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

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Diverse theoretical perspectives[1–3] 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 child[36] 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 relationships[39] 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 time[44] and their educational plan had greater focus on applied skill development (as contrasted with rote procedural goals[45]). 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 style[53] and suffer from peer victimization.[54] Highly verbal autistic adolescents or young adults with greater teacher-reported social competence[55] and lower self- and parent-reported autism symptoms experience more victimization[56] 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

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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 symptoms[63] 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 skills[88] 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

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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 contact[90] 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 adulthood[96]: 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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REFERENCES

1. Sameroff A. A unified theory of development: a dialectic integration of nature and nurture. *Child Dev*. 2010;81(1):6–22
2. Karmiloff-Smith A. Nativism versus neuroconstructivism: rethinking the study of developmental disorders. *Dev Psychol*. 2009;45(1):56–63
3. Smith LB, Thelen E. Development as a dynamic system. *Trends Cogn Sci*. 2003;7(8):343–348
4. Lewkowicz DJ. The biological implausibility of the nature-nurture dichotomy & what it means for the study of infancy. *Infancy*. 2011;16(4):331–367
5. Rutter M, Moffitt TE, Caspi A. Gene-environment interplay and psychopathology: multiple varieties but real effects. *J Child Psychol Psychiatry*. 2006;47(3–4):226–261
6. Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*. 2016;20(4):442–462
7. Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both? Autism and neurodiversity. *Dev Psychol*. 2013;49(1):59–71
8. Kapp S. Interactions between theoretical models and practical stakeholders: the basis for an integrative, collaborative approach to disabilities. In: Ashkenazy E, Latimer M, eds. *Empowering Leadership: A Systems Change Guide for Autistic College Students and Those With Other Disabilities*. Washington, DC: Autistic Self Advocacy Network; 2013:104–113
9. Ne'eman A. The future (and the past) of autism advocacy, or why the ASA's magazine, *The Advocate*, wouldn't publish this piece. *Disabil Stud Q*. 2010;30(1)
10. Robertson SM. Neurodiversity, quality of life, and autistic adults: shifting research and professional focuses onto real-life challenges. *Disabil Stud Q*. 2010;30(1)
11. Green J, Charman T, Pickles A, et al; BASIS Team. Parent-mediated intervention versus no intervention for infants at high risk of autism: a parallel, single-blind, randomised trial. *Lancet Psychiatry*. 2015;2(2):133–140
12. Harker CM, Ibañez LV, Nguyen TP, Messinger DS, Stone WL. The effect of parenting style on social smiling in infants at high and low risk for ASD. *J Autism Dev Disord*. 2016;46(7):2399–2407
13. Welch MG, Firestein MR, Austin J, et al. Family nurture intervention in the neonatal intensive care unit improves social-relatedness, attention, and neurodevelopment of preterm infants at 18 months in a randomized controlled trial. *J Child Psychol Psychiatry*. 2015;56(11):1202–1211
14. Bang J, Nadig A. Learning language in autism: maternal linguistic input contributes to later vocabulary. *Autism Res*. 2015;8(2):214–223
15. Dimitrova N, Özçalışkan Ş, Adamson LB. Parents' translations of child gesture facilitate word learning in children with autism, Down syndrome and typical development. *J Autism Dev Disord*. 2016;46(1):221–231
16. McDuffie A, Yoder P. Types of parent verbal responsiveness that predict language in young children with autism spectrum disorder. *J Speech Lang Hear Res*. 2010;53(4):1026–1039
17. Siller M, Sigman M. Modeling longitudinal change in the language abilities of children with autism: parent behaviors and child characteristics as predictors of change. *Dev Psychol*. 2008;44(6):1691–1704
18. Haebig E, McDuffie A, Ellis Weismer S. Brief report: parent verbal responsiveness and language development in toddlers on the autism spectrum. *J Autism Dev Disord*. 2013;43(9):2218–2227
19. Haebig E, McDuffie A, Ellis Weismer S. The contribution of two categories of parent verbal responsiveness to later language for toddlers and preschoolers on the autism spectrum. *Am J Speech Lang Pathol*. 2013;22(1):57–70
20. Kasari C, Paparella T, Freeman S, Jahromi LB. Language outcome in autism: randomized comparison of joint attention and play interventions. *J Consult Clin Psychol*. 2008;76(1):125–137
21. Siller M, Hutman T, Sigman M. A parent-mediated intervention to increase responsive parental behaviors and child communication in children with ASD: a randomized clinical trial. *J Autism Dev Disord*. 2013;43(3):540–555
22. Naigles LR. Input and language development in children with autism. *Semin Speech Lang*. 2013;34(4):237–248
23. Baker JK, Messinger DS, Lyons KK, Grantz CJ. A pilot study of maternal sensitivity in the context of emergent autism. *J Autism Dev Disord*. 2010;40(8):988–999
24. Sandbank M, Yoder P. The association between parental

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mean length of utterance and language outcomes in children with disabilities: a correlational meta-analysis. *Am J Speech Lang Pathol*. 2016;25(2):240–251

25. Bottema-Beutel K. Associations between joint attention and language in autism spectrum disorder and typical development: a systematic review and meta-regression analysis. *Autism Res*. 2016;9(10):1021–1035
26. Gulsrud AC, Hellemann G, Shire S, Kasari C. Isolating active ingredients in a parent-mediated social communication intervention for toddlers with autism spectrum disorder. *J Child Psychol Psychiatry*. 2016;57(5):606–613
27. Shire SY, Goods K, Shih W, et al. Parents' adoption of social communication intervention strategies: families including children with autism spectrum disorder who are minimally verbal. *J Autism Dev Disord*. 2015;45(6):1712–1724
28. DiStefano C, Shih W, Kaiser A, Landa R, Kasari C. Communication growth in minimally verbal children with ASD: the importance of interaction. *Autism Res*. 2016;9(10):1093–1102
29. Miniscalco C, Rudling M, Råstam M, Gillberg C, Johnels JÅ. Imitation (rather than core language) predicts pragmatic development in young children with ASD: a preliminary longitudinal study using CDI parental reports. *Int J Lang Commun Disord*. 2014;49(3):369–375
30. Stone WL, Yoder PJ. Predicting spoken language level in children with autism spectrum disorders. *Autism*. 2001;5(4):341–361
31. Sinclair J. Don't mourn for us.*Our Voice*. 1993;1(3):3–6
32. Hutman T, Siller M, Sigman M. Mothers' narratives regarding their child with autism predict maternal synchronous behavior during play. *J Child Psychol Psychiatry*. 2009;50(10):1255–1263
33. Milshtein S, Yirmiya N, Oppenheim D, Koren-Karie N, Levi S. Resolution of the diagnosis among parents of children with autism spectrum disorder: associations with child and parent characteristics. *J Autism Dev Disord*. 2010;40(1):89–99
34. Oppenheim D, Koren-Karie N, Dolev S, Yirmiya N. Maternal insightfulness and resolution of the diagnosis are associated with secure attachment in preschoolers with autism spectrum disorders. *Child Dev*. 2009;80(2):519–527
35. Wachtel K, Carter AS. Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism*. 2008;12(5):575–594
36. Totsika V, Hastings RP, Emerson E, Lancaster GA, Berridge DM. A population-based investigation of behavioural and emotional problems and maternal mental health: associations with autism spectrum disorder and intellectual disability. *J Child Psychol Psychiatry*. 2011;52(1):91–99
37. Dolev S, Sher-Censor E, Baransi N, Amara K, Said M. Resolution of the child's ASD diagnosis among Arab–Israeli mothers: associations with maternal sensitivity and wellbeing. *Res Autism Spectr Disord*. 2016;21:73–83
38. Yirmiya N, Seidman I, Koren-Karie N, Oppenheim D, Dolev S. Stability and change in resolution of diagnosis among parents of children with autism spectrum disorder: child and parental contributions. *Dev Psychopathol*. 2015;27(4, pt 1):1045–1057
39. Beurkens NM, Hobson JA, Hobson RP. Autism severity and qualities of parent-child relations. *J Autism Dev Disord*. 2013;43(1):168–178
40. Oppenheim D, Koren-Karie N, Dolev S, Yirmiya N. Maternal sensitivity mediates the link between maternal insightfulness/resolution and child-mother attachment: the case of children with autism spectrum disorder. *Attach Hum Dev*. 2012;14(6):567–584
41. Nahmias AS, Kase C, Mandell DS. Comparing cognitive outcomes among children with autism spectrum disorders receiving community-based early intervention in one of three placements. *Autism*. 2014;18(3):311–320
42. Woodman AC, Smith LE, Greenberg JS, Mailick MR. Contextual factors predict patterns of change in functioning over 10 years among adolescents and adults with autism spectrum disorders. *J Autism Dev Disord*. 2016;46(1):176–189
43. Kurth JA, Mastergeorge AM. Academic and cognitive profiles of students with autism: implications for classroom practice and placement. *Int J Spec Educ*. 2010;25(2):8–14
44. Kurth J, Mastergeorge AM. Impact of setting and instructional context for adolescents with autism. *J Spec Educ*. 2012;46(1):36–48
45. Kurth J, Mastergeorge AM. Individual education plan goals and services for adolescents with autism: impact of age and educational setting. *J Spec Educ*. 2010;44(3):146–160
46. Dolev S, Oppenheim D, Koren-Karie N, Yirmiya N. Early attachment and maternal insightfulness predict educational placement of children with autism. *Res Autism Spectr Disord*. 2014;8(8):958–967
47. Chang YC, Shire SY, Shih W, Gelfand C, Kasari C. Preschool deployment of evidence-based social communication intervention: JASPER in the classroom. *J Autism Dev Disord*. 2016;46(6):2211–2223
48. Goods KS, Ishijima E, Chang YC, Kasari C. Preschool based JASPER intervention in minimally verbal children with autism: pilot RCT. *J Autism Dev Disord*. 2013;43(5):1050–1056
49. Mohammadzaheri F, Koegel LK, Rezaee M, Rafiee SM. A randomized clinical trial comparison between pivotal response treatment (PRT) and structured applied behavior analysis (ABA) intervention for children with autism. *J Autism Dev Disord*. 2014;44(11):2769–2777
50. Pellecchia M, Connell JE, Beidas RS, Xie M, Marcus SC, Mandell DS. Dismantling the active ingredients of an intervention for children with autism. *J Autism Dev Disord*. 2015;45(9):2917–2927
51. Kapp SK. Including rigorous methods to improve inclusive education [comment]. Available at: http://pediatrics.aappublications.org/content/130/Supplement_2/S179.comments#including-rigorous-methods-to-improve-inclusive-education

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52. Jones AP, Frederickson N. Multi-informant predictors of social inclusion for students with autism spectrum disorders attending mainstream school. *J Autism Dev Disord*. 2010;40(9):1094–1103

53. Scheeren AM, Koot HM, Begeer S. Social interaction style of children and adolescents with high-functioning autism spectrum disorder. *J Autism Dev Disord*. 2012;42(10):2046–2055

54. Sreckovic MA, Brunsting NC, Able H. Victimization of students with autism spectrum disorder: a review of prevalence and risk factors. *Res Autism Spectr Disord*. 2014;8(9):1155–1172

55. Rowley E, Chandler S, Baird G, et al. The experience of friendship, victimization and bullying in children with an autism spectrum disorder: associations with child characteristics and school placement. *Res Autism Spectr Disord*. 2012;6(3):1126–1134

56. Shtayermman O. Peer victimization in adolescents and young adults diagnosed with Asperger's syndrome: a link to depressive symptomatology, anxiety symptomatology and suicidal ideation. *Issues Compr Pediatr Nurs*. 2007;30(3):87–107

57. Shtayermman O. An exploratory study of the stigma associated with a diagnosis of Asperger's syndrome: the mental health impact on the adolescents and young adults diagnosed with a disability with a social nature. *J Hum Behav Soc Environ*. 2009;19(3):298–313

58. Feldman DB, Crandall CS. Dimensions of mental illness stigma: what about mental illness causes social rejection? *J Soc Clin Psychol*. 2007;26(2):137–154

59. Hinshaw SP, Stier A. Stigma as related to mental disorders. *Annu Rev Clin Psychol*. 2008;4:367–393

60. Weiner B. On sin versus sickness. A theory of perceived responsibility and social motivation. *Am Psychol*. 1993;48(9):957–965

61. Shattuck PT, Wagner M, Narendorf S, Sterzing P, Hensley M. Post-high school service use among young adults with an autism spectrum disorder. *Arch Pediatr Adolesc Med*. 2011;165(2):141–146

62. Taylor JL, Seltzer MM. Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *J Autism Dev Disord*. 2011;41(5):566–574

63. Taylor JL, Seltzer MM. Changes in the autism behavioral phenotype during the transition to adulthood. *J Autism Dev Disord*. 2010;40(12):1431–1446

64. Taylor JL, Seltzer MM. Changes in the mother-child relationship during the transition to adulthood for youth with autism spectrum disorders. *J Autism Dev Disord*. 2011;41(10):1397–1410

65. Balfe M, Tantam D. A descriptive social and health profile of a community sample of adults and adolescents with Asperger syndrome. *BMC Res Notes*. 2010;3:300

66. Kanne SM, Gerber AJ, Quirmbach LM, Sparrow SS, Cicchetti DV, Saulnier CA. The role of adaptive behavior in autism spectrum disorders: implications for functional outcome. *J Autism Dev Disord*. 2011;41(8):1007–1018

67. Klin A, Saulnier CA, Sparrow SS, Cicchetti DV, Volkmar FR, Lord C. Social and communication abilities and disabilities in higher functioning individuals with autism spectrum disorders: the Vineland and the ADOS. *J Autism Dev Disord*. 2007;37(4):748–759

68. Lee HJ, Park HR. An integrated literature review on the adaptive behavior of individuals with Asperger syndrome. *Remedial Spec Educ*. 2007;28(3):132–139

69. Levy A, Perry A. Outcomes in adolescents and adults with autism: a review of the literature. *Res Autism Spectr Disord*. 2011;5(4):1271–1282

70. Myles BS, Lee HJ, Smith SM, et al. A large-scale study of the characteristics of Asperger syndrome. *Educ Train Dev Disabil*. 2007;42(4):448–459

71. Saulnier CA, Klin A. Brief report: social and communication abilities and disabilities in higher functioning individuals with autism and Asperger syndrome. *J Autism Dev Disord*. 2007;37(4):788–793

72. Volker MA, Lopata C, Smerbeck AM, et al. BASC-2 PRS profiles for students with high-functioning autism spectrum disorders. *J Autism Dev Disord*. 2010;40(2):188–199

73. Shattuck PT, Narendorf SC, Cooper B, Sterzing PR, Wagner M, Taylor JL. Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*. 2012;129(6):1042–1049

74. Taylor JL, Smith LE, Mailick MR. Engagement in vocational activities promotes behavioral development for adults with autism spectrum disorders. *J Autism Dev Disord*. 2014;44(6):1447–1460

75. Taylor JL, Mailick MR. A longitudinal examination of 10-year change in vocational and educational activities for adults with autism spectrum disorders. *Dev Psychol*. 2014;50(3):699–708

76. Lai MC, Lombardo MV, Pasco G, et al; MRC AIMS Consortium. A behavioral comparison of male and female adults with high functioning autism spectrum conditions. *PLoS One*. 2011;6(6):e20835

77. Mazurek MO, Kanne SM. Friendship and internalizing symptoms among children and adolescents with ASD. *J Autism Dev Disord*. 2010;40(12):1512–1520

78. Sterling L, Dawson G, Estes A, Greenson J. Characteristics associated with presence of depressive symptoms in adults with autism spectrum disorder. *J Autism Dev Disord*. 2008;38(6):1011–1018

79. Capps L, Sigman M, Yirmiya N. Self-competence and emotional understanding in high-functioning children with autism. *Dev Psychopathol*. 1995;7(1):137–149

80. Bishop SL, Seltzer MM. Self-reported autism symptoms in adults with autism spectrum disorders. *J Autism Dev Disord*. 2012;42(11):2354–2363

81. Vickerstaff S, Heriot S, Wong M, Lopes A, Dossetor D. Intellectual ability, self-perceived social competence, and depressive symptomatology in children with high-functioning autistic spectrum disorders. *J Autism Dev Disord*. 2007;37(9):1647–1664

82. Baines AMD. Positioning, strategizing, and charming: how students with autism construct identities in relation to disability. *Disabil Soc*. 2012;27(4):547–561

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83. Davidson J, Henderson VL. 'Coming out' on the spectrum: autism, identity and disclosure. *Soc Cult Geogr*. 2010;11(2):155–170

84. Jones RS, Meldal TO. Social relationships and Asperger's syndrome: a qualitative analysis of first-hand accounts. *J Intellect Disabil*. 2001;5(1):35–41

85. Pachankis JE. The psychological implications of concealing a stigma: a cognitive-affective-behavioral model. *Psychol Bull*. 2007;133(2):328–345

86. Renty JO, Roeyers H. Quality of life in high-functioning adults with autism spectrum disorder: the predictive value of disability and support characteristics. *Autism*. 2006;10(5):511–524

87. Hong J, Bishop-Fitzpatrick L, Smith LE, Greenberg JS, Mailick MR. Factors associated with subjective quality of life of adults with autism spectrum disorder: self-report versus maternal reports. *J Autism Dev Disord*. 2016;46(4):1368–1378

88. Jones CR, Happé F, Golden H, et al. Reading and arithmetic in adolescents with autism spectrum disorders: peaks and dips in attainment. *Neuropsychology*. 2009;23(6): 718–728

89. Geurts HM, Grasman RP, Verté S, et al. Intra-individual variability in ADHD, autism spectrum disorders and Tourette's syndrome. *Neuropsychologia*. 2008;46(13):3030–3041

90. Gernsbacher MA, Frymiare JL. Does the autistic brain lack core modules? *J Dev Learn Disord*. 2005;9:3–16

91. Davidson J. 'It cuts both ways': a relational approach to access and accommodation for autism. *Soc Sci Med*. 2010;70(2):305–312

92. Yergeau M. Occupying autism: rhetoric, involuntarity, and the meaning of autistic lives. In: Block P, Kasnitz D, Nishida A, Pollard N, eds. *Occupying Disability: Critical Approaches to Community, Justice, and Decolonizing Disability*. Dordrecht, Netherlands: Springer; 2016:83–95

93. Grandin T, ed. *Different…Not Less: Inspiring Stories of Achievement and Successful Employment From Adults With Autism, Asperger's, and ADHD*. Arlington, TX: Future Horizons; 2012

94. Perner L, ed. *Scholars With Autism Achieving Dreams*. Sedona, AZ: Auricle Books; 2012

95. Santomauro J, ed. *Autism All-Stars: How We Use Our Autism and Asperger Traits to Shine in Life*. Philadelphia, PA: Jessica Kingsley; 2012

96. Pellicano E, Dinsmore A, Charman T. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*. 2014;18(7):756–770

97. Kasari C, Kaiser A, Goods K, et al. Communication interventions for minimally verbal children with autism: a sequential multiple assignment randomized trial. *J Am Acad Child Adolesc Psychiatry*. 2014;53(6):635–646

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