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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 youths with ASD during their transition to adulthood.

IDENTIFICATION/ASSESSMENT STRATEGIES

Identification and assessment of family caregivers of transition age youth with ASD are conceptualized in terms of impact and need, allowing practitioners to be mindful of the areas that pose challenges or result in unmet needs requiring support. Few measures have been specifically designed for youth with ASD, but those identified below with an asterisk refer to measures that have been used specifically with families of individuals with ASD. These areas are identified as negative effects that these caregivers face when their needs are unmet, thus, supporting the needs for intervention to address these pertinent areas (Karst, & Vaughan Van Hecke, 2012). These areas will include: 1) parental self-efficacy/competency, 2) parental general well-being, and 3) family functioning. Furthermore, a majority of the measures identified were not originally designed for caregivers of transition-age youths. However, citations supporting the use with the ASD population are provided when available.

Parental Self-efficacy/Competency

The Parenting Sense of Competence scale (PSOC) was originally developed by Gibaud-Wallston and Wandersman (1978), but has been adapted and revised by Johnston and Mash (1989) for use with older

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 General 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>

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/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 interactions from the Circumplex Model of Marital and Family Systems (Olson, 2000). The FACES-IV is a 42-item scale completed by families of children aged 12 years or older. This measure consists of six subscales with two balanced scales (Balanced Cohesion and Balanced Flexibility) and four unbalanced scales that assess the low and high extremes of the two dimensions (Disengaged and Enmeshed) for the Cohesion dimension and two other dimensions (Rigid and Chaotic) for the Flexibility dimension. The reliability for the six scales in FACES-IV ranged between .78 and .90 in the original study (Olson, 2006).

Resource:

For an overview of the FACES-IV, visit: <http://www.facesiv.com/pdf/overview.pdf>

To purchase this instrument or for more information, visit: <http://www.facesiv.com/>

The McMaster Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983) is based on the McMaster Model of Family Functioning that measures structural, organizational, and transactional characteristics of families. The FAD is a 60-item inventory designed for use by all family members over age 12 years. The FAD consists of six domains including Affective Involvement, Affective Responsiveness, Behavioral Control, Communication, Problem Solving, and Roles, and an overall functioning domain called General Family Functioning (FAD-GF). This measure can be used to (a) screen for families with problematic functioning, (b) identify specific domains of problematic family functioning, and (c) assess changes post intervention. The FAD-GF Scale has also been used as a single index measure to assess family functioning with good psychometric properties (Boterhoven De Haan, Hafekost, Lawrence, Sawyer, & Zubrick, 2015). Internal reliability of the FAD-GF scale scores was $\alpha = .91$ (Khanna et al., 2011). High intercorrelations were found between the scale and six domains of the FAD and the principal components of the other 48 items (Mansfield, Keitner, & Dealy, 2015).

Resource:

For more information or to download a free version of the FAD, visit https://isucounselingresources2017.weebly.com/uploads/1/1/3/4/11344496/family_assessment_device.pdf

INTERVENTION STRATEGIES

In this Practice Brief, “intervention” is conceptualized as support that is provided to help family caregivers. The overarching intent of these family interventions is to equip these caregivers with the knowledge, resources, and skills to provide care for their transition-age family member with ASD. Conceptually, the objective is to increase parental involvement and engagement in the form of parent training (Karst & Van Hecke, 2012). The following family intervention provides specific transition-related knowledge and resources to increase caregiver involvement and engagement in helping the transition-age child with general life care planning. These interventions help increase empowerment, self-determination, problem-solving ability and advocacy as the mechanism of change to improve outcomes for these families and transition-age children.

Transitioning Together is an 8-week family psychoeducation program tailored for families and their teens aged 14-22 years with a diagnosis of ASD (DaWalt, Greenberg, & Mailick, 2018). This program provides education, training and activities that involve practicing problem-solving skills to reduce family stress, lower emotional expressivity, and increase empowerment. It provides two individual joining sessions, and eight weekly sessions of 90 minutes in duration that focus on pertinent transition topics for families. A teens group is offered concurrently to increase social skills and engagement. In their most recent random control trial (RCT) study on 41 families, DaWalt et al. (2018) showed significant improvement pre- and post-intervention (Cohen’s $d = 1.74-2.60$), with many significant outcomes on decreased parental depressive symptoms and caregiving burden, improved problem-solving and empowerment skills, positive feelings toward children, and increased social interaction and engagement for children. This program has been replicated in other states, including the *Spartan Transitioning Together in Michigan* (<https://msuliferresearch.wordpress.com/project/>), and has been culturally adapted to serve Latino families of youths with ASD. Published data about these replications and cultural adaptation studies are forthcoming.

Resource:

For more information and support resources, visit <https://www.waisman.wisc.edu/publications/transitioning-together-a-multi-family-group-psychoeducation-program-for-adolescents-with-asd-and-their-parents/>

Growing Together is a program that targets families with teens and young adults aged 13-26 years who have a diagnosis of ASD and aims to decrease challenging behaviors, increase positive behaviors of daily living and social skills of people with ASD, as well as increase family relationships. This program is short-term and based on principles of applied behavior analysis for teens and young adults with ASD, as well as their parents. This program consists of individual family sessions as well as weekly 90-minute multi-family group sessions focusing on learning social skills development and transition to adulthood. Families work toward 1-3 behavioral goals and strategies to achieve those goals at home and in the community. Families learn about effective strategies to promote positive behaviors, family relationships and to develop important daily living and social skills to better support the transition to adulthood for their transition-age family member with ASD. No outcome research on the efficacy of this intervention could be located.

Resource:

For more information and support resources, visit: <https://www.waisman.wisc.edu/autism-treatment-programs/growing-together-ages-13-26/>

Working Together is a research study led by DaWalt and Szidon, as well as co-investigators Mailick, Greenberg and Lainhart at the Waisman Center. It provide services for young adults (18-30 years) and

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 ASD. The VAP-T program was developed based on Burke's Volunteer Advocacy Program, VAP (Burke, 2013). A recent randomized waitlist control trial with 41 families (Taylor et al., 2017) reported significant increase in parents' knowledge about the adult service system, increase in feeling more empowered, and more comfortable and skilled with advocacy, with medium to large effect sizes ($d = 0.77-1.10$).

Resource:

For more information and support resources, visit <https://vkc.mc.vanderbilt.edu/notables/2017/03/transition-version-of-volunteer-advocacy-program-sees-large-impact-among-parent-participants/>
VAP community and parent program delivery training:

<https://fsrtc.ahslabs.uic.edu/2018/11/14/vap-seed-funding/>

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>

Specific Planning Encourages Creative Solutions (SPECS, Hagner et al., 2012) consists of six modules delivered to families of transition-age individuals with ASD over three stages. Stage 1 consists of three whole-day workshops provided in a group format tailored to provide educational information on related transition topics. Stage 2 consists of having each family participate in a structured person-centered planning (PCP) process to create transition goals tailored to the youth with ASD. The PCP takes 3-5 meetings at the family's home, with school and adult service professionals invited to provide input for the plan. Stage 3 provides assistance like career exploration activities (e.g., job shadowing, mock-up interviews, work experiences). This program empowers families and youths with ASD to work collaboratively to formulate a person-centered transition planning. Initial evidence from a randomized waitlist control study of 47 families demonstrated a significant increase in youth and family expectations for the future, as well as improved student self-determination and career decision-making ability with medium to large effect sizes ($d = 0.47-1.44$).

The Sibshops (Meyer & Vadasy, 2019) is an international informational and peer support group for siblings of children with disabilities (<https://www.siblingsupport.org/about-sibshops>). Sibshops allows siblings to meet other siblings who have similar experiences in order to gain social support in a leisurely manner. The gathering also allows information sharing about services and experiences. Sibshops has been offered specifically for siblings of children with autism (<https://www.siblingsupport.org/sibshops/providing-autism-links-and-supports-pals-sibshops>).

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