

Quality of life and autistics: the critical roles of social support and subjective well-being

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Introduction

- Autism mainly diagnosed by social communication
- Social interaction occurs *between* people
- Dynamics with others hugely affect autistics' lives
- Talk highlights roles of social support and subjective well-being for autistics' quality of life (QoL)
 - Objective QoL: adaptive functioning in major domains
 - Subjective QoL: personal judgment, feelings about life

Parental support:

Language acquisition

- Responsive parenting especially helps autistic children performing at lower levels to develop language¹⁻¹¹

Autism acceptance

- Parental autism acceptance¹²⁻¹⁵ and positive emotions toward child¹⁶ are *not* associated with child symptoms, disability
- Parental autism acceptance *is* associated with better parent-child reciprocity^{17,18} and relationship^{19,20}

School support:

Educational inclusion

- Inclusive learning settings are associated with better functioning for autistics²¹⁻²³, especially those with delays²²

Social (peer) inclusion

- Autistic youth with *more* social attempts and skills tend to suffer more victimization, stigma, distress²⁴⁻²⁷

Systemic support in adulthood

- Among autistic young adults transition from secondary school tends to produce relatively more struggle for those *without* intellectual disability²⁸⁻³⁰
 - More often lose services³¹
- Services³² and employment³³ tend to improve functioning

Subjective well-being

- Children and adults who perform or are perceived as higher skilled or functioning tend to judge their autism as more severe and endorse more anxiety and depression³⁴⁻³⁹
- Pattern may relate to victimization and mistreatment
 - Autistic adults report quality of life may relate to social support, not autistic traits⁴⁰
 - Similarly, social support tends to weigh more heavily in self- than parent report of autistic adults' quality of life⁴¹

Implications

- No direct relationship between autism symptoms and functioning
 - Importance of social context
 - (Some) autism symptoms can have neutral or positive effects on well-being
- Importance of understanding and sensitive responding to autistic people, acceptance, inclusion

References

- 1 Baker, J. K., Messinger, D. S., Lyons, K. K., & Grantz, C. J. (2010). A pilot study of maternal sensitivity in the context of emergent autism. *Journal of Autism and Developmental Disorders*, 40(8), 988-999.
- 2 Bang, J., & Nadig, A. (2015). Learning language in autism: Maternal linguistic input contributes to later vocabulary. *Autism Research*, 8(2), 214-223.
- 3 Dimitrova, N., Özçalışkan, Ş., & Adamson, L. B. (2016). Parents' translations of child gesture facilitate word learning in children with autism, Down syndrome and typical development. *Journal of Autism and Developmental Disorders*, 46(1), 221-231.
- 4 Haebig, E., McDuffie, A., & Weismer, S. E. (2013a). Brief report: Parent verbal responsiveness and language development in toddlers on the autism spectrum. *Journal of Autism and Developmental Disorders*, 43(9), 2218-2227.
- 5 Haebig, E., McDuffie, A., & Weismer, S. E. (2013b). The contribution of two categories of parent verbal responsiveness to later language for toddlers and preschoolers on the autism spectrum. *American Journal of Speech-Language Pathology*, 22(1), 57-70.
- 6 Kasari, C., Paparella, T., Freeman, S., & Jahromi, L. B. (2008). Language outcome in autism: randomized comparison of joint attention and play interventions. *Journal of Consulting and Clinical Psychology*, 76(1), 125-137.

References (continued)

- 7 McDuffie, A., & Yoder, P. (2010). Types of parent verbal responsiveness that predict language in young children with autism spectrum disorder. *Journal of Speech, Language, and Hearing Research*, 53(4), 1026-1039.
- 8 Naigles, L. R. (2013, November). Input and language development in children with autism. In *Seminars in Speech and Language* (Vol. 34, No. 4, pp. 237-248). Thieme Medical Publishers.
- 9 Sandbank, M., & Yoder, P. (2016). The association between parental mean length of utterance and language outcomes in children with disabilities: A correlational meta-analysis. *American Journal of Speech-Language Pathology*, 1-12.
- 10 Siller, M., Hutman, T., & Sigman, M. (2013). A parent-mediated intervention to increase responsive parental behaviors and child communication in children with ASD: a randomized clinical trial. *Journal of autism and developmental disorders*, 43(3), 540-555.
- 11 Siller, M., & Sigman, M. (2008). Modeling longitudinal change in the language abilities of children with autism: parent behaviors and child characteristics as predictors of change. *Developmental psychology*, 44(6), 1691-1704.
- 12 Hutman, T., Siller, M., & Sigman, M. (2009). Mothers' narratives regarding their child with autism predict maternal synchronous behavior during play. *Journal of Child Psychology and Psychiatry*, 50(10), 1255-1263.

References (continued)

- 13 Milshtein, S., Yirmiya, N., Oppenheim, D., Koren-Karie, N., & Levi, S. (2010). Resolution of the diagnosis among parents of children with autism spectrum disorder: Associations with child and parent characteristics. *Journal of autism and developmental disorders*, 40(1), 89-99.
- 14 Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2009). Maternal insightfulness and resolution of the diagnosis are associated with secure attachment in preschoolers with autism spectrum disorders. *Child Development*, 80(2), 519-527.
- 15 Wachtel, K., & Carter, A. S. (2008). Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism*, 12(5), 575-594.
- 16 Totsika, V., Hastings, R. P., Emerson, E., Lancaster, G. A., & Berridge, D. M. (2011). A population-based investigation of behavioural and emotional problems and maternal mental health: Associations with autism spectrum disorder and intellectual disability. *Journal of Child Psychology and Psychiatry*, 52, 91-99.
- 17 Hutman, T., Siller, M., & Sigman, M. (2009). Mothers' narratives regarding their child with autism predict maternal synchronous behavior during play. *Journal of Child Psychology and Psychiatry*, 50(10), 1255-1263.
- 18 Wachtel, K., & Carter, A. S. (2008). Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism*, 12(5), 575-594.

References (continued)

- 19 Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2012). Maternal sensitivity mediates the link between maternal insightfulness/resolution and child–mother attachment: The case of children with Autism Spectrum Disorder. *Attachment & Human Development*, 14(6), 567-584.
- 20 Oppenheim, D., Koren-Karie, N., Dolev, S., & Yirmiya, N. (2009). Maternal insightfulness and resolution of the diagnosis are associated with secure attachment in preschoolers with autism spectrum disorders. *Child Development*, 80(2), 519-527.
- 21 Kurth, J. A., & Mastergeorge, A. M. (2010a). Academic and cognitive profiles of students with autism: implications for classroom practice and placement. *International Journal of Special Education*, 25(2), 8-14.
- 22 Nahmias, A. S., Kase, C., & Mandell, D. S. (2014). Comparing cognitive outcomes among children with autism spectrum disorders receiving community-based early intervention in one of three placements. *Autism*, 18(3), 311-320.
- 23 Woodman, A. C., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2016). Contextual factors predict patterns of change in functioning over 10 years among adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 46(1), 176-189.
- 24 Jones, A. P., & Frederickson, N. (2010). Multi-informant predictors of social inclusion for students with autism spectrum disorders attending mainstream school. *Journal of Autism and Developmental Disorders*, 40(9), 1094-1103.

References (continued)

- 25 Rowley, E., Chandler, S., Baird, G., Simonoff, E., Pickles, A., Loucas, T., & Charman, T. (2012). The experience of friendship, victimization and bullying in children with an autism spectrum disorder: Associations with child characteristics and school placement. *Research in Autism Spectrum Disorders*, 6(3), 1126-1134.
- 26 Shtayermman, O. (2009). 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. *Journal of Human Behavior in the Social Environment*, 19(3), 298-313.
- 27 Shtayermman, O. (2007). Peer victimization in adolescents and young adults diagnosed with Asperger's Syndrome: a link to depressive symptomatology, anxiety symptomatology and suicidal ideation. *Issues in Comprehensive Pediatric Nursing*, 30(3), 87-107.
- 28 Taylor, J. L., & Seltzer, M. M. (2011a). Changes in the mother-child relationship during the transition to adulthood for youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 41(10), 1397-1410.
- 29 Taylor, J. L., & Seltzer, M. M. (2011b). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 41(5), 566-574.

References (continued)

- 30 Taylor, J. L., & Seltzer, M. M. (2010). Changes in the autism behavioral phenotype during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 40(12), 1431-1446.
- 31 Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P., & Hensley, M. (2011). Post-high school service use among young adults with an autism spectrum disorder. *Archives of Pediatrics & Adolescent Medicine*, 165(2), 141-146.
- 32 Taylor, J. L., & Mailick, M. R. (2014). A longitudinal examination of 10-year change in vocational and educational activities for adults with autism spectrum disorders. *Developmental Psychology*, 50(3), 699-708.
- 33 Taylor, J. L., Smith, L. E., & Mailick, M. R. (2014). Engagement in vocational activities promotes behavioral development for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(6), 1447-1460
- 34 Bishop, S. L., & Seltzer, M. M. (2012). Self-reported autism symptoms in adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 42(11), 2354-2363.
- 35 Capps, L., Sigman, M., & Yirmiya, N. (1995). Self-competence and emotional understanding in high-functioning children with autism. *Development and Psychopathology*, 7(01), 137-149.
- 36 Lai, M. C., Lombardo, M. V., Pasco, G., Ruigrok, A. N., Wheelwright, S. J., Sadek, S. A., ... & MRC AIMS Consortium. (2011). A behavioral comparison of male and female adults with high functioning autism spectrum conditions. *PloS one*, 6(6), e20835

References (continued)

- 37 Mazurek, M. O., & Kanne, S. M. (2010). Friendship and internalizing symptoms among children and adolescents with ASD. *Journal of Autism and Developmental Disorders*, 40(12), 1512-1520.
- 38 Sterling, L., Dawson, G., Estes, A., & Greenson, J. (2008). Characteristics associated with presence of depressive symptoms in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 38(6), 1011-1018.
- 39 Vickerstaff, S., Heriot, S., Wong, M., Lopes, A., & Dossetor, D. (2007). Intellectual ability, self-perceived social competence, and depressive symptomatology in children with high-functioning autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 37(9), 1647-1664.
- 40 Renty, J. O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism*, 10(5), 511-524.
- 41 Hong, J., Bishop-Fitzpatrick, L., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2016). Factors associated with subjective quality of life of adults with autism spectrum disorder: Self-report versus maternal reports. *Journal of Autism and Developmental Disorders*, 46(4), 1368-1378.

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Q & A

- Questions?
- Comments?
- Suggestions?



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