

Social Support, Well-being, and Quality of Life Among Individuals on the Autism Spectrum

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Diverse theoretical perspectives¹⁻³ and empirical findings^{4,5} reveal development as a complex interaction between nature and nurture, yet the diagnosis of autism spectrum disorder is used to classify neurodevelopmental disability mainly on the basis of individual-level social dysfunction. Self-advocates have organized the neurodiversity movement to reclaim autism as a part of identity (eg, using identity-first language such as “autistic person,” as in the case of the author, rather than person-first language such as “person with autism”^{6,7}) and support civil rights. We argue that social environments contribute substantially to disability and seek quality of life, defined in terms of “objective” factors of adaptive functioning, such as independent living and employment, as well as in terms of subjective well-being, which requires self-determination to play as active a role as possible in making decisions to have the experiences one wants. Yet we argue against normalization and “cure,” in part because many autistic traits can function in neutral or positive ways, although other people may misunderstand or stigmatize atypical behaviors.⁸⁻¹⁰ Indeed, the following narrative review developed from empirical evidence replicated by independent research teams argues against a linear relationship between autism symptoms and impaired functioning, across developmental periods and in multiple domains of both “objective” quality of life and in subjective well-being. In the following syntheses, I suggest that effective social support and subjective well-being mediate whether autistic people achieve a high quality of life.

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ADAPTIVE FUNCTIONING

Parental Support

Language Acquisition

Actively responsive rather than directive or less involved parenting helps to promote positive social engagement, especially in infants susceptible to autism.^{11–13} Responsive parenting (eg, parenting that follows children's focus of attention and labels objects of interest while allowing the child to take the lead) contributes to young autistic children's language development,^{14–17} particularly among those who need it most: those with lower levels of expression.^{18–21} Although the same principle applies in typical development,²² responsive caregiving and input may especially benefit language learning for autistic children,^{23,24} particularly for those who have more difficulty responding to others' attention.²⁵ Parents' strategies to synchronize their behavior in response to their autistic child's, such as matching his or her pace, may drive language gains from joint parent-child engagement^{26, 27} through encouraging the child to initiate interactions,²⁸ which may especially benefit the children who have the most difficulty producing their own goal-directed actions in reaction to others' movements.^{29, 30} This aligns well with the advice of autism rights movement founder Sinclair,³¹ in a foundational essay primarily for parents, to "let your child teach you a little of her language, guide you a little way into his world" as a means of helping the child adapt to the dominant culture and for the well-being of the family. Fortunately, "learning to speak their child's language" as a parenting strategy has had near-universal support, regardless of people's relationship to autism or support for the neurodiversity movement's beliefs.⁷

Autism Acceptance

There is evidence to support the benefits of parents' acceptance of

their children's autism across the spectrum. Parents' acceptance of their child's autism^{32–35} and positive emotions toward their child³⁶ do not relate to child characteristics such as developmental level or autism severity as assessed by experimental measures. Instead, higher autism severity, as assessed by the parents' questionnaire-based report, sometimes inversely relates to their acceptance of their child's autism,³⁷ which suggests that subjective perception rather than empirically demonstrated factors may drive acceptance. An increase in autism symptoms over time also relates to more parental acceptance of a child's autism,³⁸ likely because of a lowered perception of the possibility for the child to outgrow his or her challenges. Parent-child reciprocity^{32,35} and relationships³⁹ have often revealed independence from autism severity, whereas the parents' acceptance of autism strengthens the child's functioning in these areas.^{32,34,35} Mothers' understanding of their autistic child also may not relate to child characteristics,³⁴ but acceptance of their child's autism drives better recognition of and responsiveness to their child's communication, which in turn improves the relationship,⁴⁰ likely in part through improving maternal well-being.³⁷ These findings challenge diagnostic criteria that largely implicate difficulties with reciprocity and relationships as problems of the labeled individual, at least in the parent-child context, and demonstrate the need for further efforts to increase parents' acceptance of their child's autism.

School Inclusion

Academic Inclusion

Similarly, data reveal the benefits of classroom inclusion for autistic children with diverse intellectual and academic needs. Early intervention delivered in inclusive as opposed to segregated preschool settings predicts higher IQ in elementary

school, particularly for those with initially greater social and adaptive behavior impairments.⁴¹ In addition, higher levels of educational inclusion relate to better functioning for autistic adolescents and adults, beyond the effects of demographic and individual characteristics.⁴² Furthermore, autistic adolescents with intellectual disability had better academic performance in inclusive versus segregated classrooms,⁴³ likely in significant part because they received more structured instruction time⁴⁴ and their educational plan had greater focus on applied skill development (as contrasted with rote procedural goals⁴⁵). These benefits of inclusion appear driven in part by higher expectations based in confident understanding of needs,⁴⁶ more naturalistic and responsive teaching methods as opposed to behavioral management,^{47–50} and access to typically developing peers.⁵¹

Social Inclusion

Beyond classroom inclusion, peers' ineffective attitudes rather than severe autism symptoms pose a substantial barrier to social integration in and outside school. In educationally inclusive school environments, peers may more often reject autistic children who make more prosocial approaches but may not reject those who act shy.⁵² Similarly, among autistic youth, those with attention-deficit/hyperactivity disorder more often have an "active but odd" interaction style⁵³ and suffer from peer victimization.⁵⁴ Highly verbal autistic adolescents or young adults with greater teacher-reported social competence⁵⁵ and lower self- and parent-reported autism symptoms experience more victimization⁵⁶ and stigma,⁵⁷ in addition to having more anxiety, depression, and suicidal ideation.⁵⁶ Altogether, studies reveal that students or individuals with less severe autism may more frequently suffer from bullying, perhaps because peers interpret their

behavior as indicating oddness rather than disability and thus as more intentional or irresponsible.^{58–60}

(Transition to) Adulthood

Appropriate support rather than severity of disability plays a critical role in how the transition to adulthood impacts functioning. Autistic young adults with greater conversational skills more often lose services after high school in the United States,⁶¹ whereas those with intellectual disabilities tend to have more organized daytime activities.⁶² This may explain why high school exits among autistic people without intellectual disabilities tend to slow their reduction in autism symptoms⁶³ and add more stress in relationships with their mothers.⁶⁴ An autism-typical pattern of poor adaptive functioning relative to IQ tends to rise with greater age and IQ,^{65–72} and autistic young adults as a group tend to have lower employment rates than their peers with intellectual disabilities.⁷³ Yet the organizational and social experience of employment can improve self-regulation and interpersonal functioning because vocational engagement and independence predict improvements in activities of daily living and reductions in autism symptoms and maladaptive behavior, rather than vice versa, among autistic adults.⁷⁴ Similarly, longitudinal research has revealed that autistic adults experience declines in vocational independence over time, whereas the receipt of services improves independence in vocational activities, which are associated with more independence in other activities of daily living.⁷⁵ Adulthood appears to mark the developmental period that most challenges the validity of functioning labels, because some individuals with higher needs may function better than others with less severe autism symptoms and higher cognitive abilities, as a result of their support.

SUBJECTIVE WELL-BEING

A severe behavioral manifestation of autism or a high need for support not only does not preclude a high quality of life from a subjective perspective but also usually relates to higher well-being within the autism spectrum. Children and adults with subtler autism symptoms,^{76–78} more emotional awareness,⁷⁹ closer friendships,⁷⁷ and higher cognitive abilities^{77,78,80,81} tend to regard their autism as more severe and endorse more anxiety and depression. This may reflect not only greater self-awareness but also greater victimization among individuals with less obvious disability or supervision and more distressed reactions to bullying.⁵⁴ These individuals may make greater efforts to conceal differences amid motivations to fit in or avoid stigma or bullying, but such attempts may come at significant costs.^{82–85} Moreover, mistreatment, rather than the self-perceived degree of autism, may account for distress: adults' reports of quality of life related to their quality of social support rather than endorsed autistic traits.⁸⁶ Indeed, autistic adults' rating of their own quality of life more often relates to ecological factors such as bullying, whereas parents' (lower) report of their adult children's quality of life relates more often to clinical factors, such as their skill level.⁸⁷ Thus, the literature reveals the importance of autistic individuals' unique perspectives on their own lives and the need for research on how to help them from an early age to holistically understand their strengths, differences, and needs in an affirmative way that empowers them to constructively face their challenges.

TOWARD SOCIAL ACCEPTANCE AND SELF-ADVOCACY

Autistic people's challenges in social communication and subjective well-being seem to be more a function of dynamics with other people

than driven by individual deficits. There is much evidence to support dissociations between symptoms and functioning, as well as the benefits of accepting autism and full societal inclusion for development and well-being. Indeed, in this review, I challenge the validity and utility of functioning labels for autism and the interpretation of the "autism spectrum" as a linear continuum. Social support may mediate functioning, because individuals with initially lower skills may experience more benefits from enriched social environments, such as parental input for language growth and cognitive development from inclusive educational settings. Furthermore, subtler manifestations of autism increase individuals' risk of active peer rejection, loss of formal supports as they transition into adulthood, and distress. Thus, in this review, I provide support for the notion of autism as a cloudy constellation of uneven skills⁸⁸ and high within-person variability,⁸⁹ with performance contingent on the quality of social experiences and support well-suited for individual abilities or potential and needs. Widespread autism acceptance may help to provide enriched experiences. The benefits of parental acceptance of autism for the family summarized in this review dovetail with evidence of a positive relationship between awareness of the neurodiversity movement and a preference for referring to oneself as "autistic," an opposition to a cure, and more positive emotions toward one's own autism among individuals on the autism spectrum, alongside parallel results for nonautistic people imagining themselves in that position.⁷

The authors of future studies should consider how the complex relationship between autism and quality of life depends not only on social factors but also on the specific traits or behaviors associated with

autism, in that they may sometimes improve individuals' functioning and well-being. Individuals with the direct lived experience of autism can best explain the distinction between normalization and quality of life, such as how avoiding eye contact⁹⁰ and repetitive motor movements^{91,92} may help them to self-regulate, whereas intense interests can build success in education and employment.^{93–95} Many more researchers need to actively include autistic people throughout the scientific process and focus on their priorities, which often lean strongly toward services and adulthood⁹⁶; clearly useful and underresourced areas. Self-advocates also prioritize the need for every autistic person to have functional communication, and they may have insights into how to provide effective support or assistive technology to realize this goal, so that everyone has skills and access to clearly express personal wants and needs.^{9,10,97}

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