman et al<sup>286</sup> notes how young children diagnosed with autism increased dramatically in the 1990s—and now those children are young adults on the verge of a challenging transition to the real world.

Of particular significance in Morgan's publication is a statement by Geraldine Peacock, the then Chief Executive of the UK National Autistic Society who wrote "The first generation of adults with autism, who were being diagnosed as children, are now in their mid-forties."<sup>285</sup> If we translate that cogent statement into our current time frame, some twenty-six years later, we realize this first generation is now in the traditional "elderly" demographic bracket and within the domain of geriatric concerns.<sup>3</sup>

Included in Morgan's book, is a complete guide to walk through every aspect of transition planning, including planning for employment and postsecondary education; conducting skillful assessment to determine a young person's individual career goals; job-related strengths; independent living skills; providing community-based instruction at naturally occurring times making it easier for students to learn and generalize new skills; showing students and their families how to make the most of Social Security Disability benefits; assisting college preparation from choosing a college to managing academic and social demands; and using supported and/or customized employment strategies to help young people establish satisfying careers to play to their strengths. We highly recommend the following chapters: (6) Navigating the World of Adult Services and Benefits Planning by Grant Revell and Lucy Axton Miller; (7) Integrated Employment by Pamela Sherron Targett and Paul Wehman; (8) Post Secondary Options for Students with Autism by Lori W. Briel and Elizabeth Evans Getzel; (9) Critical Life Skills by Marcia Datlow Smith and Pamela Sherron Targett; and (10) Living in the Community also by Pamela Sherron Targett and Marcia Datlow Smith.

In her new edition of *Autism and Asperger Syndrome: Preparing for Adulthood*, Howlin<sup>68</sup> reviews what was known up to the point of publication about adults with autism in terms of their social functioning



and educational and occupational status. She focuses primarily on problems experienced by high-functioning people with autism and those working and associating with them. Also included in the new edition of her book is a chapter on the differences between autism and AS.

*Voices from the Spectrum* by Ariel and Naseef<sup>287</sup> is a compelling collection of personal accounts of people on the autism spectrum and those who care for them, including professionals, friends, and family members. The essays in this collection relay both the positive and negative effects of autism on individuals and families, and pose the question: “Is a diagnosis on the autism spectrum a puzzle to be solved or something to be embraced and accepted”? The broad scope of this book presents insights into the autism spectrum from many different perspectives, from first-hand accounts of the autistic child’s school and childhood experiences to parents’ and grandparents’ reactions to an ASD diagnosis. A number of chapters written by professionals explain their motivations for working with people with autism and reveal what they have learned from their work and how it has affected their lives. The contributors describe autism experiences from the mildest to the most severe cases and share their methods to help individuals on the spectrum adapt. *Voices from the Spectrum* appeals to a wide readership of adults and youth with ASDs, their families and friends, as well as practitioners.

Nancy Perry wrote *Adults on the Autism Spectrum Leave the Nest: Achieving Supported Independence*,<sup>288</sup> an important book examining how many young individuals on the spectrum are unable to cope effectively with the challenges of adult life.<sup>71</sup> She shows that with appropriate lifelong care from parents and support systems, it is possible for those with neurodevelopmental disabilities to achieve supported independence and live fulfilling adult lives. This book provides a guide for parents on how to prepare their children diagnosed with ASDs for adulthood and describes in detail the kinds of services they will need in order to live independently. Perry explains the importance of executive function cognitive abilities that enable us to regulate behavior, adapt to changing situations, and how executive function deficits can be especially problematic in the adult world for individual with ASDs. She also provides approaches to manage executive function

deficits and describes an innovative therapeutic program that allows adults with ASDs to successfully live with their peers and develop meaningful adult relationships.

Stoddart, Burke, and King’s book,<sup>12</sup> *Asperger Syndrome in Adulthood: A Comprehensive Guide for Clinicians* represents a unique contribution focusing on clinical topics relevant to adulthood including diagnosis, co-morbid psychiatric conditions, psychosocial issues, and types of interventions from psychotherapy to psychopharmacology. We highly recommend this as an informative resources to professionals who work with higher functioning adults.

Digby Tantum<sup>133</sup> wrote the professional textbook, *Autism Spectrum Disorders Through the Lifespan*. Even though his book is life-course oriented, we still recommend it for those interested in gerontology. It contains several chapters of direct relevance to adulthood and aging covering almost every aspect of ASD eg, science to services, from the most disabling Kanner’s syndrome to the most high-functioning Asperger, and from birth to old age.<sup>104</sup> The book contains the latest research on the assessments, diagnosing, treatments, interventions, and supports for individuals with AS. Importantly it examines these implications at various life stages. He describes the wide range of ASDs in terms of neurological, genetic, psychological, developmental, social, and emotional issues. Tantum also includes less accessible information on the diagnosis and treatment of associated psychiatric and medical conditions; the overlap between ASDs and attention deficit hyperactivity disorder; and the management of behavioral and forensic problems. Using a focused developmental approach, he highlights people with ASDs who are likely referred to mental health services at times of transitions between developmental stages when new skills or new forms of adaptation are needed.<sup>289</sup>

In addition to biomedical and demographic challenges, we (SW, DB, VA) strongly suggest everyone read Temple Grandin’s<sup>82</sup> book *Different . . . Not Less: Inspiring Stories of Achievement and Successful Employment from Adults with Autism, Asperger’s, and ADHD*. Highlighted in her edited book are the potential challenges and positive aspects of living with ASDs. It is an inspiring and informative book that will open minds on ways to improve the lives of those with autism, AS, and ADHD. Given the



sub-title, “Inspiring Stories of Achievement and Successful Employment from Adults with Autism, Asperger’s, and ADHD”, it follows the lives of fourteen adults, many who were diagnosed late in life, explaining how they met and continue to meet their challenges including their successful careers.<sup>290,291</sup> Grandin offers practical and concrete suggestions for adults on the autism spectrum on how to seek out mentors, develop portfolios, and be creative in finding career opportunities.

We also recommend Thomas Armstrong’s<sup>292</sup> *The Power of Neurodiversity: Unleashing Advantages of Your Differently Wired Brain*. A similar theme is explored in Valerie Gaus’s<sup>293</sup> book *Living Well on the Spectrum: How to Use Your Strengths to Meet the Challenges of Asperger Syndrome/High-Functioning Autism*. She emphasizes positive strengths for employment opportunities for individuals with high-functioning autism. The book, *A Full Life With Autism*<sup>294</sup> was written by a mother-son team as they examine and review the personal story of transitioning into adulthood, forming relationships, and achieving independence.

### Full citations of recommended publications

Ariel CN, Naseef RA. *Voices From the Spectrum: Parents, Grandparents, Siblings, People with Autism, and Professionals Share Their Wisdom*. London: Jessica Kingsley Publishers; 2006.<sup>287</sup>

Armstrong T. *The Power of Neurodiversity: Unleashing Advantages of Your Differently Wired Brain*. Cambridge, MA: Da Capo Press; 2011.<sup>292</sup>

Gaus V. *Living Well on the Spectrum: How to Use Your Strengths to Meet the Challenges of Asperger Syndrome/High-Functioning Autism*. New York: The Guilford Press; 2011.<sup>293</sup>

Grandin T. *Different ... Not Less: Inspiring Stories of Achievement and Successful Employment From Adults with Autism, Asperger’s, and ADHD*. Arlington, TX: Future Horizons Inc; 2012.<sup>82</sup>

Howlin P. *Autism and Asperger Syndrome*, 2nd ed. New York: Routledge; 2004.<sup>68</sup>

Morgan H. *Adults with Autism: A Guide to Theory and Practice*. Cambridge, UK: Cambridge University Press; 1996.<sup>285</sup>

Perner L, editor. *Scholars with Autism Achieving Dreams*. Sedona, AZ: Auricle Ink; 2012.<sup>290</sup>

Perry N. *Adults on the Autism Spectrum Leave the Nest: Achieving Supported Independence*. London: Jessica Kingsley Publishers; 2008.<sup>288</sup>

Santomauro J, editor. *Autism All-Stars: How We Use Our Autism and Asperger Traits to Shine in Life*. Philadelphia, PA: Jessica Kingsley; 2011.<sup>291</sup>

Sicile-Kira C, Sicile-Kira J. *A Full Life with Autism: From Learning to Forming Relationships to Achieving Independence*. New York: Palgrave-Macmillan; 2012.<sup>294</sup>

Tantum D. *Autism Spectrum Disorders Through the Lifespan*. London: Jessica Kingsley Publishers; 2011.<sup>133</sup>

Wehman P, Smith MD, Schall C. *Autism and the Transition to Adulthood Success Beyond the Classroom*. Baltimore, MD: Paul H. Brookes Publishing Company; 2009.<sup>286</sup>

### Web Sites, Video, and Additional Resources

Stephenson et al<sup>295</sup> discovered autism association Web sites provide limited information about the empirical support for interventions. In a similar perspective, Reichow et al<sup>296</sup> propose although the World Wide Web is a common method of obtaining information on ASDs, they believe there should be guidelines for finding Web sites with *high quality*. They conclude online information should not replace the information consumers obtain from professionals.

Jordan<sup>297</sup> proposes that while the internet carries the danger of spreading false information the benefits of the Web appear to outweigh the negative impact. Discussion boards and chat rooms allow individuals with ASDs to interact without the stress and anxiety that may accompany face-to-face interactions. Particularly we highlight the following three as exemplar:

Aging with Autism—<http://www.agingwithautism.org/>

Aging with Autism is dedicated to enhancing programs and services for individuals with autism and other developmental disabilities as they transition to and through adulthood. Recognizing the needs of individuals with autism will change throughout their lives, the organization will support specific programs for teens and young adults, adults in mid life, seniors and elders. To date there has been very little focus on this population and none targeting needs by adult life stage.





Autism After 16—<http://www.autismafter16.com/content/about-us>

This site is dedicated to providing information and analysis of adult autism issues, with the emphasis on analysis. Anyone can Google “autism + adults” and discover a vast array of programs, documents, and products. Our intention here is to try to help adults with ASD and their families make sense of what’s out there. Our big focus out of the gate will be transition issues, since so many of you are struggling with transition right now.

Autism Speaks—<http://www.autismspeaks.org>

### Recommended publications and video

Autism: Coming of Age. (April 11, 2011). WGBY Public television documentary and sponsored by Mass Mutual. Retrieved on Aug 10, 2012. <http://www.massmutual.com/planningtools/additional-resources/special-needs/special-care/autism-coming-of-age>

Jordan CJ. Evolution of autism support and understanding via the World Wide Web. *Intellectual and Developmental Disabilities*. 2010;48(3):220–7. doi:10.1352/1934-9556-48.3.220.<sup>297</sup>

Reichow B, Halpern J, Steinhoff T, Letsinger N, Naples A, Volkmar F. Characteristics and quality of autism websites. *Journal of Autism and Developmental Disorders*. 2012;42(6):1263–74. doi:10.1007/s10803-011-1342-6.<sup>296</sup>

Stephenson J, Carter M, Kemp C. Quality of information on educational and therapy interventions provided on the Web sites of national autism associations. *Research in Autism Spectrum Disorders*. 2012;6(1):11–8. doi:10.1016/j.rasd.2011.08.002.<sup>295</sup>

### The Challenges Now – and Ahead

The children, who represent the first wave of what is commonly referred to as the “autism epidemic,” are entering adulthood.<sup>232,298</sup> This aging epidemic creates the need for high quality, accessible services and supports that extend across the lifespan;<sup>132</sup> particularly heightened awareness among health-care professionals caring for older individuals with ASDs. In specific domains there are numerous challenges for adults with ASDs including: social and physical issues;<sup>8</sup> mental health;<sup>299</sup> cognitive tasks;<sup>71,75</sup> intellectual disabilities;<sup>46</sup> decision-making ability;<sup>300</sup> perspective-taking abilities;<sup>301</sup> symbolic capacity;<sup>302</sup> language and attention strategies;<sup>303,304</sup>

reduction in autobiographical memory<sup>305–307</sup> impairments in spatial working memory and visuo-motor information processing;<sup>308</sup> decision-making capabilities;<sup>309</sup> unusual sensory experiences;<sup>310</sup> emotion regulation;<sup>311</sup> age appropriateness of potential medication treatments;<sup>312</sup> lack of adequate health care response by medical professionals;<sup>73</sup> and greater health disparities;<sup>144</sup> concerns over the higher prevalence of ASD in the prison system;<sup>274</sup> concerns over an increased risk for suicide attempts;<sup>313</sup> Fragile X Syndrome, tuberous sclerosis, epilepsy, hearing and visual impairments, depression, anxiety, aggression, hyperactivity, obsessive compulsive disorder, oppositional conduct, and self-injurious behaviors may be more prevalent within the population of adults with ASDs and IDs.<sup>113,151,314–320</sup> Contemporary researchers in Japan established individuals with AS demonstrate a wide range of mental and behavioral symptoms and disturbances in motor skills which contribute to their heightened levels of social isolation and distress.<sup>316</sup> With respect to cognitive disabilities alone, it is estimated 59% of individuals with autism possess cognitive deficits.<sup>321,322</sup> The prototypical problems (eg, social isolation and anxiety) of younger people with ASD persist through adult life, even in individuals in high-income professions.<sup>69</sup> Although individuals with Asperger’s syndrome (AS) may have difficulties with social interactions and conversations, one team of researchers found that linguistic alignment is intact in adults with AS in structured, goal-directed social interactions.<sup>323</sup>

Spek, van Ham, and Nyklicek propose a mindfulness-based therapy intervention to help reduce depression,<sup>324</sup> anxiety, and rumination. Stuart-Hamilton<sup>69</sup> discovered adults who thought they had ASD and later diagnosed were qualitatively identical to those with a formal diagnosis but only the strength of the symptoms differed. Although daily living skills may improve for individuals with ASD from adolescence into young adulthood, a longitudinal study by Smith, Maenner, and Seltzer<sup>251</sup> found daily living skills “plateaued” during the individual’s late 20s. Smith et al<sup>54</sup> indicate future research should explore which factors and interventions may be associated with potential gains in daily living skills for adults with ASD.

For individuals, who receive the diagnosis of AS in adulthood, psychological reactions could



be problematic in the individual psyche. Punshon, Skirrow, and Murphy<sup>325</sup> indicate that diagnosis of ASD in adulthood is unique because of the timing of “knowledge” in one’s life course pathway. Spek et al<sup>324</sup> agree stating that depression and anxiety are common psychiatric concerns in individuals with ASD, especially in higher functioning adults and adolescents.

With regard to social challenges for adult individuals with ASDs, Sperry and Mesibov<sup>326</sup> found issues such as relationships at work, developing and maintaining personal relationships, appropriate behaviors around members of the opposite sex, and personal experiences were key emergent themes in their study. The prevalence of comorbid medical, psychiatric, intellectual, and behavioral problems may intensify unfavorable psychosocial life circumstances.<sup>45,46,104,113,131,327–330</sup> LoVullo and Matson<sup>330</sup> stress in lower functioning, nonverbal individuals with ASDs or ID the psychopathological symptoms are often expressed differently thus creating a challenge for clinicians who must rely on observable behavior changes in functioning and the regression of skills. They state, “further complicating the diagnosis of comorbidity is that ASD are heterogeneous, with an expression that is compounded by varying degrees of intellectual disabilities” (p. 1289).

The limited amount of credible evidence-based research on services for adults with autism is perhaps an impediment to the development of quality services. Adults with ASDs will need an accessible system that will provide services tailored to their individual needs.<sup>331</sup> The current service delivery system faces significant challenges especially for individuals with ASD and their families. The current situation presents both an opportunity and a challenge to these service systems which are already overburdened and underfunded. But fortunately, there is an increased interest in what support services will work or not work to assist individuals with ASDs in their transition to adulthood and succeed in the community.<sup>331–334</sup>

A recent PRBICI study examined many interesting home and community-based living trends for adults with ASD served by state developmental disability service systems. Challenges with communication and behavior appear to significantly influence access to independent living and self-determination. Compared to other individuals with intellectual and/or developmental disabilities in state service systems, people

with ASD were, as a group, more likely to live in their family home than in independent or group home settings. They were less likely to experience personal choice and control in major life decisions. Overall, the key findings of the PRBICI study highlight the potential gap in services for individuals with ASD. These individuals have significant functional limitations, but borderline or average IQ scores prevent them from receiving services.

The proliferation of autism waivers for children among states appears to be a policy development in response to growing need and research confirming the importance of early intervention. However, autism waivers for adults are not common across states.<sup>132</sup> Much more information and research is needed to fully understand the effects and outcomes of ASD-specific home and community-based services (HCBS). A comparative analysis of outcomes of services for adults with ASDs served through autism-only waivers versus general developmental disability waivers would provide a better understanding of what, if anything, is unique about ASD-specific HCBS and whether such services lead to superior outcomes for adults with ASD. Further investigation should also clarify whether there are differences in the characteristics (eg, demographic, diagnostic, behavioral, and functional limitations and outcomes) of people with ASD, especially in autism-specific and general developmental disability waiver programs. In depth interviews with policymakers in states with autism-specific waivers could identify how and why these waivers were developed and whether they meet expectations. More importantly, understanding the outcomes of state-specific programs will be essential in informing future ASD policy development. Also, states need to develop formal plans on how they will serve the increasing number of children with ASD diagnoses and their families across the lifespan. This influx of people with ASDs will affect waitlists, expenses, and the long-term care system.<sup>132</sup>

Successful employment for adults with ASD is a significant problem.<sup>231,335</sup> It appears “sheltered workshops” may not be conducive to better vocational outcomes for adults with autism.<sup>332</sup> Gerhardt and Lanier<sup>232</sup> report many adults with ASDs remain without any appropriate services. They state many adults have had inadequate transition programming



and there is little service coordination in this domain. For an individual with an ASD, employment has been used as a criterion for assessment of their quality of life.<sup>336</sup> Billstedt, I. Gillberg and C. Gillberg<sup>246</sup> evaluated the quality of life for 108 adults diagnosed with autism as children and found a clear need for improvements in the availability of occupations. The majority of their participants did not have any form of a regular occupation.

Griffith, Totsika, Nash, and Hastings report in their study of adults with AS living in the UK,<sup>331</sup> all participants' attempts at accessing formal support were unsuccessful. As one professional said to a participant, "You're nearly 50, so you've coped this long without support, why do you suddenly need it now?" They conclude a lack of knowledge among professionals has resulted in the inadequate support provided by health and social services. As heterogeneous as individuals with ASDs are services need to be individualized. Some adults with ASDs may require daily supportive services, while others will only need occasional help with certain tasks or situations.

Awareness and recognition of the needs of this population of adults is the first step towards the implementation of a social support system and policies mandating availability. The identification of health disparities with those with ASD<sup>144,337</sup> has also drawn the attention of scholars who propose the application of responsibilities and competencies of the National Commission for Health Education Credentialing, Inc. (NCHEC) for health educators who would work with individuals with ASD.<sup>338</sup>

In 2007 Senator Hillary Clinton (D-NY) sponsored the bill, 'Expanding the Individuals With Autism Act' which included enabling states to provide appropriate services to adults with autism (<http://www.govtrack.us/congress/bills/110/s937#>). But, this bill did not become law. The Equal Employment Opportunity Commission and the Americans with Disabilities Act Title I does protect adults with ASD against workplace discrimination. From their study on workplace discrimination of Americans with ASDs Van Wieren, Reid and McMahon<sup>339</sup> report a greater need for policies directed at education of employers and employees concerning the characteristics and unique work-related issues of individuals with ASDs. They also include the educational need

for individuals with ASDs regarding their rights in the workplace.

ASDs are lifelong conditions often requiring expensive supports and intensive interventions.<sup>272,335,340</sup> Although autism may be associated with a reduced lifespan, most of the public health burden results from the core impairment and associated morbidities.<sup>123</sup> The exact dollar amount is subject to debate and various estimates and ranges have been proposed. For example, the per capita lifetime direct and indirect costs of ASDs in the United States is estimated at estimated at \$3.16 million; a number that does not account for the costs of individuals with ASDs in the sixth decade of life and older. Without modifications to current systems, the significant expense associated with supporting people with ASD is expected to rise in coming years<sup>298</sup> with a greater hospitalization burden among individuals with autism who are growing older.<sup>341</sup> Analyses show the largest contributor to the estimated \$1.28 million per capita lifetime direct cost of ASDs is care during adulthood, that dwarfs expenditures in childhood such as special education and supportive medical care. Historically, such services and supports have been both vital and costly. It is estimated approximately \$35 billion is spent annually on both direct and indirect supports for people with ASD and their families.<sup>342</sup> This translates into a need to look at a life course perspective and efforts to mitigate the societal costs of ASDs.<sup>3</sup> The available, yet limited, research suggests the lifetime cost of supporting an individual diagnosed with ASD ranges from \$2.5 million to \$4.4 million per person.<sup>342,343</sup> Even though intellectual disabilities (IDs) and autism are associated the younger age population in terms of dependency ratios,<sup>58</sup> approximately 60% of these expenditures for individuals with ASDs are estimated to be related to adult services. Unfortunately in the existing literature the majority of individuals with ASD appear to consistently have poor adult outcomes.<sup>45,344-346</sup>

## Recommended publications

Gerhardt PF, Lanier I. Addressing the needs of adolescents and adults with autism: A crisis on the horizon. *Journal of Contemporary Psychotherapy*. 2011;41(1):37-45. doi:10.1007/s10879-010-9160-2.<sup>232</sup>



Geurts HM, Vissers ME. Elderly with autism: Executive functions and memory. *Journal of Autism and Developmental Disorders*. 2012;42(5):665–75. doi:10.1007/s10803-011-1291-0.<sup>10</sup>

Hofvander B, Delorme R, Chaste P, et al. Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*. 2009;9(35). doi:10.1186/1471-244X-9-35.<sup>113</sup>

Johnson MK, Carter MR. Autism spectrum disorders: A review of the literature for health educators. *American Journal of Health Education*. 2011;42(5):311–8.<sup>338</sup>

Kohane IS, McMurry A, Weber G, et al. The comorbidity burden of children and young adults with autism spectrum disorder. *PLoS One*. 2012;7(4):e33224. doi:10.1371/journal.pone.0033224.<sup>317</sup>

Koolen S, Vissers C, Hendriks A, Egger J, Verhoeven L. The interplay between attentional strategies and language processing in high-functioning adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2012;42:805–14. doi:10.1007/s10803-011-1310-1.<sup>303</sup>

Rydzewska E. Destination unknown? Transition to adulthood for people with autism spectrum disorders. *British Journal of Special Education*. 2012;39(2):87–93. doi:10.1111/j.1467-8578.2012.00536.x.<sup>8</sup>

Smith LE, Maenner MJ, Seltzer MM. Developmental trajectories in adolescents and adults with autism: The case of daily living skills. *Journal of American Academy of Child and Adolescent Psychiatry*. 2012;51(6):622–31. doi:10.1016/j.jaac.2012.03.001<sup>251</sup>

Sperry L, Mesibov G. Perceptions of social challenges of adults with autism spectrum disorder. *Autism*. 2005;9(4):363–76. doi:10.1177/1362361305056077.<sup>326</sup>

Stuart-Hamilton I, Morgan H. What happens to people with autism spectrum disorders in middle age and beyond? Report of a preliminary on-line study. *Advances in Mental Health and Intellectual Disabilities*. 2011;5(2):22–8. doi:org/10.5042/amhid.2011.0109.<sup>69</sup>

Totsika V, Felce D, Kerr M, Hastings R. Behavior problems, psychiatric symptoms, and quality of life for older adults with intellectual disability with and without autism. *Journal of Autism and Developmental Disorders*. 2010;40(10):1171–8. doi:10.1007/s10803-010-0975-1.<sup>131</sup>

Tregnago MK, Cheak-Zamora NC. Systematic review of disparities in health care for individuals with autism spectrum disorders in the United States. *Research in Autism Spectrum Disorders*. 2012;6(3):1023–31. doi:10.1016/j.rasd.2012.01.005.<sup>337</sup>

## The Promise of Autism Spectrum Disorders: Cultivating the Abilities, the Talents, and Strengths

While we propose it is critical to examine the personal, familial, economic, and social impacts of ASDs in an aging society, we also emphasize the potential for fulfillment and quality of life for individuals on the autism spectrum.<sup>40,41,292</sup> Most of the literature written about ASDs focuses on the triad of impairments, treatment modalities, psychopathology, developmental disabilities, and individual limitations.<sup>26,347</sup> A more limited number of articles extol the positive attributes and potentials for people with ASDs, or at least offer a balanced perspective of ASD.<sup>348</sup> For example, while Rothstein<sup>349</sup> warns of “romanticizing” the supposed advantages of neurodiversity, he also asks whether or not our society has truly contemplated “to what extent the focus on prevention and treatment means valuing or devaluing lives of affected individuals” (p. 114–115). This issue helps to throw light on the tensions between a strictly biomedical approach and a paradigm that embraces abilities and *differences* instead of disorders or disabilities.<sup>350</sup> Furthermore, some have expressed concerns that there has been a divergence from the “clinical reality of the autistic condition” compared to the stereotypic representations of autism that are found in the popular media (eg, novels, TV-series, movies or autobiographies).<sup>351</sup> In other words, Draaisma<sup>351</sup> proposes that the images and stereotypes that are constructed by novels and movies may eclipse those of experts, “be they psychiatrists, paediatricians or autistics” (p. 1479).

Some have argued that the meaning of autism is problematic and contested, and while autism may be seen as biogenetic condition, ASD has clear socio-cultural dimensions that affect how neurotypicals act toward those labeled autistic.<sup>352</sup> We highly recommend that readers seek out and review the numerous articles in a special issue of the journal of *Disability Quarterly Studies*, Volume 30, Number 1 (<http://dsq-sds.org/issue/view/43>) that presents an impressive array of perspectives on the nuances, meaning, and significance of neurodiversity and autism.<sup>41</sup>



Recent articles and books emphasize the more positive attributes and abilities of people living with autism spectrum conditions.<sup>292</sup> Some seek to explain ASD as a societal myth.<sup>353,354</sup> While others focus on society's misunderstanding of people with ASDs and the need to value their diversity, different strengths and abilities.<sup>355–359,378</sup> And the scholarship in this domain has gone further—and deeper—into the ways in which people are categorized, labeled, circled in, boxed in, identified with autism by “others” who are not autistic, thus denying (or negating) “autistic self-advocates a place in the conversations that concern them.”<sup>360</sup> In other words, the neurodiversity movement seeks a collaborative approach between professionals, researchers and autistic adults in order to achieve meaningful solutions to the challenges of ASDs in adulthood.<sup>40,361</sup>

Although representing a small percentage and with residual co-morbidities, researchers document the potential for “recovery” from autism symptoms for some children who transition into the adult years, albeit with specific treatment modalities and given certain characteristics of the individual with an ASD.<sup>70</sup> Specifically Fein et al's<sup>362</sup> article demonstrates the potential for some with ASD at a younger age to move off the autism spectrum and into normal functioning (note: the oldest individual was 21 years, 8 months). Others indicate that despite the association between increasing age, poorer physical and mental health and a smaller social network, the role of personal resources may help those with autism (and other intellectual disabilities) to still experience high levels of well-being.<sup>363</sup> Others highlight the effectiveness of interventions programs eg, face processing through training, would help with daily functioning and improve quality of life.<sup>40,364</sup>

Temple Grandin expresses that employment gave meaning to her life.<sup>82,365</sup> Unfortunately, currently the vast majority of adults with ASD are unemployed or underemployed,<sup>67,232,334</sup> with the preponderance likely employed in menial low paying jobs. Fortunately, at least one research team examined the psychosocial functioning of adults with *late* diagnosed ASDs and found the majority of those diagnosed in later life had HFASDs and most had achieved independent living status, had a higher educational status, and were able to learn social rules.<sup>66</sup> Levy and Perry<sup>154</sup> call for comprehensive studies addressing multiple outcome

domains and to examine both high and lower functioning individuals with autism.

However for some adults with autism, their social limitations impact their potential for employment. Recently researchers suggest that adult social functioning outcomes for individuals with autism may be gradually improving as a result of improvements in early identification and treatment for children with autism today.<sup>135,344</sup> Yet, S. Marriage, Wolverton, and K. Marriage<sup>366</sup> caution that research for evidence-based practice of childhood interventions and its correlations to later functional outcomes in adulthood is still limited. Individual prognostic factors including IQ score, language development and the severity of autistic symptoms must also be considered as influential to adult outcomes.

Current publications focusing on adult outcomes concur that in respect to independent living, education and occupation, individuals with HFASD have a wider range of adult attainment than individuals with co-morbid ASD and intellectual deficiencies who may have limited aptitudes, remain dependent and low functioning into adulthood.<sup>7,155,161,329,344,366–369</sup> Nevertheless, there are efforts underway to ensure better outcomes for young adults with ASD when transitioning from school to work and several kinds of employment models have been proposed.<sup>370,371</sup>

Graetz<sup>49</sup> found caregivers of an adult with ASD expressed a lack of opportunities for their family member in employment, residential living and socialization. She states “This lack of opportunity does not lie with the individual with autism but with the fault of members of society who are unable or unwilling to accept others who may bring different gifts to the community” (p. 44). In their book *Developing Talents: Careers for Individuals with Asperger Syndrome and High-Functioning Autism*, Grandin and Duffy<sup>365</sup> describe individuals with ASD will need to adapt to the work environment. They argue the workplace will need to accommodate an employee with ASD but it is possible. Grandin and Duffy stated that individuals with ASD “need to work where [their] talents are respected and colleagues are tolerant of [their] social eccentricities” (p. 40). Lawer, Brusiloskiy, Salzer, and Mandell<sup>372</sup> examine the use of vocational rehabilitative services among adults with autism and found that because of their uneven cognitive and social abilities,



individuals with ASD have very different vocational needs than individuals with other developmental disabilities. They propose individuals with ASDs were more likely to be denied services because they were considered too disabled. Lawer, Brusiloskiy, Salzer, and Mandell<sup>372</sup> state, “Successful competitive employment for people with ASD may depend on the presence of on-the-job supports, which include job coaching, follow-up and follow-along and job retention services” (p. 493). In their eight-year follow-up study on a specialized supportive employment program for high functioning adults, Howlin et al<sup>68</sup> report on the satisfaction of the program for clients, employers, and support workers alike. From their involvement in a supported employment program, highlighting the positive contributions vocational rehabilitation can provide, Garcia-Villamizar and Hughes<sup>373</sup> demonstrated the improvement of executive functions for adults with autism.

In their study of the parental dilemmas, diagnosis and de-stigmatization of having a child with ASD, Russell and Norwich<sup>374</sup> conclude “parents, autistic adults and support services may collude in redefining ASD as both different and foreign, special and valuable” (p. 12). Cognitive scientist and diagnosed with an ASD, Michelle Dawson explains that often when empirical evidence records the strengths of an individual with ASD, they are masked by a preoccupation with deficits. Dawson, Soulieres, Gernsbacher, and Mottron<sup>375</sup> conclude intelligence has been underestimated in individuals with autism. This perspective was further elaborated in the commentary article by Mottron<sup>11</sup> who proposes individuals with autism might be at an advantage in certain professional fields, especially in the domain of scientific research. Mottron further recommends greater inclusion of individuals with ASDs into viable occupational fields representing appropriate matches to their skill sets (eg, visual-spatial processing).<sup>348</sup> Grant and Davis<sup>376</sup> agree with this in their plea for greater recognition of the value of autistic characteristics to find meaningful employment for individuals with ASDs, such as fine discrimination. However, the findings of O’Hearn, Franconeri, Wright, Minshew, and Luna<sup>377</sup> indicate that such visual skills may be based on the amplified ability in individuals with autism to discriminate targets and not necessarily see more elements. In other words, individuals with autism may be able to “see” fewer items at once, but they are also

able to encode more details of those objects. O’Hearn et al<sup>377</sup> propose that how individuals see the world may affect the interpretation of social scenes.

When speaking at the 2012 TED conference, professor of animal science, Temple Grandin, who has autism, was cheered after quipping that Silicon Valley wouldn’t exist without the condition. This perspective captures the range of potential that is possible with “neurological variation” and also indicates how a strengths-based perspective can help to build bridges between the formative years and the transition to adulthood with specialty interests that match specialty occupational areas.<sup>348</sup> This orientation embraces an alternative representation of individuals with ASD as different and with abilities and not as a deficit.<sup>348</sup> It may expand the opportunities and recognition of the competencies of individuals grouped under this label. Several organizations and business groups have begun to focus their efforts in helping to bridge the capabilities of individuals on the autism spectrum in the work force and we recommend readers visit and review the information at the following Web sites: AASCEND (Autism Asperger Syndrome Coalition for Education, Networking and Development at <http://www.aascend.org>; Semperical at <http://www.semperical.com>; The Specialist Guild at <http://specialistsguild.org>; and Specialisterne at <http://www.specialisterne.com>.

Although many interpretations of autism remain grounded in the biomedical paradigm, individuals *with* autism, through narrative self-representations and organized activities are themselves changing the larger perspective of the autistic condition<sup>82,349,355,378</sup> transforming it from the autism landscape of “cure to community.”<sup>378</sup> In addition, there is the call to consider the rights of those with adults with intellectual and developmental disabilities to be actively involved in research seeking to understand their life experiences.<sup>379</sup> Most importantly this presents the significance of *respect* for adults with disabilities and their wish to be fully engaged in the research process.<sup>40,60,65,355</sup>

Researchers, including Baron-Cohen et al<sup>357</sup> acknowledge the stigmatizing potential of the ASD label and call for the term “disorders” to be replaced with the term “conditions.” The disorder



label implies a need for specialized treatment and a cure. Changing the terminology from a disorder to a condition may have positive implications on society's understanding and acceptance of the differences individuals with ASDs exhibit. What if, as Temple Grandin<sup>82</sup> proposes, neuro-developmental differences were considered *differences* and not *deficits* meaning less than normal? What if their intense focus could be constructively channeled and enhanced for the benefit of the individual and society?<sup>380–382</sup> Baron-Cohen, E. Ashwin, C. Ashwin, Tavassoli, and Chakrabarti<sup>382</sup> in their book chapter, “The paradox of autism: Why does disability give rise to talent?” propose another way of stating the promise of ASDs. Baron-Cohen, E. Ashwin et al<sup>382</sup> note while people with ASD may show areas of deficit in the social domain, the other areas of intact or superior skill may be attention to detail and systemizing.<sup>143,198,348,383</sup> They also propose much more can be done to harness potential skill sets utilizing the strong systemizing features of an individual with ASD, as well as enhancing the social skills in areas such as computer technology and other systemizing formats.<sup>198</sup> Baron-Cohen, E. Ashwin et al<sup>382</sup> speculate perhaps there is an evolutionary advantage to excellent “attention to detail,” as it represents a strong adaptive human ability in the context of human progress and civilization.

## Recommended publications

Armstrong T. *The Power of Neurodiversity: Unleashing Advantages of Your Differently Wired Brain*. Cambridge, MA: Da Capo Press; 2011.<sup>292</sup>

Baron-Cohen S, Ashwin C, Tavassoli T, Chakrabarti B. Talent in autism: Hyper-systemizing, hyper-attention to detail and sensory hypersensitivity. *Philosophical Transactions of the Royal Society B*. 2009;364(1522):1377–83. doi:10.1098/rstb.2008.0337.<sup>357</sup>

Baron-Cohen S, Ashwin E, Ashwin C, Tavassoli T, Chakrabarti B. The paradox of autism: Why does disability sometimes give rise to talent? In: Kapur N, editor, *The Paradoxical Brain*, pp. 274–88. New York: Cambridge University Press; 2011.<sup>382</sup>

Dawson M, Soulière I, Gernsbacher MA, Mottron L. The level and nature of autistic intelligence. *Psychological Science*. 2007;18(8):657–62. doi:10.1111/j.1467-9280.2007.01954.x.<sup>375</sup>

Gantman A, Kapp SK, Orenski K, Laugeson EA. Social skills training for young adults with high-functioning autism spectrum disorders: A randomized controlled pilot study. *Journal of Autism and Developmental Disorders*. 2012;42(6):1094–103. doi:10.1007/s10803-011-1350-6.<sup>368</sup>

Grandin T. *Different ... Not Less: Inspiring Stories of Achievement and Successful Employment From Adults with Autism, Asperger's, and ADHD*. Arlington, TX: Future Horizons Inc; 2012.<sup>82</sup>

Grandin T, Duffy K. *Developing Talents: Careers for Individuals with Asperger Syndrome and High-Functioning Autism*. Shawnee Mission, KS: Autism Asperger Publishing Co; 2008.<sup>365</sup>

Helt M, Kelley E, Kinsbourne M, et al. Can children with autism recover? If so, how? *Neuropsychology Review*. 2008;18(4):339–66.<sup>70</sup>

Jordan CJ, Caldwell-Harris CL. Understanding differences in neurotypical and autism spectrum special interests through Internet forums. *Intellectual and Developmental Disabilities*. 2012;50(5):391–402. doi:10.1352/1934-9556-50.5.391.<sup>348</sup>

McDonald K. “We want respect”: Adults with intellectual and developmental disabilities address respect in research. *American Journal on Intellectual and Developmental Disabilities*. 2012;117(4):263–74. doi:10.1352/1944-7558-117.4.263.<sup>379</sup>

Pers L, editor. *Scholars with Autism Achieving Dreams*. Sedona, AZ: Auricle Ink; 2012.

Santomauro J, editor. *Autism All-Stars: How We Use Our Autism and Asperger Traits to Shine in Life*. Philadelphia, PA: Jessica Kingsley; 2011.<sup>291</sup>

Schall C, Wehman P, McDonough JL. Transitions from school to work for students with autism spectrum disorders: Understanding the process and achieving better outcomes. *Pediatric Clinics of North America*. 2012;59(1):189–202. doi:10.1016/j.pcl.2011.10.009.<sup>371</sup>

## The Phenomenology and Cultural Milieu of Autism

We include this section in our review of the literature to establish the importance of the literature examining the essence of autism that uses a different framework or lens than the traditional biomedical model or associated with “professionals” publishing in mainstream scientific outlets.<sup>352</sup> The *difference* is more



than semantics or a simplistic dichotomy of “two cultures,” ie, science vs. humanities<sup>384</sup> when attempting to discover substance and significance about an interest of the human condition. Rather, there is—and this represents—an emphasis on interpretation, discourse, narrative, symbolic interaction, cultural commentary, critical theorizing, and weaving of political and rhetorical themes into the *understanding* of autism. And the desire and need for understanding has reached a fever-pitch level to where some have wondered if “being on the spectrum” has gone mainstream, such that “SpectrumVision” is everywhere and almost everyone (or so it seems) is (to some degree) a bit of an “aspie.”<sup>385</sup> It is as though “autism” has entered into the sociocultural milieu and transformed from something genetic to something mimetic. Therein, lies the heart of the matter; perhaps when we examine the domain of “autism” there has been much emphasis on the “trees” and as a result, we have lost sight of “the forest.”<sup>386</sup> In other words with so much publication activity (and currency) at the molecular level on ASD, are there larger or molar issues to also consider if we are to embrace both explanation and understanding? Glerzerman<sup>386</sup> offers the following rationale for considering the “subjectivity” of autism and advancing a “neurophenomenological” approach to autism:

“Autism—an enigmatic and devastating disorder of childhood that persists throughout life—has attracted a vast amount of research in recent years, with a focus on brain imaging and genetic studies. There is an abundance of new data and facts, but autism continues to elude understanding” (p. 4).

But while Glerzerman<sup>386</sup> looks to avoid reductionistic tendencies and considers the symbolic supra-modal level in the matrix of a neurophenomenological approach, the proposed matrix is still grounded in the *intra-cranial* structure and processes of the brain. In contrast, we consider the potential for *understanding* autism as it extends outward from anatomical issues and into the *umwelt* of the neurodiverse person—the ontological totality of the experience between person and environments embedded in sociocultural meaning. The work of Mark Osteen, Stuart Murray, Victoria McGeer<sup>23–25,387</sup>, and Ian Hacking<sup>388</sup> are exemplary publications, which capture the spirit of this perspective. We also recommend the special issue of *Popular Narrative Media* highlighting the theme,

“Autism, narrative and textuality” with a comprehensive introduction by Irene Rose.<sup>389</sup>

The sociocultural *embeddedness* perspective not only includes autistic people, but it is also an orientation that serves to understand the interpretations of professionals and researchers who seek to explain the behaviors and thinking of individuals with ASDs. For example, previously we examined the research of Happé and Frith<sup>380</sup> and Baron-Cohen et al.<sup>195</sup> One of the fundamental tenets of their work relates to the Theory of Mind (ToM) and the resulting “tragedy” of “mind-blindness” for autistic people.<sup>390</sup> However, Duffy and Dorner<sup>391</sup> critique ToM and propose the theory is really a “discourse of affect and values or a rhetoric of scientific sadness in which autistic people are mourned even as they are ostensibly explained” (p. 201). Duffy and Dorner<sup>391</sup> suggest the time has come to recognize and integrate more of the “first-person” accounts from autistic people who are “active agents in their own self-definition” (p. 214). This perspective is indicated in research that has explored the experiences of adults with Asperger syndrome by using the theoretical approaches of ethnomethodology and symbolic interactionism<sup>302</sup> and the research of Rosqvist<sup>392,393</sup> who has explored the counterhegemonic discourse of “autistic normalcy” among adults with high-functioning autism.

We have found that the journal *Disability Studies Quarterly* (DSQ) is an excellent source for scholarship in this domain. DSQ (<http://dsq-sds.org/>) is a multidisciplinary and international journal of interest to social scientists, scholars in the humanities, disability rights advocates, creative writers, and others concerned with the issues of people with disabilities. Readers are encouraged to review the special issue on “Autism and the Concept of Neurodiversity,” Volume 30, Number 1, 2012 (<http://dsq-sds.org/issue/view/43>).

## Recommended publications

Murray S. Autism functions/the function of autism. *Disability Studies Quarterly*. 2010;30(1). Retrieved from: <http://dsq-sds.org/article/view/1048/1229>

Nadesan MH. *Constructing Autism: Unravelling the ‘Truth’ and Understanding the Social*. New York: Routledge; 2005.<sup>353</sup>

Osteen M, editor. *Autism and Representation*. New York: Routledge; 2007.<sup>25</sup>





Savarese ET, Savarese RJ. "The superior half of speaking": An introduction. *Disability Studies Quarterly*. 2010;30(1). Retrieved from: <http://dsq-sds.org/article/view/1062/1230>.<sup>41</sup>

Robertson SM. Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. *Disability Quarterly Studies*. 2010;30(1). Retrieved from: <http://dsq-sds.org/article/view/1069/1234>.<sup>40</sup>

Yergeau M. Circle wars: Reshaping the typical autism essay. *Disability Studies Quarterly*. 2010;30(1). Retrieved from: <http://dsq-sds.org/article/view/1063>.<sup>360</sup>

## Synthesis

The purpose of this paper was to review the literature exploring the use of search operators in select databases to query the intersection of *autism spectrum disorders* with the life course domain of *adulthood and aging*. In other words, if A = autism spectrum disorders and B = adulthood and aging, then our set notation was  $A \cap B$ . We had several goals and objectives for the systematic review and present the outcomes for those goals and objectives with several descriptive findings and a synthesis of the major themes.

1. Conduct an ideally exhaustive, comprehensive review of the literature to derive a cumulative count of relevant publications matching the goals of this paper. We reviewed 416 sources that meet our inclusion and exclusion criteria. Within the 416 sources, there were 340 journal articles and 44 scholarly books that meet our systematic review criteria. The remainder of sources were Web sites were web sites and various scholarly reports.
2. Create an inventory of exemplar publications. Exemplar publications were based on their breadth, depth, and comprehensive nature in addressing the primary foci. We found the following preeminent publications were published between the years 2000–2013:

Bishop-Fitzpatrick L, Minshew NJ, Eack S. A systematic review of psychosocial interventions for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2012. doi:10.1007/s10803-012-1615-8.<sup>14</sup>

Edwards TL, Watkins EE, Lotfizadeh AD, Poling A. Intervention research to benefit people with autism:

How old are the participants? *Research in Autism Spectrum Disorders*. 2012;6(3):996–9. doi:10.1016/j.rasd.2011.11.002.<sup>4</sup>

Grandin T. How does visual thinking work in the mind of a person with autism? A personal account. *Philosophical Transactions of the Royal Society B*. 2009;364(1522):1437–42. doi:10.1098/rstb.2008.0297.<sup>78</sup>

Grandin T. *Different ... Not Less: Inspiring Stories of Achievement and Successful Employment From Adults with Autism, Asperger's, and Adhd*. Arlington, TX: Future Horizons Inc; 2012.<sup>82</sup>

Grandin T, Duffy K. *Developing Talents: Careers For Individuals with Asperger Syndrome and High-Functioning Autism*. Shawnee Mission, KS: Autism Asperger Publishing Co; 2008.<sup>365</sup>

Happé F, Charlton RA. Aging in autism spectrum disorders: A mini-review. *Gerontology*. 2012;58(1):70–8. doi:10.1159/000329720.<sup>74</sup>

Henninger NA, Taylor JL. Outcomes in adults with autism spectrum disorders: A historical perspective. *Autism*. 2012. doi:10.1177/1362361312441266.<sup>72</sup>

Holwerda A, van der Klink JJ, Groothoff JW, Brouwer S. Predictors for work participation in individuals with an autism spectrum disorder: A systematic review. *Journal of Occupational Rehabilitation*. 2012;22(3):333–52. doi:10.1007/s10926-011-9347-8.<sup>87</sup>

Howlin P, Moss P. In Review-Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*. 2012;57(5):275–83.<sup>83</sup>

Levy A, Perry A. Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders*. 2011;5(4):1271–82. doi:10.1016/j.rasd.2011.01.023.<sup>66</sup>

Mahan S, Kozlowski A. Adults with autism spectrum disorders. In: Matson JL, Sturney P, editors, *International Handbook of Autism and Pervasive Developmental Disorders* (Autism and Child Psychopathology Series) (Part 3), pp. 521–38. Springer: New York; 2011.<sup>6</sup>

Mukaetova-Ladinska EB, Perry E, Baron M, Povey C, Autism Ageing Writing Group. Ageing in people with autistic spectrum disorder. *International Journal of Geriatric Psychiatry*. 2012;27(2):109–18. doi:10.1002/gps.2711.<sup>76</sup>

Piven J, Rabins P; on behalf of the Autism-in-Older Adults Working Group. Autism spectrum disorders in older adults: Toward defining a research agenda.



*Journal of the American Geriatrics Society*. 2011; 59(11):2151–5. doi:10.1111/j.1532-5415.2011.03632.x.<sup>3</sup>

Poon KK. Supporting adults with autism spectrum disorders: Lessons from six decades of international research. *International Journal of Special Education*. 2012;27(3):1–14. Retrieved from: <http://www.internationaljournalofspecialeducation.com/>.<sup>89</sup>

Shattuck PT, Roux AM, Hudson LE, Taylor JL, Maenner MJ, Trani JF. Services for adults with an autism spectrum disorder, *Canadian Journal of Psychiatry*. 2011;57(5):284–91.

Smith PA. Aging in autism. *Perspectives on Gerontology*. 2012;17(2):69–75. doi:10.1044/gero17.26.9.<sup>88</sup>

3. Determine if higher order themes emerged in the comprehensive review of publications. We identified the following catchment themes. These themes facilitated a way to relay the top publications per theme in an organized heuristic structure:

- The Knowing of Autism Spectrum Disorders: Diagnosis, Prognosis, and Nosology
- The Epidemiology of Autism: Incidence, Prevalence, and the Counting of Autism
- Measurement and Methodology
- The Etiology of Autism (Environmental and Biological Factors)
- Young Adults, College Students, and Transition into Adulthood
- Older Parents and Family Issues
- Grandparent Considerations
- Long-Term Care Challenges
- Miscellaneous Topics eg, Sexuality, Marital Satisfaction, Sensory Issues
- Trade and Textbooks
- Web Sites, Videos, and Additional Resources
- The Challenges Now—and Ahead
- The Promise of Autism Spectrum Disorders: Cultivating Abilities, Talents, Strengths and the Rise of Neurodiversity
- The Phenomenology and Cultural Milieu of Autism

4. Identify the top exemplar articles per emergent theme. The goal was to identify which publications represent the emergent themes and provide the reader with scholarly breadth and depth of the higher order themes of ASDs in adulthood and aging. The emphasis was on quality and a “go-to” list for each identified theme.

5. Establish which emergent theme had the greatest number of publications. “Young Adults, College Students, and Transition into Adulthood” was the most dominant theme in the publications we identified and reviewed. This was not completely a surprise given most of the published literature has focused on the “transition to adulthood,” as a natural extension of the traditional focus on childhood and youth.

6. Document the top three journals that most frequently publish articles exploring ASDs and adulthood and aging, and related to the goals of this paper. Based on our analysis, the *Journal of Autism and Developmental Disorders* (JADD) was found to be the journal publishing the highest number of articles (57) related to adulthood and aging. Significantly, JADD is considered the leading peer-reviewed, scholarly periodical focusing on all aspects of ASDs and related developmental disabilities. JADD has an impact factor of 3.341 of a maximum of 4.0 (2011).

The journal publishing the second highest number of articles related to the theme of adulthood and aging related to the goals of this paper was *Autism* with 27 references. *Autism* is a major, peer-reviewed, bi-monthly, international journal, providing research of direct and practical relevance to help improve the quality of life for individuals with autism or autism-related disorders. *Autism* has an impact factor of 2.265.

*Research in Autism Spectrum Disorders* had the third highest number of articles (15) used in this review. *Research in Autism Spectrum Disorders* (RASD) publishes high quality empirical articles and reviews with a primary focus on applied topics and has an impact factor of 2.959.

## Author Contributions

Analyzed the data: SDW, DB, VD. Wrote the first draft: SDW. Contributed to the writing of the manuscript: SDW, DB, VD, TG. Agree with manuscript results and conclusions: SDW, DB, VD, TG. Jointly developed the structure and arguments for the paper: SDW, DB, VD, TG. Made critical revisions and approved final version: SDW.

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## Major Abbreviations

ASD, autism spectrum disorder; ASDs, autism spectrum disorders; HFASD, “high-functioning” autism spectrum disorder; AS, Asperger’s syndrome (or Asperger syndrome).

## Disclosures and Ethics

As a requirement of publication author(s) have provided to the publisher signed confirmation of compliance with legal and ethical obligations including but not limited to the following: authorship and contributorship, conflicts of interest, privacy and confidentiality and (where applicable) protection of human and animal research subjects. The authors have read and confirmed their agreement with the ICMJE authorship and conflict of interest criteria. The authors have also confirmed that this article is unique and not under consideration or published in any other publication, and that they have permission from rights holders to reproduce any copyrighted material. Any disclosures are made in this section. The external blind peer reviewers report no conflicts of interest.

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