

Family/Caregivers of Youth with Autism Spectrum Disorder (ASD)

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DESCRIPTION OF FAMILY/CAREGIVERS OF YOUTH WITH ASD

Caregivers of individuals with disabilities or health conditions are broadly defined as individuals who provide a variety of tasks, services, and support for those whose disabilities or health conditions hinder personal functioning. Caregiving tasks can take many forms. Caregivers can be paid, such as those who provide respite care, or non-paid, such as family members. Needs of the caregivers and care recipients can also take different forms depending on the disability. This Practice Brief focuses on family caregivers of youth with autism spectrum disorder (ASD). ASD is a neurodevelopmental disorder characterized by pervasive impairments in social communication skills, as well as restrictive, repetitive, and stereotyped patterns of behavior, interests, and activities (American Psychiatric Association, 2013).

Pathways for Youths (2013) defined youth as those under 25 years of age, which is composed of three stages: early adolescence (under 14 years), middle adolescence (15-17), and late adolescence and early adulthood (18-24). In education, youth with disabilities are often defined as students with a disability who are entitled to transition services with an individualized education plan (IEP) starting as early as 16 years of age (IDEA, 2014). In alignment with educational and counseling-related services, this Practice Brief will focus on people who are 14 to 24 years of age and have ASD. Rather than focus on direct service provision (e.g., medical, education, employment) for youth with ASD in this Practice Brief, we focus on service and supports considered imperative for family caregivers (e.g., Cheak-Zamora, Teti, & First, 2015; Shivers, Sonnier-Netto, & Lee, 2019). Often, these supports are in the form of knowledge and skills training that are tailored for caregiving families who assist youthse

children (birth to 17 years of age). The PSOC scale is a 17-item parent-report measure of parenting self-efficacy with two subscales: Satisfaction and Efficacy. The Satisfaction subscale represents the social value of the parent role and feelings of frustration and anxiety in their role while the Efficacy subscale represents feelings of competency, ability to problem solve, and familiarity with parenting (Johnston & Mash, 1989). This measure has been the most commonly used scale for measuring parental self-efficacy. Although this measure was originally intended to measure caregiver-perceived general parenting competence in non-ASD population, this measure has been used in ASD studies to measure general parenting competence (e.g., Arellano, Denne, Hastings, & Hughes, 2019). Internal reliability was acceptable with $\alpha = .82$ (Gibaud-Wallston & Wanderman 1978), and $\alpha = .75$ (Johnston & Marsh, 1989). Arellano et al. also reported an acceptable level of internal consistency reliability of both mothers' satisfaction ($\alpha = .74$) and mothers' self-efficacy ($\alpha = .76$) in their ASD study.

Resources:

To download a free version of the PSOC measure and the scoring information, visit <https://www.bristol.ac.uk/media-library/sites/sps/documents/c-change/parenting-sense-of-competence-scale.pdf>

For more information on the PSOC, visit https://cyfar.org/sites/default/files/PsychometricsFiles/Parental%20Satisfaction%20%28parents%20of%20children%200-17%2C%20elementary-high%20school%29_0.pdf

The Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992) is a 34-item measure, originally developed to assess levels of empowerment in families whose children have emotional disabilities. The FES consists of three subscales comprising different levels of empowerment: Family, Service System, and Community and Political Environment. The FES is useful in assessing the empowerment components of service system advocacy, knowledge, parental competence and self-efficacy (Singh et al., 1995). The original measure was designed for non-ASD populations, but studies have used this measure for the ASD population (e.g., Taylor, Hodapp, Burke, Waitz-Kudla, & Rabideau, 2017). This measure has demonstrated score reliability and validity appropriate for caregivers/family members of an individual with a disability in other studies (Koren et al., 1992); high levels of internal consistency were reported to be .92 and .95 at pre-test and post-test, respectively (Taylor et al., 2017).

Resource:

To download a free version of the FES measure and the scoring information, visit <http://maine.gov/dhhs/ocfs/cbhs/provider/word/fes-scoresheet-rev.doc>

Parental Quality of Well-Being

In addressing parental outcomes, there are a multitude of indicators one can consider. Some common indicators can include specific constructs such as the absence/presence of psychopathology (e.g., anxiety, depression), parenting stress, health, mental health, general well-being, and marital adjustment. Some examples include the Beck Depression Inventory (Beck, Steer, & Brown, 1996), the Beck Anxiety Inventory (Beck & Steer, 1993), the Caregiver Strain Questionnaire (CGSQ; Khanna et al., 2012) for autism, which is modified from the original Caregiver Strain Questionnaire by Brannan, Heflinger, and Bickman (1997). Khanna et al.'s (2011) study applied the original 21-item Caregiver Strain Questionnaire by Brannan on 304 caregivers of children with ASD of age ranged from 5-18 years of age. Results indicated the modified version of 21 items showed a preferred 3-factor model with good internal consistency and validity. Another common broad conceptualization of well-being is quality of life. The MOS 36-item Short Form is also a commonly used well-being measure.

Resources:

See links for more extensive lists of quality of life and related measures on https://www.rand.org/health-care/surveys_tools/mos.html; <https://www.sheffield.ac.uk/scharr/sections/heds/mvh/sf-6d>

Resources:
The Beach Center Family Quality of Life (FQOL; Beach Center on Disabilities, 2006) scale is a 25-item self-administered measure designed to assess families' perceptions of their satisfaction with different aspects of family quality of life. The focus of the FQOL scale was on families of children with disabilities ages birth through 21 years. The FQOL scale consists of five subscales: Family Interaction, Parenting, Emotional Well-being, Physical/Mental Well-being, and Disability-Related Support. The FQOL has been used to assess general family quality of life among families of individuals with ASD (e.g., Boehm, Careter, & Taylor, 2015; Pozo, Sarria, & Brioso, 2014). This scale is designed to be used as (a) a pre- and post-test to measure the effectiveness of an intervention, (b) an outcome measure for programs or services, and (c) a measure of a dependent or independent variable from research perspective. Internal reliability for the FQOL subscales on importance ratings was $\alpha = .94$ and on satisfaction ratings was $\alpha = .88$ (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). Boehm et al. (2014) also found good internal consistencies ($\alpha = .94$) for the total score.

Resources:

The FQOL Scale is available free of charge. To order, email beach@ku.edu

For more information, visit: [https://beachcenter.lsi.ku.edu/sites/default/files/inline-files/](https://beachcenter.lsi.ku.edu/sites/default/files/inline-files/Family%20Quality%20of%20Life%20Psychometric%20Characteristics%20and%20Scoring%20Key.pdf)

[Family%20Quality%20of%20Life%20Psychometric%20Characteristics%20and%20Scoring%20Key.pdf](https://beachcenter.lsi.ku.edu/sites/default/files/inline-files/Family%20Quality%20of%20Life%20Psychometric%20Characteristics%20and%20Scoring%20Key.pdf)

Family Functioning

Family functioning is defined as the general interaction and dynamics within families which include relationships with various family members such as parents (e.g., the Parent-Child Relationship Questionnaire; Furman & Giberson, 1995) and siblings [e.g., the Sibling Inventory Behavior (Schaeffer & Edgerton, 1981); the Sibling Relationship Scale (McHale & Gamble, 1989). Additional examples include the Parenting Relationship Questionnaire (PRQ; Kamphaus & Reynolds, 2006), the Family Assessment Measure (FAM; Skinner, Steinhauer, & Santa-Barbara, 1983), the Impact on Family Scale (IFS; Stein & Jessop, 2003), and the Brief Family Relationship Scale (BFRS; Fok, Allen, Henry, & People Awakening Team, 2014), which is adapted from the Family Environment Scale (Moos & Moos, 1994).

The Family Adaptability and Cohesion Scale (FACES-IV; Olson, Gorall, & Tiesel, 2006) is the latest version of a family self-report assessment designed to measure cohesion and flexibility dimensions in family

their families. No outcome research on the efficacy of this intervention could be located.

Resource:

For more information and support resources, visit <http://www2.waisman.wisc.edu/family/working-together.html>

Volunteer Advocacy Program Transition (VAP-T; Taylor et al., 2017) is a 12-week program at 2.5 hours each. This program aims at increasing advocacy skills for parents of children who are within two years of high school graduation to participate. Local experts provide information on specific service, steps to access these services as well as ways to share resources with other families who have a transition-age child with

- Beach Center on Disabilities. (2006). *Manual for the Family Quality of Life Scale*. Lawrence, KS: Beach Center on Disabilities.
- Beck, A.T., & Steer, R.A. (1993). *Beck Anxiety Inventory manual*. San Antonio, TX: Psychological Corporation.
- Beck, A.T., Steer, R.A., & Brown, G.K. (1996). *Manual for the Beck Depression Inventory-II*. San Antonio, TX: Psychological Corporation.
- Boehm, T. L., Carter, E. W., & Taylor, J. L. (2015). Family quality of life during the transition to adulthood for individuals with intellectual disability and/or autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities*, 120, 395-411. <https://doi.org/10.1352/1944-7558-120.5.395>
- Botelho De Haan, K. L., Hafekost, J., Lawrence, D., Sawyer, M. G., & Zubrick, S. R. (2015). Reliability and validity of a short version of the general functioning subscale of the McMaster Family Assessment Device. *Family Processes*, 54, 116–123. <https://doi.org/10.1111/famp.12113>
- Brannan, A. M., Heflinger, C. A., & Bickman, L. (1997). The Caregiver Strain Questionnaire: Measuring the impact on the family of living with a child with serious emotional disturbance. *Journal of Emotional and Behavioral Disorders*, 5, 212-222. <https://doi.org/10.1177/106342669700500404>
- Burke, M. M. (2013). Improving parent involvement: Training special education advocates. *Journal of Disability Policy Studies*, 23, 225-234. <https://doi.org/10.1177/1044207311424910>
- Cheak-Zamora, N. C., Teti, M., & First, J. (2015). 'Transitions are scary for our kids, and they're scary for us': Family member and youth perspectives on the challenges of transitioning to adulthood with autism. *Journal of Applied Research in Intellectual Disabilities*, 28, 548-560. <https://doi.org/10.1111/jar.12150>
- DaWalt, L. S., Greenberg, J. S., & Mailick, M. R. (2018). Transitioning Together: A multi-family group psychoeducation program for adolescents with ASD and their parents. *Journal of Autism and Developmental Disorders*, 48, 251-263. <https://doi.org/10.1007/s10803-017-3307-x>
- Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster Family Assessment Device. *Journal of Marital and Family Therapy*, 9, 171-180. <https://doi.org/10.1111/j.1752-0606.1983.tb01497.x>
- Fok, C. C. T., Allen, J., Henry, D., & People Awakening Team. (2014). The Brief Family Relationship Scale: A brief measure of the relationship dimension in family functioning. *Assessment*, 21, 67-72. <https://doi.org/10.1177/107319111425856>
- Furman, W., & Giberson, R. S. (1995). Identifying the links between parents and their children's sibling relationships. In S. Shulman (Ed.), *Human development, Vol. 7. Close relationships and socioemotional development* (pp. 95-108). Westport, CT: Ablex Publishing.
- Gibaud-Wallston, J., & Wandersman, L. P. (1978). *Parenting Sense of Competence Scale*. Mahwah, NJ: Lawrence Erlbaum Associates.
- Hagner, D., Kurtz, A., Cloutier, H., Arakelian, C., Brucker, D. L., & May, J. (2012). Outcomes of a family-centered transition process for students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 27, 42-50. <https://doi.org/10.1177/1088357611430841>
- Hoffman, L., Marquis, J. G., Poston, D. J., Summers, J. A., & Turnbull, A. (2006). Assessing family outcomes: Psychometric evaluation of the Family Quality of Life Scale. *Journal of Marriage and Family*, 68, 1069-1083. <https://doi.org/10.1111/j.1741-3737.2006.00314.x>
- Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).
- Johnston, C., & Mash, E. J. (1989). A measure of parenting satisfaction and efficacy. *Journal of Clinical Child Psychology*, 18, 167-175. https://doi.org/10.1207/s15374424jccp1802_8
- Kamphaus, R. W., & Reynolds, C. R. (2006). *PRQ: Parenting Relationship Questionnaire manual*. Minneapolis, MN: NCS Pearson.
- Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review*, 15, 247–277. <https://doi.org/10.1007/s10567-012-0119-6>
- Khanna, R., Madhavan, S. S., Smith, M. J., Patrick, J. H., Tworek, C., & Becker-Cottrill, B. (2011). Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 41, 1214-1227.

<https://doi.org/10.1007/s10803-010-1140-6>

- Khanna, R., Madhavan, S. S., Smith M. J., Tworek, C., Patrick, J. H., & Becker-Cottrill, B. (2012). Psychometric properties of the Caregiver Strain Questionnaire (CGSQ) among caregivers of children with autism. *Autism, 16*, 179-199. <https://doi.org/10.1177/1362361311406143>
- Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology, 37*, 305. <https://doi.org/10.1037/h0079106>
- Mansfield, A. K., Keitner, G. I., & Dealy, J. (2015). The Family Assessment Device: An update. *Family Process, 54*(1), 82–93. <https://doi.org/10.1111/famp.12080>
- McHale, S. M., & Gamble, W. C. (1989). Sibling relationships of children with disabled and nondisabled brothers and sisters. *Developmental Psychology, 25*, 421-429. <http://doi.org/10.1037/0012-1649.25.3.421>
- Meyer, D., & Vadasy, P. (2019). *Sibshops*. Retrieved from <https://www.siblingsupport.org/about-sibshops>
- Moos, R. H., & Moos, B. S. (1994). *Family Environment Scale manual*. Palo Alto, CA: Consulting Psychologists Press. <https://doi.org/10.1111/1467-6427.00144>
- Olson, D. H. (2000). Circumplex model of marital and family systems. *Journal of Family Therapy, 22*(2), 144-167. <https://doi.org/10.1111/1467-6427.00144>
- Olson, D. H., Gorall, D. M., & Tiesel, J. W. (2006). *FACES IV package*. Minneapolis, MN: Life Innovations.
- Pathways for Youths. (2013). *Pathways for Youths: Draft strategic plan for Federal collaboration*. Retrieved from <https://youth.gov/feature-article/strategic-plan-iwgyp>
- Pozo, P., Sarriá, E., & Brioso, A. (2014). Family quality of life and psychological well-being in parents of children with autism spectrum disorders: A double ABCX model. *Journal of Intellectual Disability Research, 58*, 442-458. <https://doi.org/10.1111/jir.12042>
- Schaefer, E. Y., & Edgerton, M. (1981). *The Sibling Inventory of Behavior*. Chapel Hill, NC: University of North Carolina.
- Shivers, C. M., Sonnier-Netto, L., & Lee, G. K. (2019). Needs and experiences of family caregivers of individuals with autism spectrum disorders across the lifespan. *Journal of Policy and Practice in Intellectual Disabilities, 16*(1), 21-29. <https://doi.org/10.1111/jppi.12272>
- Singh, N. N., Curtis, W. J., Ellis, C. R., Nicholson, M. W., Villani, T. M., & Wechsler, H. A. (1995). Psychometric analysis of the Family Empowerment Scale. *Journal of Emotional and Behavioral Disorders, 3*, 85-91. <https://doi.org/10.1177/106342669500300203>
- Skinner, H. A., Steinhauer, P. D., & Santa-Barbara, J. (1983). The Family Assessment Measure. *Canadian Journal of Community Mental Health, 2*, 91-105.
- Stein, R. E., & Jessop, D. J. (2003). The Impact on Family Scale revisited: Further psychometric data. *Journal of Developmental & Behavioral Pediatrics, 24*(1), 9-16.
- Taylor, J. L., Hodapp, R. M., Burke, M. M., Waitz-Kudla, S. N., & Rabideau, C. (2017). Training parents of youths with autism spectrum disorder to advocate for adult disability services: Results from a pilot randomized controlled trial. *Journal of Autism and Developmental Disorders, 47*, 846-857. <https://doi.org/10.1007/s10803-016-2994-z>