

The Trajectory of Development in Adolescents and Adults with Autism

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## I. Introduction

Autism is a developmental disorder that is ordinarily diagnosed during early childhood. However, the impairments of autism are thought to last a lifetime, and continue to pose challenges for the affected individual and his or her family. Understanding the nature of this disorder and developing appropriate interventions and systems of support require answers to many questions about the life course pattern of the disorder. How are the core symptoms of autism manifested during adolescence and adulthood? Are there changes in cognitive abilities across the life course, as is evident in other developmental disabilities? What is the expected pattern of social role attainment by adults with autism with respect to outcomes such as living arrangements, occupational status, and friendships? What factors are predictive of better outcomes in adulthood? These are the questions that we address in the present paper, which summarizes the limited evidence about the life course manifestation of autism.

The relevant corpus of research is limited because autism as a disorder was first identified only about 60 years ago, when Kanner published his seminal 1943 paper on 11 children who had “autistic disturbances of affective contact.” Thus, the first cohort of individuals to have been diagnosed with autism has only now reached old age, which means that only recently have we had the opportunity to obtain a glimpse into the course and outcomes associated with this developmental disorder.

Although autism is now recognized to be part of a spectrum of disorders, we limit our attention in this paper to past research on autistic disorder per se. We do not summarize studies focused exclusively on Asperger disorder or PDD-NOS, as these less severe spectrum diagnoses may be associated with more favorable adult outcomes than autistic disorder. We also limit our review to studies that offer direct results or that lead to inferences about outcomes in adulthood

and age-related changes in the behavioral and social phenotype of autism. However, we recognize that there have been significant changes in the definition and diagnostic criteria of autism over the past decades, and thus we are cautious in reaching developmental conclusions on the basis of what is largely a cross-sectional research base.

Inevitably, when summarizing a limited knowledge base about an important set of scientific issues, many questions remain unanswered. Therefore, the paper aims to identify fruitful avenues for future research on the life course of this disorder, as well as methodological challenges. Autism is recognized to be a complex disorder with multiple etiologies likely leading to its common diagnostic profile. Whether the behavioral and social phenotype unfolds in a homogeneous way across the life course, or whether there are distinct trajectories that define sub-groups of the population affected by this disorder, is a central question for future research.

## **II. Manifestation of and Changes in the Core Autism Symptoms in Adolescence and Adulthood**

The core symptoms of autism include impairments in communication and reciprocal social interaction, and restricted and repetitive behaviors and interests (American Psychiatric Association 2000). The Autism Diagnostic Interview – Revised (Lord et al. 1994) presents a systematic procedure for assessing these core symptoms and has become the “gold standard” for diagnosing autism. For most symptoms, severity at age 4 to 5 is the focus of this assessment, reflecting the empirically supported belief that autism is an early emerging condition. Despite its early emergence, autism is thought to be an enduring condition that persists throughout the life course; however, little is known about the manifestation of the core deficits of autism in adolescence and adulthood (Schroeder et al. 1996).

There have been only a handful of studies that have addressed questions about the

developmental course of the autism phenotype from childhood through adolescence and into adulthood, although there is a somewhat larger cross-sectional literature on the behavioral phenotype at these stages of the life course. In general, studies have focused on age-related differences and/or changes in the severity of the symptoms of autism, asking (1) whether symptoms abate, remain stable, or become more severe over the life course and (2) whether individuals continue to meet the diagnostic criteria for having an autism diagnosis after the early childhood years.

Studies addressing changes in core symptoms have spanned four decades, and therefore they differ in the diagnostic practices in force across time. Despite this variability in diagnostic practices, as well as differences in design, sample, and measures, the accumulated evidence summarized in this paper indicates that the core symptoms of autism abate to some degree during adolescence and young adulthood. Recent studies (e.g., Seltzer et al. 2003b) provide a more nuanced characterization of symptom change, suggesting that development may be “splintered,” with improvement in only some of behaviors that define autism and with somewhat different timing of improvements across behaviors.

Importantly, however, improvements are not seen for all individuals and even in those who do improve, changes are seldom substantial enough to move the individual into the normal range of functioning. Kanner (1971), for example, reported on the outcomes of 10 of the 11 original cases of autism he first described in his 1943 paper (Kanner 1943). In these clinical case studies, he noted a wide range of outcomes over the three decades since the original observations. Several members of the sample failed to develop an appreciable level of socially appropriate language or any level of independence, whereas a few individuals held jobs, achieved some degree of independence, and even had a network of acquaintances, although

usually through organized and highly structured activities (e.g., church groups and clubs). Kanner noted that across all cases, the core symptoms of the disorder, especially the social deficits and ritualistic and repetitive behaviors, largely remained. Other investigators (e.g., Rumsey et al. 1985) have also documented the improving, but lasting, symptoms of autism.

Additionally, although the overall trajectory for many with autism is improvement during adolescence and adulthood, there can be plateaus or even periods of symptom “aggravation” along the way, and for some individuals, symptoms may not abate or even may worsen. For example, in a study of 23 people between the ages of 16 and 23 years diagnosed with autism as part of a total-population epidemiological survey, Gillberg and Steffenberg (1987) found that 35% of the sample experienced temporary (1-2 years) periods of aggravation of behavioral symptoms (aggression, hyperactivity, insistence on sameness), and 22% (5 individuals) exhibited continuing deterioration throughout puberty in these same areas of behavior plus loss of language skills and cognitive abilities. Of these 5 individuals, 3 experienced the onset of seizures in puberty. It is important, therefore, to keep in mind throughout this review that group trajectories summarizing change over wide spans of time can obscure individual differences and transient changes of clinical and theoretical importance.

### Impairments in Communication

Impairments in communication are a hallmark of autism. Such impairments can affect both receptive and expressive language, although there are very large individual differences. Developmentally, most children with autism have significantly delayed expressive language, and many never develop meaningful communication skills. Not only is language delayed in comparison to age norms, language is often impaired *within* individuals in comparison to expectations based on their performance IQ, indicating that communication skills are more

impaired than would be expected, given the individual's general cognitive ability (Lord et al. 2004). Of those who do speak, many exhibit abnormalities in prosody and volume, and may have echolalia. Finally, speech may be overly focused on particular topics, and the individual with autism may perseverate on the topic regardless of the listener's level of interest (Tager-Flusberg 1999). In addition to abnormalities in speech, individuals with autism tend to be impaired in their use of nonverbal communication, such as gesturing and making eye contact (Lord and Paul 1997). Most of these impairments in communication are evident in childhood (Tager-Flusberg 2001; Wilkinson 1998). How are they expressed in adolescence and adulthood?

In an early study, Rutter, Greenfeld, and Lockyear (1967) conducted a 10-year follow up of 63 children who were diagnosed with infantile psychosis (i.e., autism) around the age of 5 years, focusing on, among other issues, the continued appropriateness of a diagnosis of autism and various dimensions of behavioral functioning, including social uses of language. Measures were derived from ratings of clinical evaluations and informant reports. Language use was characterized largely in terms of presence/absence of socially "useful speech." Improvements in language were noted in approximately 50% of the autism sample, with only about 10% showing declines in the domain of language. However, even among the sample members who had useful speech, echolalia and pronominal reversal were present in three-fourths and half of the adolescents, respectively. Many in the sample were also characterized by obsessive questioning and other socially inappropriate patterns of language use (e.g., flat intonation, literalness).

More recently, Seltzer et al. (2003b) conducted a retrospective study of a community sample of more than 400 adolescents (10-21, mean age = 15.7) and adults (22 or older, mean age = 31.6) who had been diagnosed as having an autism spectrum disorder (ASD) when they were young children. Seltzer et al. used the ADI-R to make comparisons between current symptoms

and lifetime symptoms, with the latter defined relative to childhood functioning, especially at age 4 to 5 years. Nearly all (94.8%) met ADI-R criteria for autistic disorder (based on lifetime ratings) and the other 5.2% had ADI-R scores consistent with their primary ASD diagnosis (Asperger's or PDD-NOS). In general, Seltzer et al. found that the symptoms of autism abated with age. Importantly, however, the extent of improvement over the life course varied across the adolescent and adult cohorts and according to the domain of behavior being considered. In the communication domain, 99.5% of the sample met cutoff criteria for a diagnosis of autistic disorder based on lifetime ratings, whereas only 67.9% scored above the cutoff according to ratings of symptoms as they currently were manifested. The adult cohort showed the greatest improvement overall, although the adolescent cohort also improved significantly from the lifetime to current ratings of communication. There was also considerable variability in the course of change across communicative behaviors. For example, speech symptoms that are the "classic" signs of autism (e.g., pronominal reversal, neologisms) improved the most, whereas limitations in pointing to express interest and use of gestures to communicate less likely to improve from childhood within each cohort. Other retrospective and prospective longitudinal studies have also documented improvements in communication, on average, from childhood to adolescence and adulthood (e.g., Nordin and Gillberg 1998).

Rutter, Howlin, and colleagues (Howlin et al. 2004; Mawhood et al. 2000) provided data about language level in a British sample of adults with autism who were initially diagnosed as having an ASD when they were age 7 years on average. Overall, their level of communicative competence in adulthood showed a pattern of modest improvement, although their impairments remained pronounced. The sample as a whole gained about one-fourth of a standard deviation in the measure of communication over time. Of those who had little or no language when assessed

in childhood, over 40% had developed useful language by adulthood. However, even in adulthood, only 16% of the sample scored at or above the level expected for a typical 15-year-old, 35% had language skills between the age 6- and age 15-year levels, and fully 48% had language below the age 6-year level. The significance of language skills in adulthood cannot be underestimated; according to the results of this study as well as many others (e.g., Venter et al. 1992), the better an individual's language skills, the more likely he or she is to have favorable psychosocial outcomes in adulthood across a range of areas.

A pattern of improvement in communication abilities was also evident in a Japanese sample of 187 adults with autism between the ages of 18 and 33 (mean age = 21.5 years) who were initially studied at age 6 (Kobayashi and Murata 1998). Whereas only 1.5% was judged to have "very good" speech in childhood, 16% met this standard as adults. Very good speech was defined as the ability to speak naturally and freely with a rich vocabulary. The percentage characterized as having "good" speech also increased, from 18.1% at age 6 to nearly one-third (31.6%) in adulthood. Good speech was defined as the ability to communicate, even if sometimes unnaturally and inappropriately. Nevertheless, similar to the findings of the previously reviewed studies (Howlin et al. 2004; Mawhood et al. 2000; Seltzer et al. 2003b), the majority of the sample continued to manifest substantial deficits in speech, with approximately half of the sample (52.4%) said to lack the ability to communicate using speech or to vocalize mainly through echolalia.

Not all studies have documented improvements in communication. Loveland and Kelley (1988) compared 16 adolescents and adults with autism with a matched sample of 16 age peers with Down syndrome (DS). Relative to those with DS, the individuals with autism were more delayed in communication abilities. Furthermore, although adults with DS had better



communication skills than adolescents with DS, there were no age-related differences in communication skills for participants with autism. Similarly, Janicki and Jacobson (1983) studied 314 adults with autism between the ages of 21 and 65, and revealed a pattern of speech impairments not changed from that manifested in childhood. Fully 78% had marked expressive or receptive language impairments and 19% had speech characterized by echolalia and perseveration.

In summary, the available studies indicate that the core deficit in communication may ameliorate to some degree by adolescence and adulthood. Nevertheless, the majority of individuals with autism remain impaired in this domain. Although the small sized sample in the Loveland and Kelley (1988) study limits generalizability of findings, this study suggests the benefit of comparisons of individuals with autism and those with other developmental disabilities in assessing the severity of communication deficits and other aspects of the autism phenotype in adolescence and adulthood.

#### Impairments in Reciprocal Social Interaction

A second core deficit of autism is impairment in reciprocal social interaction. There are a number of indicators of this core deficit, including impairments in use of nonverbal behaviors to regulate social interaction, difficulty making friends, limitations in shared enjoyment of interests with others, and a general lack of social or emotional reciprocity (American Psychiatric Association 2000). Although individuals with autism show considerable heterogeneity in the extent to which they manifest each of these symptoms, impairments in social interaction are a defining characteristic of the disorder.

There is a considerable knowledge base about the manifestation of the social deficits of autism during childhood (Bauman 1999). However, very little is known about this dimension of

the phenotype of the disorder in adulthood. The available evidence suggests that the social deficit remains significant in adulthood, with approximately half of the population having severe deficits in this domain. For example, in an early large-scale study of adults with autism, Janicki and Jacobson (1983) reported that 52% had inappropriate affect or social non-responsiveness.

The long-range follow-up studies of Rutter, Howlin, and colleagues provide insights into the friendships and social deficit symptoms among adults with autism. For example, Howlin et al. (2004), in their study of adults between the ages of 21 and 48 (mean = 29), reported that about one quarter (26%) had a relationship with at least one other person in their age group that involved participation in a range of interests or activities. However, more than half (56%) had no friendships or even acquaintances. These findings confirm earlier studies by this group (e.g., Howlin et al. 2000).

In Rutter et al.'s (1967) 10-year follow-up, social adjustment was rated from information gleaned from both clinical observations of the participants and informant reports. Several aspects of social behavior were rated and found to have improved by adolescence. One area of noteworthy improvement was in the tendency to physically withdraw from the social initiations of others, which characterized about one-third of the autism sample during childhood, but only about 8% during adolescence. Nevertheless, problems in the social domain continued to plague virtually all of the children. Rutter et al. found that only 9% of the children with autism were rated as having good social adjustment in adolescence, whereas 30% were rated as having very poor adjustment in this stage of life. In contrast, 20% and 15% of samples of age-, gender-, and IQ-matched control children were rated as having good and very poor social adjustment, respectively. Moreover, clinical descriptions of the children who had improved by adolescence still suggested lingering, and significant, social limitations (e.g., little "social know how").

In the Seltzer et al. (2003b) study, a similar pattern was evident. Whereas 100% of their sample of adolescents and adults with autism spectrum disorders met the ADI-R criterion for autistic disorder in the reciprocal social interaction domain in early childhood, this percentage dropped to about 85% based on current ratings in adolescence and adulthood. Thus, although symptoms abated in the social reciprocity domain, the degree of improvement was less prominent than in the communication domain. In a related analysis of data from the same study, Orsmond, Krauss, and Seltzer (2004a) reported that fewer than one-tenth (8.1%) of the sample had peer relationships that qualified as friendships (defined as a relationship with a same aged peer with whom varied, mutually responsive, and reciprocal activities were engaged in outside of organized settings), and almost half (46.4%) had no peer relationships whatsoever.

Other studies have also concluded that improvements in social functioning, while clinically important, are modest in nature. In a prospective longitudinal study, Mesibov, Schopler, Schaffer, and Michal (1989) used ratings on the Childhood Autism Rating Scale (CARS) to describe the course of symptom change between childhood and adolescence for a clinic sample of 59 individuals with an autism diagnosis. Most children improved with age on several of the dimensions rated; however, the group did not show improvement on all dimensions. In fact, the least improvement occurred for those dimensions capturing the social limitations of the disorder. Mesibov et al., therefore, suggest that the social impairments may be the most intractable core symptoms associated with autism.

In a retrospective longitudinal study, Piven, Harper, Palmer, and Arndt (1996) used the ADI-3<sup>rd</sup> edition to collect parental reports of current status and previous status near age 5 years for 38 high-functioning male and female adolescents and young adults with autism (ages 13-30, mean = 17.6). The participants all had nonverbal IQs of at least 65, qualified for a diagnosis of

autistic disorder according to the ADI algorithm, and had developed phrase speech by age 5. For the group as a whole, as well as for males and females considered separately, there was significant improvement with age on the mean ADI composite social domain score. Indeed, more than 80% of the participants were reported to have improved in the social domain, although limitations in this domain remained for virtually all members of the sample.

Examining the social deficit of autism from a different perspective, Baron-Cohen and Wheelwright compared adolescents and adults with high functioning autism (HFA) or Asperger Syndrome (AS) with non-autistic controls and found that those with HFA or AS had significantly lower scores on the measure of friendship than the controls. They concluded that "...although many adults with AS/HFA do have friendships, compared with people in the normal population, their relationships are less close, less empathic, less supportive, and less important to the individual" (p. 513).

A comparative approach was used in several other studies to characterize the social deficit of autism in adolescence and adulthood. For example, Gilchrist et al. (2001) compared samples of individuals with HFA (n = 13), AS (n = 20), and conduct disorder (n = 20), and reported that the mean scores of the HFA children were about 50% higher than the AS children on the ADOS measure of reciprocal social interaction. However, this result was not a statistically significant difference, and both autism groups were significantly more impaired than those with conduct disorders. Howlin et al. (2000) compared adults with autism with adults who had language disorders and found that the individuals with autism had significantly more impairments in greeting, social overtures, social responses, shared enjoyment, and rapport. Among those with autism, fully 53% had no or very limited social contacts, and 46% had no friends with whom they shared activities.

In summary, the social deficit of autism is a persistent component of the behavioral phenotype in adolescence and adulthood, with severe impairments affecting about half of the population. As many have noted (Mesibov et al. 1989; Orsmond et al. 2004a; Rutter 1970), it is not clear whether the lower rate of social relationships of adults with autism implies a lack of a desire or motivation for friendships, or rather a lack of skills needed to form and maintain desired social relationships. In fact, Wing and colleagues (Wing 1997; Wing and Gould 1979) have long argued for a three-group typology of autism based on the quality of social motivation (i.e., aloof, passive, active but odd), and they suggest that this categorical conceptualization would be useful for informing intervention. This is an issue for future research.

#### Restricted, Repetitive Behaviors and Interests

A third hallmark of autism is the manifestation of restricted, repetitive behaviors and interests. These can range from mild to severe and can involve behavioral (e.g., stereotypies), communicative (e.g., echolalia), and cognitive (e.g., obsessions, insistence on sameness) features. As in the other domains of the autism triad, improvements in restricted and repetitive behaviors from childhood to adolescence and beyond have been documented in nearly every published study to date, whether prospective (e.g., Mesibov et al. 1989) or retrospective (e.g., Seltzer et al. 2003b). Nevertheless, there is some evidence that the degree of improvement may be more limited in the domain of in restricted and repetitive behaviors than in the domains of communication and reciprocal social interaction. In Rutter et al.'s (1967) 10-year follow up of 63 children with autism, for example, although a lessening of restricted and repetitive behaviors was observed for many in the autism sample, virtually all of the cases continued to have problems in this domain. Moreover, clinical impressions suggested that the complexity of the remaining rituals and obsessions had actually increased from childhood to adolescence (e.g., involving

longer sequences of behaviors).

In the Howlin et al. (2004) follow-up study, 12% of the sample of adults were symptom free in the behavioral domain, but the remainder had mild (42%), moderate (35%), or severe (11%) behavioral symptoms. Similar levels of impairment were reported by Seltzer et al. (2003b), who found that fully 87.7% of their sample of adolescents and adults with ASD currently met the diagnostic criteria for autism in the domain of restricted, repetitive behaviors and interests, although this percentage was significantly lower than the 97% who met criteria at an earlier point in their lives. Additionally, comparisons between the adolescents and adults in the Seltzer et al. sample indicated that for two symptoms in particular, the adults were significantly less impaired than the adolescents: unusual preoccupations and complex mannerisms. Thus, as in the other domains comprising the core symptoms of autism, there is at least some evidence that symptom abatement is the dominant pattern.

In contrast, in Piven et al.'s (1996) retrospective study of high-functioning individuals with autism, it was found that, for the group as a whole, as well as for males and females considered separately, there was somewhat less improvement with age in the restricted and repetitive behaviors and interests domain than in the social and communicative domains. Indeed, more than 80% of the participants were reported to have improved in both social and communication domains compared to slightly more than half who showed improvement in restricted and repetitive behaviors and interests. Piven et al. suggested that repetitive behavior may be the core, or primary, symptom of autism, with social and communication problems being secondary.

Comparative studies provide additional insights into the severity of autism symptoms in adolescence and adulthood. Bodfish et al. (2000) compared 32 adolescents and adults with

autistic disorder (mean age = 33.1) with 34 adolescents and adults with mental retardation (mean age = 37.7) and found that those with autism were significantly more impaired in stereotypies, compulsions, and self-injurious behavior. The two groups did not differ in tics, dyskinesias, or in aggression. In another comparative study, Gilchrist et al. (2001) contrasted those with diagnoses of high functioning autism, Asperger syndrome, and conduct disorder. Although those with HFA and AS did not differ from each other in ADI-R or ADOS measures of restricted and repetitive behavior, both of these groups were more impaired in this domain than those with conduct disorders.

Jacobson and Ackerman (Jacobson and Ackerman 1990a) conducted a cross-sectional study of more than 20,000 individuals with mental retardation and 1,200 individuals with autism organized into child, adolescent, and adult cohorts. Data came from cases in the New York Developmental Disabilities Information System, which included reports of maladaptive behavior, including those reflective of autism (e.g., echolalia) as well as other domains of adaptive and maladaptive behavior. Interestingly, group differences favored the participants with autism during childhood, but during adolescence and adulthood the group with mental retardation scored higher. Although these results may reflect the confounding of age and diagnostic practices (Seltzer et al. 2003b), it is also possible that declines in maladaptive behavior and increases in new skill domains are more limited in those with autism than in other groups with mental retardation.

In summary, substantially fewer studies have examined the extent of impairment in the domain of restricted and repetitive behaviors than in the other two core deficits of autism. The limited available evidence suggests that a large majority of persons with autism remain impaired in this domain across the life course, although for some, symptoms may abate over time.

## Change in Diagnosis

As indicated in the foregoing sections, improvement is typically seen in terms of the acquisition of new skills and a decline in maladaptive behaviors. Nevertheless, studies have shown that few if any individuals who receive a diagnosis of autism in childhood recover fully and achieve levels of functioning typical of their age peers. For example, in their prospective longitudinal study, Mesibov et al. (1989) used ratings of the Childhood Autism Rating Scale (CARS) to decide on the appropriateness of the autism diagnosis in a clinical sample of 59 adolescents, who as children had received an autism diagnosis also using the CARS. More than 80% of the children who met criteria for autism before age 10 continued to do so after age 13, although the group as a whole showed improvement on most dimensions of behavior rated. Retrospective studies provide a similar picture. In an analysis of ADI-R data from 76 adolescents and adults with autism, Boelte and Poustka (2000) found that 82% of the individuals who qualified for a diagnosis of autistic disorder based on the retrospective reports of caregivers still qualified based on responses about current functioning.

Individuals who outgrow the ASD diagnosis are largely those who are initially diagnosed as having AS or PDD-NOS (Seltzer et al. 2003b). Even among those with HFA, however, most continue to meet criteria for the diagnosis in adolescence and adulthood. In the Piven et al. (1996) retrospective study, for example, only 13% of their sample had improved sufficiently to no longer warrant the HFA diagnosis as adolescents despite the fact that all had IQs above 70. This finding is similar to that of the Rutter (1967) study in which 15% of the sample improved enough by adolescence so that the diagnosis of autism no longer seemed appropriate. Change in diagnostic status among more severely affected individuals may be less likely. In an Israeli study of 28 institutionalized adults with autism, with a mean age of hospitalization of 13 years,



all participants continued to qualify for a diagnosis of autism with no significant signs of abatement from childhood to adulthood (Stein et al. 2001).

In summary, only a small percentage of individuals show improvement during the adolescent and adult years that is of sufficient magnitude to render the diagnosis of autism invalid. Those most likely to “outgrow” the diagnosis are those who as children manifested the least severe symptoms. Future research should investigate the sub-group who improve sufficiently to outgrow the diagnosis, as the pathways to normative functioning are unexplored. Indeed, it is astonishing that as many as between 10% and 20% outgrow the diagnosis, as autism is arguably among the most severe and pervasive of the developmental disorders. Nevertheless, given this severity and pervasiveness, its continuity across the life course is not a surprising finding.

### **III. Changes in Cognitive Abilities in Adolescence and Adulthood**

The co-occurrence of cognitive impairment in a significant proportion of people with autism is one of the most well-established psychological findings in the field. Fombonne (2003) summarized the findings of 20 epidemiological studies of autism that included cognitive assessment data. Across these studies, the median percentage of individuals with some degree of cognitive impairment was 70% (range 40%-100%). Furthermore, the studies reviewed by Fombonne (2003) indicated a strong gender by cognitive status interaction. In particular, although the overall male:female sex ratio among people with autism is about 4.3:1, the median ratio among those with autism and moderate to severe cognitive impairment is only 1.9:1, suggesting that females with autism are likely to be among the most cognitively impaired .

How does cognitive ability tend to change over time among people with autism? The

evidence suggests that the trajectory varies across different domains of cognitive functioning. In a study of 68 adults with autistic disorder ages 21-48 (mean = 29) who were initially evaluated at a mean age of 7 years, Howlin et al. (2004) found that mean performance IQ declined significantly from 80.2 to 75.0, whereas mean verbal IQ increased significantly from 61.5 to 69.6. Despite these changes, there was considerable stability in the participants' rank-ordering, as evidenced by correlations between childhood and adult scores of 0.54 for performance IQ and 0.67 for verbal IQ.

A similar story of declines in performance IQ and improvements in verbal IQ was reported by Mawhood et al. (2000) in a study involving 19 individuals with autism, 11 of whom had child and adult scores on the Raven's Matrices, 9 had repeated measures on the WISC and WAIS-R verbal score, and 18 had repeated measures on the WISC and WAIS-R performance score. In this study, mean verbal IQ scores improved significantly, while mean performance IQ and Raven's scores both declined (though the Raven's decline was not significant). In four cases, the verbal IQ increase was greater than 15 points, and was 50 points in one case. Conversely, performance IQ declined by 15 points or more for 8 individuals with autism. The findings from this study are especially interesting because they suggest that not only do many individuals experience gains in verbal cognitive abilities from childhood to adulthood, the gains can be quite dramatic in a subset of cases.

An earlier study paints a picture of stability in cognitive functioning in general over the life course. Lockyer and Rutter (1969) reported findings on a group of 63 adults with autism with a mean initial age of assessment of 5 years of age and a mean follow up age of 15 years. Half the sample was completely nonverbal at age 5. Mean scores on the Wechsler performance subscale were 79.2 initially and 73.7 at follow up (n = 24). Mean verbal IQ was 80.2 in

childhood and 76.4 at follow up ( $n = 18$ ), and mean full-scale IQ was 80.5 in childhood and 76.7 in adulthood ( $n = 17$ ). Although none of the mean differences across ages were statistically significant, they do suggest the possibility of decline rather than improvement in cognitive ability for some individuals with autism. In this study, there were significant correlations between childhood and adult scores, with all correlations above 0.50, suggesting stability in the rank-ordering of participants across time.

Given the larger sample in the Howlin et al. study (2004) and the corroboration found in Mawhood et al. (2000), the weight of the evidence indicates a tendency towards modest declines in performance IQ coupled with modest improvements in verbal IQ from childhood to adulthood. In some cases, the gains in verbal abilities can be quite striking. Interestingly, none of these studies performed analyses to examine potential associations between changes in cognitive ability and adult outcomes in autistic symptoms or social role attainment. As will be reviewed below, studies that examined predictors of adult outcome have sometimes examined level of childhood cognitive ability, but not changes in cognitive ability, as a predictor of later outcomes. This is a line of inquiry worth pursuing given that intensive early intervention can significantly improve IQ and overall functioning in this population (National Research Council 2001).

#### **IV. Patterns of Social Role Attainment in Adulthood**

In contrast with research that has elucidated changes or age-related differences in the core symptoms of autism in adolescence and adulthood, another body of research has examined the extent to which adults with autism have attained normative social roles in domains such as education, employment, friendships, and romantic and marital relationships. These studies complement studies of symptom change in describing the life course of autism. Long-term

follow-up studies of social outcomes in individuals with autism provide valuable insights in the life course trajectory of the disorder and help identify service needs and possible points of intervention. Follow-up studies over the past 30 years have demonstrated considerable heterogeneity in the social role attainment outcomes for persons with autism.

In one of the first follow-up studies, Kanner (1972) reported on 9 individuals with autism who were in their twenties and thirties and who had attained a high level of social role attainment. The majority lived with their parents or in residential settings, and were highly dependent on their caregivers. Rutter and his colleagues followed a group of 63 individuals 16 years and older who were originally diagnosed in the 1950s and early 1960s (Lockyer and Rutter 1969; Rutter et al. 1967; Rutter and Lockyer 1967). Only 2 individuals had jobs and the great majority lived with their parents or in a hospital or residential community. However, 14% of the adults with autism were identified as having made a good social adjustment, which was defined as having a normal or a near-normal social life and functioning satisfactorily at school or work. Another 25% were rated as fair, and 61% as having made a poor social adjustment.

Kobayashi and colleagues (1992) conducted a follow-up study of 201 people, aged 18 to 33 years in Japan. Only 5% were still attending school or college, and about a fifth was employed, mostly in service industries. Only two adults lived independently in their own apartment and no one was married. In the rating of each subject's overall outcome based on their adaptive skills, Kobayashi et al. judged that 27% had a good or very good outcome, 27% fair, and 46% poor. Ballaban-Gil, Rapin, Tuchman, and Shinnar (1996), in a telephone survey, found that of the 45 adults with autism they followed, only 11% were in regular employment, and all of these were in low-level and poorly paid positions, with another 16% working in a sheltered setting.

In another large follow-up study, Kobayashi and Murata (1998) surveyed 187 young adults (18 years and older) with autism. The mean age of the sample was 21.5, 75% of the participants had mental retardation, and approximately half had no communicative speech. The participants were initially recruited in early childhood and selected because they had a therapeutic relationship with the investigators. Parents completed the Child Behavior Checklist and two measures of language development and adaptive functioning (Present Language Development Level and the Present Adaptive Level). The investigators found that the majority of adults with autism were functioning poorly, which was defined as behaving oddly, being unemployed or not in school, and having great difficulty adapting socially. However, 25% of the sample showed good adaptation, which was indicated by being employed and being relatively independent in daily activities. Another quarter were able to carry out daily activities but unable to work.

Given the known group differences in the early years between AS and autism, Howlin investigated whether these differences narrowed or became more pronounced in adulthood. Howlin compared 42 adults (age 18+) with AS syndrome to 34 HFA adults, matched on age and IQ. Individuals in both groups met all cutoffs for a diagnosis of autism using the ADI-R and had nonverbal IQ scores above 70. Those with no parent-reported language delays in early childhood were designated as having AS. Although the pattern across different domains of attainment favored those with AS, the differences were for the most part small and not statistically significant. There were no significant group differences in the likelihood of living independently, in ratings of current friendships, or in employment levels, although the proportion of adults with AS working (in sheltered or competitive jobs) was significantly higher than in the HFA group (38% versus 52%). The majority of adults in both groups lived with their parents

(55.9% and 61.9% for HFA and AS, respectively), and those living apart from their families required considerable support from family members or social services. It was only with respect to education that adults with AS surpassed those with HFA. A significantly greater number of individuals in the AS group were admitted to college compared to those in the HFA group (52% vs. 24% respectively). However, given the low rates of employment and low status of their occupational positions, this educational advantage did not result in higher levels of achievement.

In an effort to shed light on the degree to which poor outcomes in adulthood are due to language and communication impairments, Howlin, Mawhood, and Rutter (2000), followed-up 19 adults with autism (mean age 24.9 years) and 20 adults with developmental language disorders (mean age 23.8 years) who had originally been studied in early childhood by Bartak et al. (1975). On almost all of the outcome measures, the adults with autism fared less well, although the differences on several outcomes were small. Only 15.8% of the adults with autism had close friends compared to 26.3% of those with language disorders. None of the adults with autism had ever married compared to four in the language disorder group. Individuals with autism were less likely to be living with their parents (31.6%) than adults with a language disorder (65%), and more likely to be living in residential settings (47.4% vs. 5% respectively). At follow-up, 60% of the adults with language disorders were working compared to 5% of adults with autism. Based on parental reports, 72% of the adults with autism had little independence in basic daily living skills compared to 10% of those with language disorders.

In summary, the available evidence from long-term follow-up studies indicates that there is considerable heterogeneity in social role attainment outcomes for persons with autism. Few adults with autism live independently, marry, go to college, work in competitive jobs, or develop large network of friends. The majority remain dependent on their families or professional service

providers for assistance with tasks of daily living. Even among those who work, jobs are often poorly paid and do not provide a living wage. Furthermore, adults with autism tend to have poorer outcomes than others with disabilities. However, there is a subgroup of between 15% and 25% of adults with autism who show more favorable outcomes. They live independently, work in competitive jobs, and may have a network of social relationships. Factors that differentiate these two profiles of outcomes in adulthood are explored in the next section and warrant investigation in future lifespan research.

## **V. Childhood Predictors of Outcomes in Adolescence and Adulthood**

There have been only a small number of attempts to identify the early predictors of outcomes in adolescence and adulthood, and in the available studies, the emphasis has been primarily on characteristics of the individual (e.g., IQ, language ability). Very few studies have examined whether contextual variables (e.g., parental socioemotional functioning, place of residence, and educational or intervention history) predict later outcomes. In some studies, the outcome variables have included symptoms used to diagnose autism (e.g., stereotypies), while in other studies the outcome variables have reflected more distal social role attainment indicators (e.g., whether the individual has had romantic relationships or lives and works independently). In the majority of studies, however, the outcomes are broadly defined and are amalgams of the core symptoms of autism as well as behaviors and achievements or impairments that are likely to be secondary consequences of the core symptoms.

There is considerable consistency across studies regarding predictors of outcomes in adolescence and adulthood. IQ is perhaps the strongest predictor of outcome. In Rutter et al.'s (1967) longitudinal follow up, children who could not complete intelligence testing had very

poor outcomes as adolescents; for the remaining, testable, children, higher IQs were associated with more favorable outcomes, with IQs above 60 leading to the best outcomes (i.e., relatively independent functioning and near-normal social relationships). In another prospective longitudinal study, Gillberg and Steffenburg (1987) found that IQ was an especially strong predictor, with better adaptive outcomes being more likely for individuals with IQs above 50 before the age of 5 or 6 years. Howlin, Goode, Hutton, and Rutter (2004) found that individuals with autism who had a childhood performance IQ of at least 70 had significantly better outcomes (i.e., more friends, more years of education, higher rates of employment, and more likely to live independently) than adults in the lower (50-69) IQ range. And finally, in a study comparing adolescents and young adults with autism to their age peers with Down syndrome, Loveland and Kelley (1988) reported that higher levels of nonverbal and verbal IQ were related to higher levels of adaptive functioning as measured by the Vineland Adaptive Behavior Scale.

Despite the prediction of adolescent and adult outcomes afforded by child IQ, it is important to recognize that it explains only a small portion of the variance in outcome. In a small scale study of 12 males and five females who were 17 years and older and had a mean IQ of greater than 90, Szatmari, Bartolucci, Bremner, Bond, and Rich (1989) reported that although half of the sample was functioning independently and approximately half attended college or a university, over half never formed close relationships, and only a third had full-time employment. Thus, even for adults with normal-range IQs, there is considerable variability in outcomes. Moreover, Howlin et al. (2000) found that performance IQ in childhood accounted for only 3% of the variance in a composite rating of outcome (reflecting achievements in language, friendship, independence, and stereotypes) in adulthood for their sample of 19 high-functioning men.



Early language status has also been found to be a predictor of outcomes in adolescence and adulthood (Lord and Bailey 2002; Nordin and Gillberg 1998; Szatmari 2000). Kanner (1971) found that adults with autism who had better early language skills were more successful than those who had more compromised communication skills. Gillberg and Steffenburg (1987) found that the presence of social language at age 5 or 6 years contributed to better outcomes in adolescence and adulthood. In the Rutter et al. (1967) study, failure to be responsive to, or to produce, speech before age 5 or 6 years all but precluded good outcomes (i.e., relatively independent functioning and near-normal social relationships) in adolescence. And finally, Howlin et al. (2000) found that childhood scores on the Peabody Picture Vocabulary Test, a test of receptive vocabulary, accounted for fully 32% of the variance in a composite rating of outcome in adulthood for their sample of 19 men with autism.

Several other predictor variables have led to inconsistent results, with evidence of an association with outcome in some studies but not others. These include child gender, with some studies showing better outcomes for boys (Gillberg and Steffenburg 1987) and others better outcomes for girls (Piven et al. 1996), and other showing no difference (Rutter et al. 1967); place of residence or years of schooling, which have been found to be unrelated to outcomes in some studies (Seltzer et al. 2003b) but a predictor of outcome in other studies (Rutter et al. 1967); and the presence of affective disorders or other mental health problems in other family members, which is related to child outcomes in some studies (Gillberg and Steffenburg 1987), but not in others (Rutter et al. 1967). There is clearly more work to be done to identify predictors of symptom change and outcome. Even more critical, however, will be identification of the mechanisms by which more or less favorable outcomes result among individuals with autism.

As noted earlier, the existing studies investigating the predictors of adult outcomes have

focused rather narrowly on factors internal to the individual such as IQ score and language, and paid little attention to the influence of environmental factors that may encourage or impede individual efforts to work, live independently, and pursue friendships. In their follow-up study of 9 successful adults with autism, Kanner, Rodriquez, and Ashenden (1972) spoke to the importance of formal and informal support for adults with autism who seek independence. Although anecdotal and clinical experience points to the importance of the family and services as supports to adults with autism, researchers have yet to investigate the role of such external resources to the functioning of adults with autism. Yet, there is a growing body of research suggesting that informal support from family and friends is related to better outcomes for adults with psychiatric disabilities (Collings et al. 2000). It is quite possible that adequate functioning in adulthood for individuals with autism may depend as much on the degree of support offered by families, friends, and service providers as on basic intelligence and language skills. More research on the contributions of informal and formal supports to outcomes for persons with autism is critical if we are to develop new and effective interventions and services targeted to the unique needs of this population in adolescence and adulthood.

## **VI. Comorbid Medical Conditions in Adolescence and Adulthood**

Very little research has been conducted to examine the age-specific occurrence or manifestation of health problems for individuals with autism. Yet autism is known clinically to be a disorder with high rates of psychiatric and physical health comorbidity, and medication usage. First-person accounts by high functioning adults with autism have indicated that comorbid psychiatric conditions like anxiety, rather than core diagnostic features like stereotyped interests, can be perceived by individuals with autism as the most disabling feature of their

disorder. Discovering which conditions are unique to autism versus being common with other developmental disorders, finding the risk factors for particular comorbid conditions, documenting the interactions between comorbid conditions and developmental trajectories within people with autism, and understanding the related costs to families and society are all essential elements needed to improve intervention and care for this population.

### Psychiatric and Behavioral Comorbidity

The comorbidity of a variety of psychiatric symptoms in people with autism has been widely noted but seldom documented with much precision (Howlin 2002). Whether the co-occurrence of psychiatric symptoms is tantamount to dual diagnosis is also not well established. Many of the core symptoms of autism, such as difficulty with compulsions, attention, affect, and emotional self-regulation, overlap with other mental health disorders, thereby making clear differential diagnosis difficult in some cases (Volkmar et al. 1999). Also under-explored is variation across the lifespan in the prevalence and qualitative manifestation of psychiatric symptoms (Howlin 2002).

Affective disorders are the most commonly reported co-occurring psychiatric diagnoses in this population. Prevalence estimates of affective disorder diagnoses have ranged as high as 64%, with depression being the most common and occurring in as many as 28% of cases (Ghaziuddin et al. 2002; Howlin 2002). Clinical reports indicate the likelihood of depression may increase with age, peaking in adolescence and young adulthood (Ghaziuddin et al. 2002).

Retrospective studies have sometimes been used to suggest that adults with autism are at higher risk for developing schizophrenia (e.g., Petty et al. 1984). However, both prospective studies and those based on a current standardized psychiatric assessment indicate that the incidence of schizophrenia in people with autism is low. For example, Howlin et al. (2000)

conducted a follow-up study of 19 adults with autism and 20 adults with a receptive language disorder, who were first assessed at the ages of 7-8 years. Whereas two of the 20 individuals in the language group developed a florid paranoid psychosis in late adolescence, there were no such cases in the autism group. In a follow-up of 16 high-functioning children with autism, only one developed schizophrenia (Szatmari et al. 1989). However, 6 (37.5%) reported symptoms of schizotypal symptoms such as magical thinking, paranoid ideation, and auditory or visual hallucinations. Rumsey, Rappoport, and Sceery (1985) recruited 14 men, with a mean age of 28 years. They conducted psychiatric interviews with the parent and the adult with autism, neither of which revealed the presence of any current psychotic disorder in the adult (e.g., the occurrence of hallucinations, delusions or mania).

Adults with autism have more behavior problems than their counterparts with other developmental disabilities, such as Down syndrome. Seltzer, Krauss, and Shattuck (2002) compared 154 adults with autism to 149 adults with Down syndrome, and found that the adults with autism exhibited significantly higher levels of internalizing, externalizing, and asocial behaviors. The mean number of behavior problems was 4.3 for the adults with autism as compared to 1.4 for those with Down syndrome – nearly a fourfold difference.

These findings suggest that adults with autism tend not to develop schizophrenia or other psychotic disorders, but rather have elevated rates of less severe mental health symptoms that may significantly interfere with their capacity for independently functioning and positive outcomes.

#### Physical Health Comorbidity and Mortality

A variety of physical health problems have been documented in the epidemiological and clinical literature (Fombonne 2003). With respect to associated medical conditions that are

particularly salient in adolescence and adulthood, the occurrence of epilepsy in autism is one of the most well-established findings. The incidence of seizures in autism exhibits a bimodal distribution, with peak periods of onset in early childhood and adolescence (Tuchman and Rapin 2002; Volkmar et al. 1999). In a review of eleven epidemiological studies, Fombonne (2003) found a median prevalence of seizure disorders of 16.8% with a range from 0-26.4%. A broader review that included clinical reports found a range of prevalence from 5% to 38.3% (Tuchman and Rapin 2002). More severe mental retardation is associated with an elevated likelihood of seizures in autism (Tuchman and Rapin 2002; Volkmar et al. 1999).

Health status has an influence on the services needed by adults with autism. Those with poorer health tend to be less likely to live with their parents than those in better health. In one report on 154 adults with autism (mean age = 31.5, range 22-53), 38% were living with parents and 62% were living elsewhere (Seltzer et al. 2002). On a global health rating measure, parent-reported health status was significantly better for the individuals residing with parents (Seltzer et al. 2002).

Mortality risk in people with autism has been found to be at its height in childhood and lower in young and middle adulthood. Shavelle, Strauss and Pickett (2001) reported findings from analyses of 13,111 ambulatory individuals with autism who had been enrolled in California's developmental disabilities service system at any time from 1983 to 1997. There were 202 deaths among these individuals with autism during that time period. Standardized mortality ratios (SMR, the ratio of observed to expected deaths) were computed for four age groups, for different causes of death, and by sex, using the general California population as the baseline for computing expected deaths. Among those with autism, the highest SMR across all causes of death was among the 5- to 10-year-olds (SMR = 5.4) and the lowest SMR was among

those 20-years old and above (SMR = 2.1). When broken out by level of mental retardation, those 20 and older still had the lowest SMR across all causes of death as compared to other age groups. The major exception to this pattern of lower mortality for adults versus children was for deaths due to seizures. There were no deaths due to seizures in this sample among those under 20-years old. However, the SMR for seizure-related deaths among those 20 and older ranged from 33.1 to 38.0, depending on level of intellectual disability. Relative to children, adolescents and adults with severe intellectual disability also had high SMRs for deaths related to suffocation and respiratory- or digestion-related causes.

### Medication Usage

The likelihood among people with autism of using psychoactive medications increases with age. In a study of 417 individuals with autism, a significantly higher percentage of adolescents and young adults than children were using antipsychotics, antidepressants, and mood stabilizers. Approximately one-third were taking antipsychotics, one-third were taking antidepressants, and about 13% were taking mood stabilizers (Aman et al. 2003). These data confirm patterns reported earlier by these investigators (Aman et al. 1995).

A similar pattern was reported in a study of 154 adults with autism, of whom 75.3% took at least one prescription medications (Seltzer et al. 2002). Thirty-eight percent of the sample members were taking anti-convulsants, 35% were taking anti-depressants, 25% were taking anti-psychotics, and 18% were taking anti-anxiety medications. Among those who took prescription medication, the mean number of medications taken was 2.75, and those who lived away from the parental home took significantly more medications than those who lived with their parents.

Few studies have considered medication history as a predictor of behavioral change, which is unfortunate because many individuals with autism are on a rather dynamic (and often

idiosyncratic) medication regimen from childhood throughout their lives. Whether and how medication history contributes to the developmental course of symptoms is therefore not clear.

In summary, adults with autism are clearly at risk for elevated levels of polypharmacy, multiple health problems, and serious behavioral problems. Many of these health challenges are unique to autism when compared to adults with other developmental disorders. Adults living in non-family settings are especially likely to have poor health. Investigation of the risk factors associated with varying rates of comorbid psychiatric, behavioral, and physical health problems among adolescents and adults with autism is a high priority for research at the present time. The interaction between various comorbid conditions and the trajectory of autism symptoms and social role attainment in adulthood is also poorly understood. The costs to families and society associated with providing intervention and support across the lifespan, and how costs vary in relation to the presence of comorbid conditions, are unknown. This is another area of inquiry that deserves increased attention.

## **VII. Families of Adolescents and Adults with Autism**

Questions about the interactions between family context and the developmental trajectory of autism are relatively understudied, especially during adolescence and adulthood. How do families adapt to having a child with autism, and how do these adaptations and their consequences shift as the person with autism ages? How does the family context, and changes in family context, impact the development and life outcomes of the person with autism in adolescence and adulthood? The available data come from extrapolating the results of studies of family caregiving for children with autism, a handful of studies related to caregiving for adults with autism, some comparative studies that contrast the experiences of families across different

diagnostic groups, and an emerging understanding of the broader autism phenotype. For a review paper, see (Seltzer et al. 2001).

Mothers and fathers of children with autism have consistently been found to exhibit higher levels of stress, more mental health symptoms, and more marital discord as compared with parents of children with Down syndrome, fragile X syndrome, cystic fibrosis, behavior disorders, mental retardation of unknown etiology, and typically developing children (Bouma and Schweitzer 1990; Donovan 1988; Dumas et al. 1991; Fisman et al. 1989; Holroyd and McArthur 1976; Kasari and Sigman 1997; Rodrigue et al. 1990; Rodrigue et al. 1992; Wolf et al. 1989). For instance, a comparative study of parents of children with Down syndrome, children with autism, and typically developing children found that mothers and fathers of the children with autism had significantly higher scores on a measure of stress and significantly lower scores on a measure of marital intimacy as compared to the other two groups (Fisman et al. 1989; Wolf et al. 1989). Furthermore, the mothers in the autism group also displayed significantly higher levels of depressive symptoms. These findings were similar to those of Dumas et al. (1991) in a study comparing 150 families who either had a child with autism, Down syndrome, behavior disorder, or who was typically developing. Again, mothers and fathers of children with autism scored significantly higher on measures of parenting stress as compared to the parents of children with Down syndrome and the parents of typically developing children. And the mothers (but not fathers) of the children with autism or behavior disorders also had significantly higher relative levels of depressive symptoms.

In contrast to the abundance of studies focused on childhood, very little research has focused attention directly on how families of individuals with autism cope with their child's teen and adult years. Chief concerns of families during adolescence include challenging behaviors,



social and communication skills, restrictions in family activities due to caregiving demands, management of school and related services, and worries about the future independence of their son or daughter with autism (Fong et al. 1993). There is some evidence indicating that psychological distress increases during adolescence among parents of children with autism (Bristol and Schopler 1983; Harris 1984; Koegel et al. 1992; Marcus 1984). Mirroring the findings from studies of childhood, there are comparatively higher levels of stress among parents of adolescents and adults with autism. For instance, mothers of adolescents with autism scored significantly higher on multiple measures of parenting stress as compared to mothers of adolescents with mental retardation (Donovan 1988). Abbeduto, Seltzer and colleagues (Abbeduto et al. 2004) compared the mental health of mothers of adolescents and adults with either fragile X syndrome (n = 22), Down syndrome (n = 39), or autism (n = 174). They found that mothers of adults with autism had significantly higher levels of pessimism and depressive symptoms compared to the Down syndrome group. These mothers also had significantly lower scores than mothers in the Down syndrome group on a rating of perceived closeness, and scored lower than mothers in both groups on a rating of perceived reciprocated closeness.

Parenting any adult with a disability can be more stressful than parenting a typically functioning adult (Seltzer et al. 2003a). What accounts for the extra level of strain that appears to accompany parenting an adult with autism? Several studies have pointed towards the extensive accommodations families make in the course of establishing caregiving routines, the high levels of challenging behaviors, the difficulty maintaining positive family interactions, and the social isolation that can accompany caring for an adolescent or adult with autism (Harris 1984; Harris and Powers 1983; Norton and Drew 1994). In a study of caregiving tasks, parents of adults with autism were significantly more likely than parents of adults with Down syndrome

to report being stressed by challenging behaviors and perceiving that caregiving demands were increasing with age (Holmes and Carr 1991). The negative influence of challenging behaviors on parent mental health was also confirmed in the analyses of Abbeduto, Seltzer and colleagues (Abbeduto et al. 2004). In a comparison of mental health among mothers of adolescents and adults with either Down syndrome, fragile X syndrome, or autism, they found that behavioral symptoms of autism and related maladaptive behaviors were consistently the most powerful predictor of maternal outcomes including depressive symptoms, pessimism, and the perceived quality of the mother-child relationship, and that the individuals with autism displayed significantly more such symptoms than did participants in either of the comparison groups.

Characteristics of the son or daughter with autism are not the only factors that predict parental mental health. Greenberg, Seltzer and colleagues (2004) conducted comparative analyses of mothers of adults with either schizophrenia ( $n = 292$ ), autism ( $n = 102$ ), or Down syndrome ( $n = 126$ ) to examine the effects of maternal optimism and the quality of the mother-child relationship on maternal psychological well-being. They found that a positive appraisal of relationship quality was significantly associated with lower levels of depressive symptoms and higher levels of psychological well-being among the mothers of adults with schizophrenia and autism. However, these effects were partly or completely mediated by maternal optimism, particularly among mothers of adults with autism. That is, mothers whose relationship with their adult with autism was close were more optimistic about their adult child's future, and in turn this level of optimism was associated with less maternal depression and better psychological well-being.

In a related line of inquiry, Orsmond, Seltzer, and Krauss (Orsmond et al. 2004b) asked a prior question by examining the factors that were associated with quality of the mother-child

relationship in 202 families who had an adolescent or adult with autism living at home. In multiple regression models controlling for age, sex, and a variety of child and maternal characteristics, they found that behavior problems of the individual with autism and maternal pessimism were strongly associated with poorer quality of the mother-child relationship, while higher levels of maternal self-esteem were positively related to better relationships between the mother and the adolescent or adult with autism. Thus, the psychological resources mothers bring to the tasks of caregiving, especially self-esteem, optimism, and pessimism, can substantially influence maternal mental health.

In sum, parents of adolescents and adults with autism appear to experience elevated levels of stress and caregiving demands when compared to parents of adolescents and adults with a variety of other developmental disorders. This is likely due, in part, to the unique impairments and behavioral challenges associated with autism. It may also be due partly to factors related to the broader autism phenotype affecting family members (Bailey et al. 1998; Piven et al. 1997; Piven et al. 1994). Parents of individuals with autism may be faced with the dual challenge of caring for their affected child while also coping with elevated levels of developmental and psychiatric difficulty in themselves or other family members. The bi-directionality of effects should be investigated in future research in order to assess the reciprocal influence of family context and well-being on one hand and the trajectory of symptoms and social role attainment for the person with autism on the other.

## **VII. Research Design Considerations**

Studies examining the development of the phenotype of autism during the adolescent and adult years have involved three types of designs, with each type characterized by both strengths and limitations (Church and Coplan 1995; Gillberg and Steffenburg 1987; Kanner 1971;

Mesibov et al. 1989; Rutter et al. 1967). First, there have been a number of prospective longitudinal studies. These studies have the advantage of charting, often in great detail, changes within individuals, thereby avoiding the confounding of cohort and diagnostic practices that plague cross-sectional studies. The labor-intensive nature of most prospective longitudinal studies, however, typically leads to reliance on small, clinic-based samples, which thereby reduces statistical power to detect behavioral change and limits the generalizability of results.

Second, some studies have employed a retrospective longitudinal design (Piven et al. 1996; Seltzer et al. 2003b). In these studies, informants (typically parents) provide accounts of both the developmental history of the individual with autism and his or her current level of functioning. Such studies are less labor-intensive than prospective studies and thus can involve larger, community based samples. They also have the advantage of analyzing both past and current functioning through the same diagnostic perspective, thereby avoiding the confounding of age and diagnostic practices inherent in cross-sectional designs. Retrospective studies also take advantage of the wealth of knowledge that parents and other informants can have about the individual with autism. Of course, concerns about the accuracy of retrospective accounts of even the most knowledgeable informant cannot be completely discounted in such designs.

Third, there have been several large-scale cross-sectional studies in which comparisons along behavioral dimensions have been made between children and adolescents or adults with autism (Jacobson and Ackerman 1990b; Seltzer et al. 2003b). As in all cross-sectional studies, the confounding of age and cohort is a threat to internal validity. In studies of autism across the life course, cohort differences are of special concern given the dynamic nature of diagnostic practices.

Whatever the design, studies in this area have conceptualized developmental change

largely in quantitative terms, tracking changes in the severity of the individual's symptoms or the degree to which the individual has approached a "normal" level of functioning. Such an approach is limited by the fact that judgments about severity or normalcy, whether made by a parent or clinician, are influenced not only by the behavior of the individual with autism but by the context in which he or she lives (Nordin and Gillberg 1998). So, for example, a child who hits when frustrated might be seen as problematic, but an adult engaging in precisely the same behavior might be seen as dangerous by virtue of his or her increased size and physical strength. In this case, the behavior may be seen to have become more severe not because the behavior has changed but because it is less tolerable in context. As another example, parents may be especially concerned about their child's lack of spoken language, judging it to be highly problematic because it limits performance in school; however, this same lack of spoken language may be judged by parents to be less problematic in adulthood because they have grown accustomed to it and their son or daughter no longer participates in school or other contexts in which the limitations imposed by a lack of language are so apparent.

The quantitative approach is also limited from a clinical perspective in that it supplies relatively little information about the nature of the individual's behavioral repertoire that exists at any point in development. That is, knowing that the symptoms of autism have abated provides no detail about the skills that need to be taught or the problem behaviors that remain and thus, need to be minimized. An alternative approach would be to trace in detail the ways in which the particular behaviors that define autism early on are transformed or reorganized over the course of development. Such an approach would require dense (relative to the life course) observations of specific behaviors or behavioral sequences rather than a focus on broad domains such as "communication" or "repetitive and ritualized behavior" and changes in those domains over

broad swaths of the life course.

Finally, studies to date have been limited in that they have typically involved only two or at most three time points of observation. In some of the longitudinal studies reviewed in this review, for example, assessments have been made only at two time points separated by no less than seven years on average (Mesibov et al. 1989) and typically more than 10 years. This makes it impossible to characterize the shape of the developmental function, the timing of changes, or the possibility that there are different subtypes of individuals with autism characterized by different trajectories to the same outcome. Such data are especially important as there have been conflicting claims in the literature, typically based on clinical impression, that symptoms improve or decline over time (Rutter et al. 1967), have a periodicity (i.e., a waxing or waning, Gillberg and Steffenburg 1987) or that there is an aggravation of symptoms at the onset of adolescence, which is then followed by a “smoother” trajectory of change in adulthood (Gillberg and Steffenburg 1987).

It is generally agreed that autism arises through multiple routes. In some cases, autism is associated with identifiable genetic syndromes, such as tuberous sclerosis or fragile X syndrome. In many, but not all, studies, individuals with identifiable genetic causes are excluded. This variability in exclusionary criteria makes comparisons across studies difficult. Moreover, even in studies that exclude fragile X syndrome and other genetic syndromes, the procedures for exclusion are typically based solely on informant report or review of existing clinical records, which do not guarantee that the medical tests needed to unambiguously ascertain the exclusionary condition have even been conducted. Consequently, some individuals who should be excluded are not. This becomes particularly problematic if there are differences in the expression of the symptoms of autism in conditions with identifiable genetic causes.

There is no dearth of methodological challenges facing future researchers aiming to characterize the life course of autism. Studies with large well-characterized samples, using prospective as well as retrospective assessments, offering quantitative profiles and qualitative descriptions of symptoms, and that parse the sub-groups of the heterogeneous population with autism diagnoses are called for, although the difficulties in achieving such methodological rigor and sophistication remain daunting.

### **VIII. Conclusions**

In conclusion, although there has been only a small amount of research, fraught by many methodological limitations, describing the life course manifestation of autism, some consistent findings have emerged. It appears that modest improvement in symptoms is evident, at least in some individuals, from childhood to adolescence and into adulthood. However, this improvement seldom leads to levels of functioning in the normal range, which reinforces the notion that autism is a lifelong condition. Moreover, improvement is not seen for all behaviors and not all individuals improve. Some individuals even decline, especially if they are very low functioning, have very severe symptoms, or develop seizures (Nordin and Gillberg 1998). Indeed, it is noteworthy that few longitudinal studies have compared the course of development in individuals with autism to those with other psychiatric or cognitive disabilities (see Rutter et al. 1967, for example), which leads to the question of whether the level and rate of improvement observed for autism is characteristic of other disorders as well.

Future research is needed to learn more about the 10-15% who seem to recover and become symptom free. This is a very important group to study to identify both individual predictors of improvement and also to determine if certain types of family, school, or therapeutic

environments or interventions have a salutary effect on children with autism.

Given the current more widespread access to more effective early intervention, special education, and intensive treatments and services, it is unlikely we will ever again be able to study the “natural course” of autism. Indeed, some of the sample members in the studies reviewed in this paper received the best practice interventions of their time, and thus the patterns of symptom change and social role outcomes are not truly reflections of the natural course of the disorder. Nevertheless, the trajectories of the social and behavioral phenotype of autism in adolescence adulthood that have been described in existing research provide a benchmark or a threshold for future investigations in which more intensive interventions may alter the rate, shape, and timing of the developmental course of autism. With the goal of determining which interventions and supports are the most promising in producing symptom abatement and favorable adult outcomes, we need to develop better measures of the types and intensity of interventions and services received to use in future longitudinal studies of the life course manifestation of autism.

Finally, no study in the published literature to date has focused on individuals with autism in late midlife or old age. Other developmental disorders show atypical patterns of change in cognitive, functional, and health status during the later years of the life course, and therefore there is a need for dedicated research on aging in individuals with autism. The apparent increase in the prevalence of autism noted in recent research (Charman 2002) will result in a very substantial increase in the need for specialized services throughout the life course. Plans for such services should be informed by an understanding of the changing social and behavioral phenotype and health status of this population at different life stages, from childhood through old age.



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