Early Childhood Education Journal (2022) 50:97–106
https://doi.org/10.1007/s10643-020-01145-2

Assessing Caregiver Stress and Coping at Time of Autism Spectrum Disorder Diagnosis

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Accepted: 10 December 2020 / Published online: 2 January 2021

Abstract

Research and practice emphasize the importance of family involvement in early intervention for children with autism spectrum disorder (ASD). However, in order to address the unique and diverse challenges of families, support and resources may need to be prescribed on a case-by-case basis. This article suggests ways early intervention programs can assess parent stress, self-efficacy and disability specific knowledge at time of ASD diagnosis to inform family centered intervention programs with attention to individualized support for children with ASD and their families. A variety of assessment tools are provided with rationale for their use of results to inform program intervention and service plans for families of young children with ASD.

Keywords Autism spectrum disorder · Early intervention · Parent stress · Parent coping

Parent involvement is a vital component of special education. In recent decades, parent empowerment, advocacy, and educational involvement have become the norm. This family-centered approach was incorporated in the 1986 amendments to the Individuals with Disabilities Education Act (IDEA) and remains a key aspect of the law today. Part C of IDEA is a federal grant program that supports states in operating a statewide program of coordinated Early Intervention (EI) services for infants and toddlers, aged birth through three years, and their families.

According to Part C of IDEA (2004), an Individualized Family Service Plan (IFSP) must be developed for every child who qualifies for services through EI programs (birth to three years of age). The purpose of the IFSP is to enhance family capacity and engagement (IDEA 2004). It documents a family's services, resources, treatment outcomes, priorities, and concerns related to the child's development and stresses that the treatment plan be implemented in the natural environment (Jones 1999). Services are specifically designed to meet a child's needs, and they may relate to physical development, cognitive development, communication, social or emotional development, and adaptive development. Parents are expected to play a leading role in determining and implementing the components of their child's education. The process of obtaining an IFSP begins with intake and is followed by a comprehensive evaluation. Then, if a child meets diagnostic criteria, assessment reports are utilized in order to create the IFSP.

While it is the expectation of EI programs to require parent carryover and implementation of developmental and therapeutic goals, parents are not typically evaluated on their ability to effectively partner with providers for the benefit of their child. Nor are they evaluated to see how comfortable or efficacious they feel about implementing programs and goals at home, when service providers are not present. It is not standard practice to conduct a parent evaluation in order to determine which services and supports will benefit a family in order to apply natural environment teaching strategies to help children reach their greatest potential.

Additionally, there are factors that can interfere with a parent's ability to play an integral and effective role in their child's education, especially in families of children with disabilities and particularly those with autism spectrum disorder (ASD). While parent training is frequently a key aspect of EI services for children with ASD, parents are not always emotionally or strategically equipped to implement education goals with their children.

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Compared to typically developing children and children with other disabilities, significantly higher levels of stress have been found among parents of children with ASD (Davis and Carter 2008; Kasari and Sigman 1997), highlighting the importance of better supporting parents of children with ASD. ASD is a neurodevelopmental disorder characterized by deficits in social communication and social interaction (e.g., deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviors, deficits in developing, maintaining, and understanding relationships) and restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association 2013). Drawing on data from 2016, in 2020 the Centers for Disease Control and Prevention reported that 1 in 54 children in the U.S. is diagnosed with an ASD, and boys are four times more likely to receive an ASD diagnosis. Although children may not be diagnosed until they are older, ASD can be diagnosed as young as eighteen months. Children diagnosed at a younger age (prior to the age of three) receive an IFSP, and parents are vital to implementing their services in the natural setting.

While clinical practice and research emphasize the importance of parent involvement in both EI and school programs for children with ASD, certain factors like parent stress can affect these families in many ways. According to Belsky's Determinants of Parenting Framework (1984), individual parent beliefs and psychology will influence parenting as will individual parent psychosocial factors such as stress. Numerous studies have examined stress levels in parents of children with ASD. Some studies have found that the more severe the child's ASD symptoms, the more stress parents report (Baker-Ericzen et al. 2005; Lyons et al. 2009). It has been well documented that parent stress can greatly affect the ability of parents to be effectively involved in their child's education (e.g., Solish and Perry 2008). Researchers have found that parents of children with ASD experience higher levels of stress when compared with parents of children with other developmental disabilities due to their unique set of challenges (Bouma and Schweitzer 1990; Estes et al. 2009; Hayes and Watson 2013; Hinman 2019). Specifically, mothers of children with ASD report higher levels of depression, burnout, and symptoms of anxiety (Baker-Ericzen et al. 2005; McKinney and Peterson 1987; Weiss 2002). Furthermore, researchers have also found that stress proliferation (the tendency for stressors to lead to additional stressors) contributes to depression among caregivers of children with ASD (Benson and Karlof 2009) which can further affect parents' ability to be effectively involved in special education. Beyond educational involvement, parent stress has been shown to affect attachment, coping, and parent–child interactions which can relate to child behavior problems. Specific mental health problems, which can be exacerbated by stress, like maternal emotional disorder, have been shown to be a significant risk factor for elevated hyperactivity and conduct problems in the child: "Maternal emotional disorder significantly increased the odds for elevated emotional symptoms in the child, and this was more pronounced in families experiencing high adversity," (Totsika et al. 2011). Better understanding parent stress and how best to support parents as they navigate a diagnosis and special education services may not only support parents, but also children.

According to McKee et al. (2020), parents and caretakers of children with ASD may recognize themselves as an integral part of their child's treatment, but they may poorly ascertain the difference between personal and treatment control. McKee et al. (2020) argues that this may then lead to higher levels of parenting stress. It becomes imperative to understand parent stress and parent involvement during EI, particularly for children with ASD, as those parents have been identified as having higher levels of stress. However, "Most existing clinical tools assess impairment in an individualized manner, whereas for many young children, impairment is more accurately conceptualized as a family-oriented, multidimensional construct, impacting various parental and family activities" (Mian et al. 2018, p. 530). By better understanding the cyclical relationship between disability and parent stress, service providers may be better able to support families, especially when developing an IFSP.

Parent stress is particularly pertinent at the time of diagnosis for families of children with ASD (MacDermott et al. 2006) and currently, there is a disconnect between stress reported and services provided for families of young children with ASD. Parents who experience high levels of stress do not necessarily receive more services or support compared to families who experience lower levels of stress. Families who accessed more community services actually had lower levels of stress (Greeff et al. 2006) highlighting the need for support services, especially for families of children with disabilities. Families may need specified and individualized support at both the time of diagnosis and at the initial IFSP meeting. When families are in crisis, supports and resources may need to be prescribed on a case-by-case basis in order to address the unique challenges each of these families face. Current practice does not include a stress evaluation for families as standard common practice prior to intervention design and implementation for families of children with ASD. Few programs, if any, conduct a formal stress evaluation for parents of children with ASD and disabilities who qualify for EI and special education preschool programs. Guidance and support for families of children with ASD is not customized and based on individual families and their unique challenges. As a result, the needs of many families are not being met, leaving them unable to process, understand, and alleviate their stress. This results in a lack of support in crucial areas for parents served by EI and preschool programs (Cassidy et al. 2008; Schwichtenberg and Poehlmann 2007). Gaining information in these areas can allow for changes to be made on a case by case basis instead of a general prescription for all families, based on child diagnosis. It can allow administrators and service providers to gear their practice to treat families depending on their unique needs and circumstances.

Purpose

The purpose of this article is to suggest how EI programs can assess parent stress and self-efficacy at time of diagnosis and initial IFSP planning in order to inform individualized family supports. Four key areas of assessment for parents are suggested in order to guide program intervention and service plans. These areas include: 1) general stress index, 2) stress index due to having a child with a disability, 3) self-efficacy, and 4) knowledge of ASD. In order to effectively individualize family intervention to best support children with ASD and to foster developmental, communicative, and social growth, these areas must be addressed. The rationales for these areas as well as specific tools are discussed.

Using Evaluation Tools to Determine Supports for Families

Parent Stress Evaluation

Upon diagnosis of an ASD, as well as throughout childhood, families are known to experience high levels of stress (e.g., Macdermott et al. 2006). It is important to note that parents' support needs change throughout the life cycle, and certain types of support may be more helpful at different life stages (Todd and Shearn 1996; White and Hastings 2004). Pierce et al. (1996), found that timing is critical; if implementation of specific parent supports are premature or delayed, they may not support coping to the fullest extent possible. In order to effectively recommend treatment for families both in terms of frequency and intensity of parent and child services, it is important to understand parent stress levels as these may be an indicator of parent ability to effectively implement and carryover child treatment goals as well as general quality of life. We suggest measuring two types of parent stress: 1) general stress, and 2) stress due to having a child with a disability.

General Parenting Stress

General parenting stress is not necessarily specific to parents of children with disabilities. It is known that parents of children report general stress more than adults without children. However, it is important to collect a baseline level of stress of families of children with disabilities as they embark on intervention for their child with ASD. In order for teachers and service providers to guide them appropriately, a general stress level can be collected and analyzed. For example, if a parent is experiencing stress related to daily tasks such as maintaining household chores (which in turn may affect their ability to address communication skills for their child) perhaps the team social worker may play a role in respite care and/or helping the family to secure household assistance or prioritize everyday tasks. If results show high levels of stress in areas of external control and feelings of being overwhelmed, program developers can suggest available supports such as parent support groups. We suggest a number of tools that can measure overall stress and parenting stress. These measures can be administered individually or in partnership with one another. The Perceived Stress Scale (PSS), Inventory of Parent Experience (IPE), Beck Anxiety Inventory (BAI) and Parenting Stress Index—Short Form (PSI-4-SF) can be utilized to measure general stress and parenting stress. Each measure is listed in Tables 1 and 2 where a brief description, estimated completion time and sample items can be found. Once the measures are completed, scores indicate levels of stress and specific areas where practitioners can target areas of need to support families. Each measure takes an estimated 10–15 min to complete and can be used in combination. Practitioners may choose the measure that best fits the family based on initial intake notes and parent report during the evaluation and IFSP meeting.

Stress Based on Having a Child with a Disability

While general parenting stress can provide critical background information on the overall stressor and stress levels of a parent, it is also important to measure if and how parental stress is related to the disability of the child. This information can inform providers about the contexts, environments and specific child behaviors that are associated with parent stress in order to customize the intervention. We suggest a variety of tools to assess parent stress in this area. Since these tools investigate the level of stress associated with the disability of the child, it is essential these tools are administered post-diagnosis of ASD. These tools include the Family Stress and Coping Interview (FSCI), Questionnaire on Resources and Stress (QRS-F), Family Adjustment Measure (FAM) and Family Life Impairment Scale (FLIS). Each tool measures stress related to the disability of the child specific to the parent and within the family system. The majority of questions are quantitative with a few qualitative questions. Practitioners can adapt these measures based on family characteristics and they can be administered in a 10–20 min time period post-diagnosis at the initial IFSP meeting or at any time during the duration of treatment. However, it is suggested the results are used to inform IFSP plans and service duration and frequency. Results can inform a range

Table 1 Summary of suggested measures

Measure	Description	Estimated amount of time to complete
Perceived Stress Scale (PSS) (Cohen et al. 1983)	Measures perceptions of stress according to how uncontrollable, unpredictable, and overloaded participants view their lives. This 14 item self-report test measures stress from ongoing life circumstances, from anticipating future events, and reactions to specific events	10 min
Inventory of Parent Experience (IPE) (Crnic and Greenberg 1981)	Measures parents' social support network and assesses satisfaction with parenting. Two distinct parts comprise the measure: Social Support (16 items) and Parenting Satisfaction (12 items)	15 min
Beck Anxiety Inventory (BAI) (Beck et al. 1988)	Measure that assesses anxiety using self-report in 21-items	15 min
Parenting Stress Index—Short Form (PSI-4-SF) (Abidin 2012)	Measures parents' perceptions of stressful aspects of their parenting experience and parent–child interactions in 36 items	10 min
Family Stress and Coping Interview (FSCI) (Nachshen et al. 2003)	Measures stress associated with having a disability. Designed to measure stress related to the events in the lives of families of a child with a developmental disability. This is a 23-item quantitative instrument and five question qualitative instrument	10 min
Questionnaire on Resources and Stress (QRS-F) (Glidden and Floyd 1997)	Measures stress and resources. This is a 31-item questionnaire used to understand stress in families of children with disabilities	20 min
Family Adjustment Measure (FAM) (Carlson et al. 2014)	Measure developed as a screener for parental stress and coping. Four aspects of family adjustment: Parental Distress, Social Support, Family-Based Support, and Positive Coping. This is a 75 item scale	10 min
Family Life Impairment Scale (FLIS) (Briggs-Gowan et al. 1997)	Measure that assesses the level of impairment a family experiences due to developmental, behavioral, or emotional difficulties experienced by their child. 19-item parent-report measure that captures how families might be affected in positive ways related to child difficulties/disabilities	15 min
Early Intervention Parent Self Efficacy Scale (EIPSES) (Guimond et al. 2008)	Measures the independent variable of Self-Efficacy. 16 item scale used to assess EI related competence beliefs of parents of children with disabilities	10 min
Parenting Sense of Competence scale (PSOC) (Johnston and Mash 1989)	Measures the perceived degree to which parents feel competent and confident in their parenting role. 16-item scale broken into a Satisfaction subscale (nine items) and an Efficacy subscale (seven items)	5 min
Knowledge about Childhood Autism among Health Workers (KCAHW) (Bakare et al. 2008)	Measures knowledge and awareness of ASD and its symptoms. 19-item questionnaire divided into four domains	10 min
Autism Stigma and Knowledge Questionnaire (ASK-Q) (Harrison et al. 2017a, b)	Measure that includes questions in three domains of ASD knowledge: symptoms/diagnosis (18 items), etiology (16 items), and treatment (14 items). Fourth domain of ASD stigma endorsement (seven items) that includes items also included in one other knowledge subdomain	30 min
Autism Knowledge Questionnaire (AKQ) (Kuhn and Carter 2006)	Measure assesses parent knowledge of diagnosis, symptoms, treatments, and epidemiology using true/false statements. 43-item questionnaire	15 min

of programmatic decisions. For example, if parents express high levels of stress due to the cause of disability, this is an area that can be explored through parent training and suggestions of evidence and medical based resources can be provided and explored with professional guidance. Please see Tables 1 and 2 for summaries, estimates for completion time and sample questions for each measure.

Table 2 Sample questions from suggested measures

Measure	Sample questions
Perceived Stress Scale (PSS) (Cohen et al. 1983)	In the last month, how often have you been upset because of something that happened unexpectedly?; In the last month, how often have you felt that you were unable to control the important things in your life?; In the last month, how often have you felt nervous and "stressed"? and In the last month, how often have you dealt successfully with irritating life hassles?
Inventory of Parent Experience (IPE) (Crnic and Greenberg 1981)	How satisfied are you with the availability of family or friends to talk to whose advice you trust, in a typical week about how many times do you talk on the phone with a friend, and if sometime you were to have bad or angry feelings about your child, how many people could you talk to about this?
Beck Anxiety Inventory (BAI) (Beck et al. 1988)	Feel of worst happening, terrified or afraid, and fear of losing control
Parenting Stress Index—Short Form (PSI-4-SF) (Abidin 2012)	I feel trapped by my responsibilities as a parent; Since having a child, I feel that I am almost never able to do things that I like to do
Family Stress and Coping Interview (Nachshen et al. 2003)	The diagnosis of my child as having a developmental disability; Explaining to others about my child's developmental disability; Your feelings about the cause of your child's disability; Dealing with friends/family/people in the neighborhood on a day-to-day basis"
Questionnaire on Resources and Stress (QRS-F) (Glidden and Floyd 1997)	Our family agrees on important matters and I worry what will happen to__when I can no longer take care of him/her
Family Adjustment Measure (FAM) (Carlson et al. 2014)	As a parent of a child with a disability I feel disappointment; As a parent of a child with a disability I feel numbness; As a parent of a child with a disability I feel angry; I feel depression because I have a child with a disability; As a parent of a child with a disability I feel burdened; I feel sadness because my child has a disability; As a parent of a child with a disability I feel frustration
Family Life Impairment Scale (FLIS) (Briggs-Gowan et al. 1997)	All items begin with the sentence starter "Because of my child's behavior, personality, or special needs…" and are followed by an item specific sentence conclusion
Early Intervention Parent Self Efficacy Scale (EIPSES) (Guimond et al. 2008)	If my child is having problems, I would be able to think of some ways to help my child; When my child shows improvement, it is because I am able to make a difference in my child's development; When it comes right down to it, parents really can't do much because most of a child's development depends on their early interventionists; Children will make the most progress if their early interventionists work with them rather than if the parents work with the children; If my child learns something quickly, it would probably be because I know how to help my child learn new things
Parenting Sense of Competence scale (PSOC) (Johnston and Mash 1989)	The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired and I meet my own personal expectations for expertise in caring for my child
Knowledge about Childhood Autism among Health Workers (KCAHW) (Bakare et al. 2008)	Marked impairment in use of multiple non-verbal behaviors such as eye to eye contact, facial expression, body postures and gestures during social interaction? Failure to develop peer relationship appropriate for developmental age? Lack of spontaneous will to share enjoyment, interest or activities with other people?
Autism Stigma and Knowledge Questionnaire (ASK-Q) (Harrison et al. 2017a, b)	Many children with autism have difficulty using everyday language to communicate their needs; There is currently no medical test to diagnose autism; Autism is a result of a curse or evil eye put upon/inflicted on the family; Autism is a developmental disorder; The earlier treatment of autism starts, the more effective it tends to be; Early intervention demonstrates no additional benefit to children with autism; Autism holds a social stigma in some communities; In some communities, people would feel ashamed if someone in their family was showing symptoms of autism

Table 2 (continued)

Measure	Sample questions
Autism Knowledge Questionnaire (AKQ) (Kuhn and Carter 2006)	There is currently no medical test to diagnose autism. The biggest problem with diagnosing autism is that symptoms do not appear until age five or older. Autism occurs in roughly equal numbers of boys and girls. There is no one recognized treatment for autism. Typically, autistic children can outgrow autism Autistic children have poor communications and social skills because they are geniuses in math. True (T), False (F), or Don't Know (DK)

Parent Self-Efficacy

Self-efficacy is defined as individual beliefs about the ability to perform and exert influence over specific events in one's life (Bandura 1994). More specifically, parenting self-efficacy is the feeling of confidence in the parental role, and it has been associated with both parent well-being and positive parenting outcomes (Kuhn and Carter 2006). Researchers have found that self-efficacy has been associated with lower levels of parenting stress and higher levels of parenting satisfaction among parents of typically developing children as well as enhanced social adjustments in children (Coleman and Karraker 2003; Jones and Prinz 2005; Sevigny and Loutzenhiser 2010). This extends to parents of children with ASD, as self-efficacy among parents of children with ASD has also been associated with lower levels of stress (May et al. 2015). However, efficacy can be affected by disability characteristics, and raising a child with ASD presents unique stressors because of atypical behaviors and sensory regulatory difficulties. Parenting self-efficacy could be affected by this additional stress (Hinman 2019). When parents have strong self-efficacy and believe they can make a difference in the life of their child, they may perform better in the caregiving capacity as well as perform specific tasks and address challenges related to parenting (Teti et al. 1996).

While positive self-efficacy has been associated with lower levels of stress in parents of children with ASD (May et al. 2015), it can be affected by disability characteristics, and raising a child with ASD presents unique stressors. Atypical child behaviors, sensory regulatory difficulties, and parenting self-efficacy could be affected by this additional stress (Hinman 2019). When parents have strong self-efficacy and believe they can make a difference in the life of their child, they may perform better in the caregiving capacity as well as perform specific tasks and address challenges related to parenting (Teti et al. 1996). Carryover of child goals in the areas of social, communication, motor, speech and language, and overall cognitive goals should be implemented by parents and primary caregivers in natural environment settings. The degree to which parents and primary caregivers feel they are able to effectively embed these goals within everyday lives, can vary greatly. Therefore, it is suggested that comprehensive intervention programs for young children with ASD should evaluate parent self-efficacy at the onset of treatment in order to gauge the specific needs of family training and gear specific instructional training to the individual needs of parents.

The Early Intervention Parent Self Efficacy Scale (EIPSES) and Parenting Sense of Competence scale (PSOC) are two suggested tools that can be utilized to measure self-efficacy in the context of parenting a child with a disability. While they are not ASD specific, they can both apply to parenting a child with ASD and can be adapted as desired. These two scales are completed in a brief amount of time and can be easily implemented with parents in order to gather information to guide a range of practitioners working in EI settings including special educators, speech language pathologists, occupational therapists, physical therapists and other related professionals. The results of these scales can provide indicators for parent training and coaching across areas of interventions and developmental domains. For example, if results indicate low levels of self-efficacy in areas of parent implemented communication intervention, special education and speech/language pathology service providers can work collaboratively to address systematic ways to carry over treatment goals in the natural environment by coaching parents in real-time. Tables 1 and 2 provide summaries of each tools, estimated time completion and sample items.

Parental Knowledge of ASD

Understanding what parents know about ASD upon receiving a diagnosis may better support professionals and service providers when creating an IFSP plan. Parents who have little to no knowledge about ASD may need additional resources to better understand their child's diagnosis, the importance of services, and available support. On the other hand, parents who may already have a child with an ASD diagnosis or who may know other families who have a child with an ASD diagnosis or even work in the education field may already feel they have a great deal of knowledge about ASD and may require less background information. Understanding parent baseline knowledge of ASD could allow service providers and families to create more meaningful service plans. For example, if the results show minimal knowledge in the core deficits of ASD, family training can first focus on diagnostic criteria and understanding how a child's behaviors relate to these characteristics prior or simultaneous to coaching parents to address them. Evaluating parental knowledge of ASD is not part of the typical IFSP planning process. We suggest three current autism knowledge questionnaires, but it is important to note that these types of tools are new and still being developed. The Knowledge about Autism among Health Workers (KCAHW), Autism Stigma Knowledge Questionnaire (ASK-Q), and the Autism Knowledge Questionnaire (AKQ) are three measures that provide practitioners with an understanding of their ASD knowledge in order to inform parent training, communication, and use of language/ASD-specific terms. While the KCAHW and the AKQ can be administered in about 10 min each, the ASK-Q is more time intensive. Practitioners can choose a scale that works best for families and best fits their time constraints.

A complete list of suggested measures with approximate completion time for each can be found in Table 1. A complete list of suggested measures with examples of items can be found in Table 2.

Application of Assessment Results

The results of the stress, self-efficacy, and ASD questionnaires can provide useful measures by which program administrators and service providers can make informed decisions on the frequency, intensity, and duration of services such as counseling, support groups, respite, and individual therapy eligibility for primary caregivers. These results can provide guidance for service delivery eligibility as well as areas to focus on within those services, creating a unique and individualized support model for families of children with ASD. By gathering information on stress specifically related to disability, practitioners may be better able to target areas related to child disability (e.g., understanding the disability, knowing where to look for resources, knowing how to respond to and interact with children, etc.). For example, the Family Stress and Coping Interview (Nachshen et al. 2003) can support service providers in better understanding stress specific to having a child with a disability, specifically a developmental disability, which differs from stress from everyday pressures or stress from other disabilities like terminal illnesses or physical disabilities. By implementing these measures, practitioners can gather a clearer picture of what specific events are stressful for parents and provide support based on those results like helping parents better understand when to explain the disability and connecting with friends and family members. Related, but adding another perspective, is the QRS-F (Glidden and Floyd 1997), which seeks to better understand stress within families. This tool can help inform practitioners of intrafamilial stressors and worries like whether or not family members agree and/or worry about the future for their child with a disability. Again, by having this information, EI providers may be better able to provide specific, targeted resources to parents based on their responses. If parents are stressed about who will care for their child after their passing but not stressed about other areas related to disability, the practitioner may recommend specific resources related to out of home care. The FAM (Carlson et al. 2014) can assess both stress and coping, giving EI practitioners an idea of how parents are *adjusting* to the diagnosis of ASD in addition to the stress they may be feeling. As this measure provides an idea of stress in four different areas (parental distress, social support, family-based support, and positive coping), this may better serve practitioners as they plan the IFSP and recommend specific programs. For example, if family-based support is an area that indicates needed support, practitioners may recommend respite agencies and other services that give parents needed time to themselves. Alternatively, if parents indicate social support is an area of concern/stress, service providers may recommend different parent support groups and social gatherings. By having all of this information which is relevant to parent well-being and in turn relevant for the child's well-being, interventionists can provide individualized support that is tailored to each parent's individualized needs and concerns. Another example, the FLIS (Briggs-Gowan et al. 1997) provides information regarding another dimension of parent stress by examining a family's level of impairment due to developmental, behavioral, or emotional difficulties experienced by their child. As children with ASD may experience developmental delays, behavioral problems (both externalizing and internalizing), and emotional difficulties (e.g., lack of friendship perhaps due to difficulties in communication), the FLIS is an important measure to understand parent stress related to multiple areas of concern.

As parenting self-efficacy, the feeling of confidence in the parental role, has been associated with parent well-being and positive parenting outcomes (Kuhn and Carter 2006), it is important to understand how efficacious parents feel and provide them with the support to feel more efficacious if they are not confident in their role as a parent, particularly as a parent of a child with a disability. Notably, daily stressors can impact both parenting and self-efficacy (Rutgers et al. 2007), and higher levels of stress as reported on the PSI (Abidin 2012) have been associated with negative perceptions (Kuhn and Carter 2006; Tomanik et al. 2004). These negative perceptions have also been related to lower levels of self-efficacy (Meirsschaut et al. 2011). Thus, by having information on parent stress and self-efficacy, EI providers will be able to target the two domains simultaneously to help parents feel more successful as both parents and providers of services during EI. The EIPSES (Guimond et al. 2008) assesses EI related competence beliefs of parents of children with disabilities and can provide valuable information in terms of how to tailor services for parents and families. If results indicate a feeling of helplessness (i.e., feeling like parents really cannot do much because most of a child's development depends on EI providers or indicating children will only make progress if their EI practitioners work with them rather than if the parents work with the children), EI providers may be aware of a more serious need for parental support and guidance. Additionally, the efficacy scale of the PSOC (Johnston and Mash 1989) can provide further information on parent efficaciousness to support EI practitioners as they plan for and provide support and resources for problem solving, managing expectations, taking care of daily chores, and working with children to implement services and goals in the natural environment. As mothers who report more agency or activeness in their child's development report higher feelings of self-efficacy and mothers who report more guilt report less agency and less efficaciousness (Kuhn and Carter 2006), having a clear picture of parent self-efficacy can support both parents and interventionists as parents learn to persist through the challenges of parenting a child with a disability and implementing goals in the home.

Assessing parent knowledge of ASD is an emerging concept. Kuhn and Carter (2006) suggested that parent knowledge of ASD may help parents understand how the challenging behavior of their child with ASD is associated with characteristics of ASD rather than with their parenting skills. The most recent assessment tool for parent knowledge of ASD is one that combines the research base of a number of evidence based tools. ASD knowledge questionnaires are still novel and continue to be developed as the knowledge base and evidence based practices surrounding ASD evolve.

Future Directions

Cultural background and ethnicity may influence how parents interpret a diagnosis of ASD, deal with stress, and understand ASD. Better understanding how cultural background influences parents' day to day activities and interactions with friends and family may help practitioners as they work with families to provide support throughout the EI process. In addition to the assessments we suggest here, we believe it could be useful to collect demographic information for program developers and interventionists to better account for cultural and ethnic family characteristics when planning. Additionally, while the current article provides suggestions based on valid and reliable assessment tools, as well as research on parent stress, self-efficacy, and knowledge of ASD, a targeted study looking at how these tools can inform program development and intervention choices at times of diagnosis across diverse urban and suburban settings as well as a varied sample with regard to SES, ethnicity, culture, can help to provide further specified guidance on the use of these tools and their impact on programmatic decisions for families.

Conclusion

Parents need to know how to access resources, seek out support, and promote positive child development, especially after receiving an ASD diagnosis (Hinman 2019). Using assessment tools to measure parent stress (general stress and stress related to disability of the child), parent self-efficacy, and parent knowledge of ASD, can help interventionists to individualize family resources and supports. For example, if a parent reports the highest levels of stress related to ability to access self-care and everyday family needs, perhaps accessing respite services and parental support groups can help to address those issues. If parents report not feeling equipped to support their child in learning new skills, perhaps interventionists can create increased opportunities where parents are coached and supported in real-time natural environment settings. With regard to knowledge of ASD, interventionists can customize parent training based on parent understanding of ASD as a diagnosis, core characteristics, and evidence based practices. By implementing time sensitive yet minimally time consuming efforts to administer 15–20 min stress, self-efficacy, and autism knowledge inventories, the potential to address individualized parent needs and intervention services can provide unique support to families in a great time of need and positively impact the trajectory of family and child outcomes.

Compliance with Ethical Standards

Conflict of interest All authors declare that they have no conflict of interest.

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