When children with autism become adults

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Autism and related conditions have been described since the 1940s, but official recognition did not come until 1980, with the publication of the DSM-III. Early confusion centered on the validity of the condition, that is, whether it could be considered distinct from childhood schizophrenia. This confusion was clarified with work on clinical phenomenology and genetics of the two conditions. Specifically, differences in clinical features were identified, with autism being marked by profound social difficulties and very early onset relative to schizophrenia. It also became clear that autism was a strongly genetic disorder, distinct from schizophrenia.

Autism was associated, at least initially, with a rather poor outcome, with the earliest studies suggesting that about two-third of individuals, as adults, required institutional care (1,2). Early treatment approaches were centered on psychotherapy (often of parent and child), but gradually shifted as work indicated that structured behavioral and educational approaches were associated with better outcome, as was earlier diagnosis and intervention. It has become increasingly clear that greater public awareness, earlier intervention, and more effective management have had a major impact on the outcome of the condition (1).

OUTCOME IN AUTISM

There is some evidence that the core symptoms of autism abate to some degree in adolescence and young adulthood (3), with improvements in communication skills most common. Social impairments and repetitive behaviors tend to persist into adulthood. Further, not all individuals show improvements, and it is rare that individuals show gains to the extent that they no longer meet diagnostic criteria for autism spectrum disorders (ASD) (1-3).

With regard to neuropsychological functioning, intelligence quotient (IQ) is generally found to be stable over time. Adults with autism commonly have a range of challenges with regard to neuropsychological functions, including difficulties with social cognition, memory, executive functioning, and motor coordination, which can impact their ability to navigate the complexities of adult independence (4).

In terms of functional and daily living outcomes, early studies of individuals born in the 1970s and earlier consistently reported poor to very poor outcomes for the majority of subjects in adulthood (3,5,6). A minority of adults were found to live independently, with most remaining

dependent on families. Likewise, a minority was employed or had attended college. The percentage of adults with autism who were found to have favorable outcomes ranged from 15 to 44% across studies (3,5). Early communication skills and level of cognitive functioning were found to be the strongest predictors of outcome, with those individuals with an IQ above 70 having the greatest likelihood of living independently. Some have also suggested that outcome is contingent on the amount of perceived social support available to the individual (7).

More recent studies have suggested a less bleak picture. Farley et al (8) found that outcomes had improved over earlier estimates, with half of their sample reporting "good" to "very good" overall outcomes. Likewise, Eaves and Ho (9) found about half of their sample to have "fair" to "good" outcomes, with the other half rated "poor" (but none rated "very poor"). The authors attribute this improvement to progress in early detection and intervention in recent years. However, with 50% of individuals still achieving poor outcomes, it is clear that additional supports and interventions are needed to further improve quality of life for adults with autism.

Outcomes with regard to social functioning suggest that difficulties making and maintaining friendships persist into adulthood. Twenty-five percent or less of adults with ASD were found to have true friendships (6,10). Predictors of participation in social activities in adulthood include greater independence in activities of daily living, better socialization skills, and greater number of services received. Peer victimization may remain a concern for young adults with ASD as well (11). Although sexual functioning develops normally, the social aspects of navigating sexual relationships and understanding appropriate sexual behavior present a challenge for many young adults. Impairments in social cognition and the tendency for rigid behaviors or obsessional interests can also result in legal challenges (e.g., failure to defer to authority figures, inappropriate online behaviors, stalking). Explicit education for young adults around these issues is important to ensure they understand the impact of their actions. Educating first responders is also critical for ensuring that these behaviors are not misunderstood.

The recognition of autism and severe social vulnerabilities in more cognitively able individuals was reflected in the inclusion of Asperger's disorder in DSM-IV and ICD-10. Both for Asperger's disorder and higher functioning autism, more and more individuals are able to seek higher educational and vocational training, although social and learning supports are often significant needs. Countries

vary considerably in the degree to which a disability like autism is eligible for special accommodations.

ISSUES OF DIAGNOSIS AND COMORBIDITY

Very early approaches to diagnosis centered on autism in young children. Over time, the need for a more developmental and life-span approach was recognized, for example, in DSM-III-R and particularly in ICD-10 and DSM-IV. The recognition of the broader range of the autism phenotype and of higher intellectually functioning individuals with severe and impairing social difficulties (e.g., those with Asperger's disorder) has raised important diagnostic issues that remain the topic of considerable debate and are reflected in the currently proposed DSM-5 approach. It remains to be seen how the latter will impact diagnostic practice.

Having a chronic condition like autism may predispose to other difficulties (11). The currently available literature does suggest increased rates of several clinical problems in adulthood, including anxiety and depression (both of which may respond to different treatment modalities). The limited treatment literature available specific to this age group and indeed the overall lack of research in adolescents and adults with autism remain significant obstacles for our understanding the best approaches to intervention.

CONCLUSIONS

The outcome in autism appears to have markedly improved over the past several decades – presumably reflecting a number of factors including earlier intervention and improved treatments. At the same time, many adults, even while living independently, need some supports, and a lack of treatment research and available services limits our knowledge of this population.

Often significant gaps exist between cognitive abilities and the capacity to generalize these to “real world” settings – this gap between intellectual function and

adaptive skills can be quite significant and may be one of the factors that serve to predispose cases to other mental health problems. Many individuals are now attending college or vocational school, but can have persistent problems with social isolation and communication, which may also increase risk for anxiety and depression.

Research and service provision in this area remain extremely high priorities (11).

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