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The Role of Family Dynamics in Receiving Autism and Neurodevelopmental Services:

A Needs Assessment

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A Capstone Project submitted in partial fulfillment of the requirement for the degree of Master of Public Health and Master of Science in Behavioral Health

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Abstract

Purpose. This study aims to document the effects an autism spectrum disorder (ASD), neurodevelopmental disorder (NDD) diagnosis, or other behavior disturbances has on the family unit as a whole. Through this analysis, we can develop measures that are personalized for the child with autism as well as the caregiver and family unit.

Methods. Qualitative data was gathered from an online survey called the 'Caregiver Questionnaire Pre-Intake Form,' given to all families scheduled for an intake appointment prior to their visit at the ASD and NDD clinic. We evaluated responses from one question; "*What effects has your son/daughter had on other aspects of your life? (Marriage, family relations, social relations, work situation, etc.)*" We developed a codebook containing 46 individual codes clustered into ten main themes while exploring the valence of the responses by coding the 'negative', 'positive', or 'neutral' nature in the overall response. While 251 responses were originally coded, 143 responses properly fit the analysis criteria and were input for qualitative analysis.

Results. The three aspects of the caregivers' lives most impacted by their child's behavioral disturbances included *family life*, *career*, *and social/daily life* in both caregiver responses of individuals with ASD and non-ASD spectrum (other NDD) diagnosis. While the valence of the responses consisted of some positive and neutral tones, the overwhelming majority felt negative effects on their life.

Conclusion. A child's ASD or NDD diagnosis is a significant event in the caregiver and family's life. The various stages in a child's life ultimately affect the family dynamic, and these affects should be examined within treatment services to provide quality care.

Keywords. Autism spectrum disorder, neurodevelopmental disorders, family dynamics, caregiver stress, sibling stress, needs assessment

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1. Literature Review

Introduction to Autism Spectrum Disorder and Neurodevelopmental Disorders

Background. Neurodevelopmental disorders (NDDs) are a diverse set of conditions distinguished by irregular function in behavior, communication, cognition, and motor skills as a result of abnormal brain development (Mullin, et al., 2013). Some common NDDs include intellectual disability (ID), communication and speech disorders, motor/tic disorders, attention deficit hyperactivity disorder (ADHD), and ASD (Homberg, et al., 2016). Autism affects an individual's communication and behavior skills. The term 'spectrum' in ASD refers to a wide range of motor skills, cognitive ability (National Institute of Health [NIH], 2020). It is highly common for individuals with autism to have other psychiatric diagnoses, referred to as comorbidities (Lai et al., 2019). Although symptoms for autism usually appear in the first two years of a child's life (National Institute of Mental Health [NIMH], 2018), this disorder can be diagnosed at any point of time in an individual's life span. ASD research would benefit from providing interventions/treatment and support that address a wide range of developmental behaviors while supporting the entire family, and one that occurs daily and provides skills that can be maintained across the lifespan (Hodgetts, Zwaigenbaum, & Nicholas, 2014).

Prevalence. An experienced clinician can diagnose ASD in children as young as 2 years old, however there is increasing evidence that ASD is frequently diagnosed several years after the initial onset of symptoms or misdiagnosed with another psychiatric disorder with similar symptoms (Mandell, et al., 2009). A delay in diagnosis can negatively impact the lives of those living with ASD or an NDD but have not yet been diagnosed. This delay can be because of inadequate screening practices by clinicians, parental concerns for their child not being addressed immediately, or a general lack of awareness of symptoms (Mandell, et al., 2009). The

Center for Disease Control and Prevention’s (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network combined data from all 11 of their sites within the United States (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin) in 2016 for children aged 7-8 years old (2008 birth year) and found that 1 in 54 children across these 11 sites have autism (Appendix A). As a comparison, in 2000 the ADDM had reported data from six sites [states] and found that 1 in 150 children aged 7-8 years old had autism. These findings show evidence for increasing prevalence in autism over the years. Further, prevalence rates among minority groups based on race/ethnicity, gender, sex, residential locations highly differ.

Racial and ethnic disparities in prevalence. Between 2009-2017, a national study conducted at the CDC found 1 in 6 children (17%) aged 3-17 years were diagnosed with a developmental disability, as reported by parents. These disabilities included autism, attention-deficit/hyperactivity disorder, blindness, cerebral palsy, among others. ASD and NDDs occurs in all racial, ethnic and SES groups but the prevalence of a developmental disability was more likely to be diagnosed in boys, older children, non-Latino white and Latino children, children with private insurance only, and children living in urban areas and with less-educated mothers (Zablotsky et al., 2019). While ASD studies have shown mixed results in specific racial/ethnic disparities in identifying ASD, most studies have consistently found that Latino caregivers were less likely to be open about their child's ASD diagnosis than non-Latino caregivers (Mandell, et al., 2009) (Appendix B). A study by Mandell et al. (2009) enrolled 2568 children aged 8 years old who met surveillance criteria for ASD. Of these, 58% of these children had a documented ASD diagnosis, with minority children (e.g. Black, Latino children, or any other race/ethnicity) (Odds Ratio [OR] of 0.79, 95% Confidence Interval [CI]) being less likely to have a documented ASD diagnosis compared to their white counterparts (0.76 OR, 95% CI). These results were adjusted for gender, IQ, birthweight, and maternal education. These findings suggest significant racial/ethnic disparities in documenting ASD diagnoses, but highlight the importance of the provider's role in accurately recognizing ASD in children with continued professional education.

International prevalence. The current prevalence of ASD in developing countries is about 1.5%, with recent evidence showing climbing rates in individuals who do *not* have a coexisting intellectual disability (ID) (Lyall et al., 2018). In 2010, the WHO estimated that 0.76% of the world's children had ASD but this study was representative of only 16% of the global child population. Studies reported differences in prevalence of autism in South Asia with ranges from 0.09% in India to 1.07% in Sri Lanka (Akhter, et al., 2018). Much of the lack of evidence is because of the burden and stigma associated with an autism or neurodevelopmental disorder diagnosis in global nations which may prevent families from obtaining an initial diagnosis (Elsabbagh, et al., 2012). Many autism prevalence studies put focus on populations that are more likely to have autism, extracting from those with a history of special needs or developmental delays (Kim et al., 2011). A population-based sample study conducted by Kim et al. (2011) in a South-Korean community examined the prevalence and characteristics of ASD in school-aged children. The samples were extracted from both a high-probability group from special education schools and a disability registry and a low-probability group from a general population in regular schools was conducted. It was found that two-thirds of ASD cases in the overall sample size was in the regular school, without a diagnosis or treatment. The findings highlight the importance of screening and inclusive coverage to produce accurate ASD prevalence rates. Further, this suggests the critical need for better assessment measures and services globally.

Socioeconomic Factors and Risk of Autism on Individuals and Family

Environmental and genetic factors and risk of autism. The role of environmental and genetic factors are crucial in understanding ASD and NDDs. Research suggests that several environmental factors including vaccination, maternal smoking, and assisted reproductive technologies are not related to the risk of ASD (Modabbernia, Velthorst, & Reichenberg, 2017). On the other hand, environmental factors that have shown evidence in influencing the risk of autism include advanced parental age at time of conception, prenatal exposure to air pollution or certain pesticides, maternity obesity, diabetes, or immune system orders, extreme prematurity or very low birth weight, and any birth difficulty leading to periods of oxygen deprivation to the baby's brain (National Institute of Environmental Health Sciences, 2020). These factors in themselves are not likely to cause autism but rather appear to increase risk for developing autism in combination with genetic factors (NIEHS, 2020).

Prenatal exposure to pharmaceutical agents is representative of some major environmental health concerns as it relates to increased risk of autism. Chemicals such as thalidomide and valproic acid (VPA), for example, have been linked to the increased risk of autism (Dietert, Dietert, & Dewitt, 2011). While there are numerous studies analyzing rates of ASD in preterm infants, the general demographics of these study samples consistently show a higher rate of ASD in preterm infants compared to their general population counterparts. One study found the prevalence of autism in preterm infants almost seven times higher than the general population with rates being even higher in infants with extreme prematurity due to the neurodevelopmental vulnerability, maternal stressors, or injury to the cerebellum (Agrawal, Rao, Bulsara, & Patole, 2018). It is widely considered that individuals who have an underlying biological vulnerability experiencing a variety of external stressors during the critical time of brain development are at an increased risk of ASD (Limperopoulos, 2009).

Cultural factors and the risk of autism. As defined by Helms and Cook (2000), culture is "the values, beliefs, language rituals, traditions, and other behaviors that are passed from one generation to another within any social group". The culture within a family setting is unique to each household. These cultural differences likely influence the early perception and diagnosis of ASD and NDDs (Ratto, Reznick, & Turner-Brown, 2016) and parental beliefs on ASD have shown to impact the intervention choices for the child (Blacher, Cohen, & Azad, 2014). Current DSM-V criteria for an ASD diagnosis includes "deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication, to abnormalities in eye contact and body language." In many Asian cultures for example, body language and verbal signs of respect may be presented differently than some western attributed habits and behaviors such as finger-pointing, and eye-contact, and thus can be seen as disrespectful within different cultures and communities (Deweerdt, 2012). Furthermore, the Autism Diagnostic Observation Schedule, Second Edition *(ADOS-2; Lord, Rutter, DiLavore, Risi, Gotham, & Bishop 2012)*, an autism diagnostic gold-standard instrument, includes a task in which the child sings the "Happy Birthday" song during an observational play activity. This is not a universal practice among all families and cultures; thus many developing children possibly needing to be assessed for ASD, who are unfamiliar with this birthday ritual, may have invalid scores on the ADOS-2 for this particular task (Deweerdt, 2012). Research on ASD and NDD interventions that is mindful of the cultural differences in a family unit is necessary; this research would emphasize the need for educational and psychological services in households where autism is undiagnosed and stigmatized (Samadi, 2020).

Socioeconomic status and risk of autism. Up until recently, ASD was considered to have been a condition most prevalent in individuals/families with higher-income backgrounds. Findings have shown that children living in low-income neighborhoods where fewer adults have college degrees, are less likely to be diagnosed with ASD compared to children from higher-income neighborhoods (Durkin et al., 2017). This underdiagnosis rate could be a result of the lack of awareness surrounding early onset ASD symptoms and stigma surrounding mental health care, preventing caregivers from seeking assistance. Additionally, studies within the U.S. have shown significant correlation between age at time of ASD diagnosis and maternal education (earlier diagnosis being correlated with higher maternal education) (Dickerson et al., 2017). It would be extremely useful to conduct further extensive research to understand the link between socioeconomic status and epidemiology of ASD.

Existing research consistently shows low rates of diagnosis in Latino children (Appendix B) as compared to non-Latino white children. A study in California consisting of 267 primary care pediatricians wanted to assess the ASD developmental screening process, attitudes towards ASD diagnosis, and the barriers to identifying ASD in Latino children. It was found that while 81% of pediatricians offered developmental screening of some form, only 29% of providers offered ASD screening in Spanish, and merely 10% offered *both* ASD screening and general developmental screening in Spanish. Providers from this study had a difficult time assessing families whose primary language was Spanish and thought that Latino caregivers were less knowledgeable about ASD than non-Latino white caregivers. A key finding of the study was that Latino families finding access to developmental specialists was the most frequent barrier (Zuckerman et al., 2013).

Social and economic impacts of autism. Supporting a child with ASD throughout their lifetime in the U.S. can cost upto $2.4 million dollars (Accordino, Green, & Diaz, 2017), with annual U.S. costs associated with ASD of about $250 billion and numbers looking to rise to over $450 billion by the year 2025 (Lyall et al., 2018). This could result in a significant financial loss and psychological impact on the family unit because of factors like poor insurance coverage, traveling far for services, finding ASD-experienced babysitters, providing extra food for diet changes, and more (Nealy, O'hare, Powers, & Swick, 2012). Understandably, this raises concerns on better understanding the foundation of autism to help lower costs for treatment/interventions and further assist individuals with ASD and families supporting the individual.

ASD presents various challenges for not just individuals diagnosed, but for their families too. While there is a range of research diving into the economic impacts of ASD and NDDs, social impacts are not as well known. ASD-related stressors can manifest in various aspects for all family members, including (but not limited to): feeling a sense of loss, feelings of depression, a decrease in opportunities for quality family time including vacations and outings, loss of personal time, loss of social support, and professional sacrifices (Nealy, O'hare, Powers, & Swick, 2012). While negative social impacts are the majority, positive social impacts are also present with evidence that family members start viewing the autism experience as a life-changing one which challenges their values, belief systems, priorities, causing the family unit to view their lives in a new way (Myers, Mackintosh, & Goin-Kochel, 2009).

Understanding Caregiver Stress and the Transactional Model of Stress and Coping.

The Transactional Model of Stress and Coping (TSC) model would be beneficial in understanding the caregivers perceptions on the effects of the diagnosis on various aspects of their life. The model (Table 2 & Figure 2) emphasizes appraisal to evaluate threat, harm, and challenges which results in the coping strategies for these stressful events (Lazaurus, 1966; Lazarus & Folkman, 1984). The model helps evaluate the valence of their responses as it relates to other stressors (for example, a parent stating financial burden of appointments but feeling very blessed and lucky to have their child in their life and wouldn't change it any other way), general adjustment to illness, and their own health behavior.

The TSC model was developed by the works of Lazarus and Folkman (1984) as a way of evaluating coping mechanisms related to stressful events. An ASD or NDD diagnosis for a child is a significant, stressful event in a caregivers personal life. As the TSC Model suggests, stressful experiences are interpreted as 'person-environment transactions' where the impact of the stressor (in this case, the diagnosis) is dependent upon the person's *appraisal* (evaluation) of that stressor and the psychological and social resources that are available to them. A caregiver can find negative or positive meaning from a diagnosis, so it becomes important to take both psychological states into account. As per this model, individuals go through two stages of appraisal, or judgement, before they feel and respond to stress. First, they evaluate the potential threats and harms (primary appraisal) and whether the stressor is relevant to them. If they feel that it is a relevant stressor, they evaluate their capacity to cope with the situation and their negative emotions by their perceived resources (e.g. emotional support, risk, social support, etc.) (secondary appraisal). If they conclude that they do not have sufficient resources, and their stressor demands are heavier, they will begin coping strategies.

Concept	Definition	Application
Primary appraisal	Evaluation of the significance of a stressor or threatening event	Perceptions of an event as threatening can cause distress. If an event is perceived as positive, benign, or irrelevant, little negative threat is felt.
Secondary appraisal	Evaluation of the controllability of the stressor and available coping resources	Perceiving the ability to change the situation, manage emotional reactions, and/or cope effectively can lead to successful coping and adaptation.
Coping Efforts	Actual strategies used to mediate primary and secondary appraisals	
Problem Management	Strategies aimed at changing a stressful situation	Strategies include active coping, problem solving, and seeking information.
Emotional Regulation	Strategies aimed at changing the way of thinking or feeling about a stressful situation	Strategies include venting feelings, behavioral avoidance, disengagement, denial, and seeking social support.
Meaning-based coping	Coping processes that produce positive emotions, which in turn sustain the coping process by allowing reenactment of problem or emotion-focused coping	Processes include positive reappraisal of the stressor, revising goals, drawing on spiritual and religious beliefs, and focusing on positive events.
Outcomes of coping (adaptation)	Emotional well-being, functional status, health behaviors	Coping strategies may result in short- and long-term positive or negative adaptation.
Dispositional coping styles	Generalized ways of behaving that can affect emotional or functional reaction to a stressor; relatively stable across time and situations	
Optimism	Tendency to have generalized positive expectancies for outcomes	Optimists can experience fewer symptoms and/or faster recovery from illness.
Benefit Finding	Identification of positive life changes that have resulted from major stressors	Benefit finding may be related to the use of positive reappraisal and active coping.
Information Seeking	Use of attentional styles that are vigilant (monitoring) versus those that involve avoidance (blunting)	Monitoring may increase distress and arousal; it may also increase active coping. Blunting may mute excessive worry, but may also reduce adherence

Table 2: Transactional Model of Stress and Coping, with Extensions: Definitions and Applications

(Glanz, Rimer, & Viswanath, 2015)

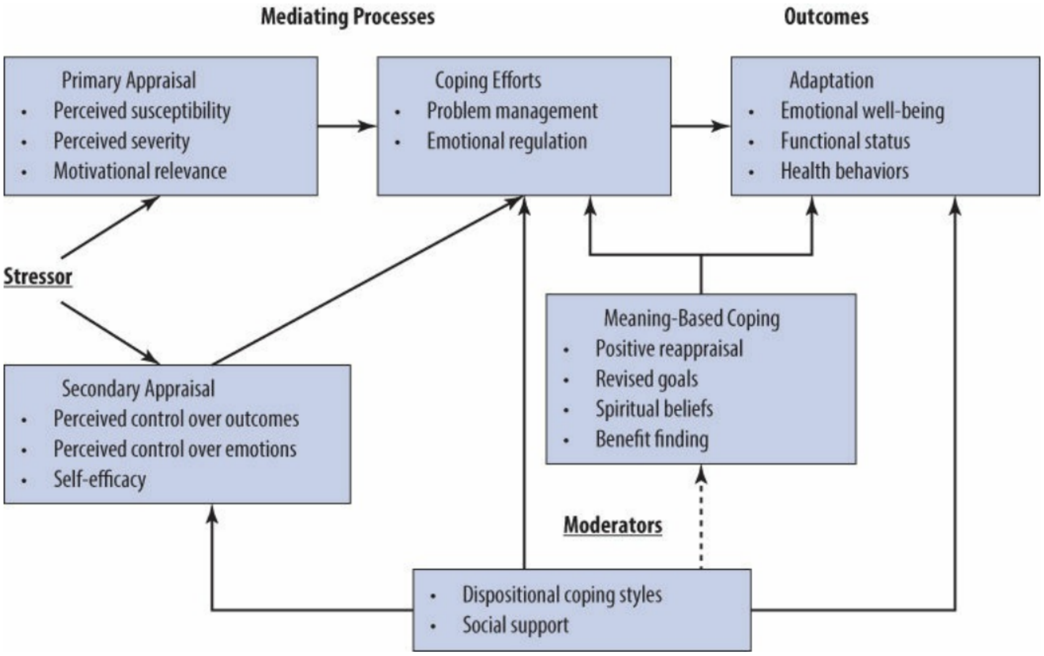


Figure 2: Transactional Model of Stress and Coping and Its Major Extensions (Glanz, Rimer, & Viswanath, 2015)

Assessment and Management of the Autism Disorder.

Behavioral interventions. Early behavioral interventions are one of the most effective, well-established forms of treatment in individuals with autism. Behavioral interventions are also one of the most researched and evidence-supported forms of treatment, thus the most commonly used among children with ASD (Richdale & Tennison, 2017). Applied Behavior Analysis (ABA) is an evidence-based technique with beliefs in improving the social and physical environment while emphasizing positive behaviors with incentives and negative behaviors with remediation (Lindgren & Doobay, 2011). ABA in itself is not an intervention, but an approach that applies principles from the learning theory. ABA further encompasses specific types of behavioral therapy, some of which are (but not limited to): Discrete Trial Training, Pivotal Response Training, Picture Exchange Communication System (PECS), and other incentive-based interventions. Depending on the individuals' clinical needs, ABA can be delivered in a group setting, one-on-one, in school, at home with caregivers, or in a community setting (Raising Children Network AU, 2017).

Developmental Interventions. Developmental interventions strive to focus on building social-emotional relationships (e.g. parent-child relationship), meeting developmental milestones, and how the child with ASD is developing in other aspects of their life (social-emotional skills, cognitive skills, gross motor skills, etc.). Some well known examples include developmental social-pragmatic model (DSP model), Relationship Development Intervention (RDI), and responsive teaching. The DSP model is one way of supporting preschool children diagnosed with ASD by creating treatment options that aim to improve social communication and language skills (Binns & Oram, 2019). Relative to the social pragmatic theory, developmental interventions such as the DSP model shift focus away from content and form of spoken language but instead on the importance of symbols within context, social engagement, and intent of the communication (Gerber, 2003). Developmental interventions are taught and applied by professionals as well as caregivers through careful evaluation in their homes. Rigorous research would be beneficial in comparing and contrasting developmental interventions with other models of care.

Family-based interventions. One study found that 85% of individuals with ASD require assistance from their family across their lifespan, highlighting the impact the child with ASD can have on the lives of family members (Factor et al., 2019). Family-based interventions highlight the importance of family involvement in interventions while meeting child's treatment goals and milestones. Family members of individuals with ASD play a key role in the decision-making process and in delivering the interventions (Richdale & Tennison, 2017). A study comparing

Latino and non-Latino white caregivers to children with ASD highlighted the importance of culturally appropriate family-based interventions. Family based interventions allow caregivers to work directly with their children in natural environments to develop and generalize skills over the life-span; culturally-sensitive family based interventions incorporate family structure/dynamic, values, and expectations into the interventions to ensure higher levels of participation and response to treatment (Dubay, Whatson, & Zhang, 2017). Failure to consider cultural factors in interventions can result in potential strain on social relationships within the family, failure to correctly implement recommendations, and possible discontinuation of services (Dubay, Whatson, & Zhang, 2017). An example of a family based intervention is the More Than Words program, developed at The Hanen Centre in Toronto, Canada for caregivers of children with ASD and other social communication difficulties under 5 years of age (The Hanen Centre, 2016). The program consists of 8 personalized training sessions with a speech pathologist between the caregiver and the child, to promote skills that would benefit the child. These skills include: improving play, social communication, imitation, and making friends.

Medication interventions. While there is no medication to cure ASD, there are some medications that can mitigate certain symptoms associated with autism and other co-occurring disorders. Healthcare providers such as psychiatrists can often prescribe medications to target behavioral manifestations of aggression and/or self-injurious behaviors, for example (NIH, 2019). Common medications include (but are not limited to):

- *Selective serotonin reuptake inhibitors (SSRIs)*, a group of antidepressants resulting from chemical imbalances which help treat behaviors such as anxiety, irritability, aggressive behavior, and improving eye contact.

- *Tricyclics*, another group of antidepressants used to treat depression and obsessive-compulsive behaviors.
- *Antipsychotics* to help reduce irritability, decrease hyperactive behaviors as well as aggressive and stereotyped behaviors.
- *Stimulants* to increase focus and increase activity in the individual taking the medication.
- *Anti-anxiety medications* to reduce feelings of anxiety and panic

With proper planning between the physician, patient, and family, medications can have positive behavioral improvements for the child with ASD allowing for better focus on other aspects of care such as building social communication skills and improving relationships.

Alternative Interventions.

Music therapy. Music-based therapy can be used as a non-invasive, inexpensive, therapeutic tool. While there is not much evidence on alternative interventions like music therapy for autism, existing research is promising. Music-based developmental interventions and therapy for motor and attention functions may provide significant improvement on ASD symptomatic behaviors (Devlin, Alshaikh & Pantelyat, 2019). Music has a means of provoking a neurological response in our brain, leading to stimulation of emotions and movement (Trimble & Hesdorffer, 2017). As found in a study by Sharda et al. (2018), the structured approach of music can help improve social communication skills over time, while being a form of creative expression. Furthermore, the study found that culturally variable music therapy can be adapted at home, school, and in community settings. Aside from social communication skills, this type of therapy can help encourage confidence, stimulation of senses through dance exercises thus enhancing fine motor skills, verbal advancements through understanding lyrics and singing, and relaxation. Music therapy can either be done by a professional musical therapist or by caregivers.

Diet changes. Restrictive diets or ‘elimination diets’ are commonly established in individuals with ASD to control for symptoms, although limited research is available with controversial results. A meta-analysis study suggests that specific nutritional diets have some impact in managing certain symptoms and functions in patients with ASD while nonspecific diets do not have any significant impact in managing symptoms of ASD (Fraguas et al., 2019). This study examined 1028 patients with ASD and found that while they would not support nonspecific dietary interventions as a form of treatment, dietary supplements such as Omega-3 and other vitamin supplementations played a role in helping manage certain symptoms and functions as it relates to ASD and NDDs (Fraguas et al., 2019). Another randomized control trial looked at vitamin/mineral supplement intake treatments which included a ‘gluten-free, casein free, soy free’ diet, digestive enzymes, Epsom salt baths, and essential fatty acids and found a significant improvement in non-verbal intellectual ability (categorized by IQ) in the treatment group as compared to the non-treatment group (+6.7 ± 11 IQ points vs. -0.6 ± 11 IQ points, p = 0.009) (Adams et. al., 2018).

A Specific Carbohydrate Diet (SCD) is one that has been found useful in individuals with autism who might also experience gastrointestinal (GI) distress. It is highly common for individuals with autism to have other medical comorbidities. GI distress in particular has gained attention with reported increases in prevalence rates and an association with ASD symptom severity (Hsiao, 2014). This diet requires eating foods with no carbohydrates or ones that contain monosaccharides. The premise of a SCD is starve the microbial flora, which otherwise would feed off disaccharides and polysaccharides and lead to microbial overgrowth in the digestive tract, leading to the manifestation of the core ASD symptoms such as anxiety-like behaviors, emotional/depressive behaviors, among others. While dietary changes are a newer form of intervention, it provides some promising benefits to individuals with ASD with GI comorbidities. Dietary changes could be something to discuss with a healthcare professional to further create a personalized care plan.

Combined interventions. With a myriad of interventions available for the child with ASD, combining various forms of interventions have proven to be most effective (NIH, 2019). Each child with autism displays unique symptoms and traits. An intervention or group of interventions which works for one individual, may or may not work for another. Speaking to a multi-disciplinary team of providers in a family setting can provide a more holistic approach to treatment and increase chances of bettering symptoms over the course of the affected individuals life-span. This approach can decrease caregiver stress and improve general well-being of the family unit (Jamison et al., 2017).

Recommended clinical interventions. While there is no cure for autism, the appropriate clinical services and interventions can provide extensive relief for ASD symptoms over the span of a lifetime. Applied Behavioral Analysis, or ‘ABA’, is perhaps the most widely utilized form of intervention for autism. ABA encompasses all behavioral interventions that aim to reinforce desirable behaviors while decreasing behaviors of concern. ABA is helpful in promoting social communication skills, emotional skills, and speech as well as increasing academic and professional performance. Overall, there are many forms of interventions available for consideration as highlighted in this paper. There is no “best” care practice, rather interventions that are personalized to fit the needs of the child and family dynamic which prove to be the most effective. Ideally, this personalized care plan would include expertise from a variety of healthcare providers to assure that all needs are met. This would include health professionals in autism, speech pathologists, social workers, psychologists, psychiatrists, behavioral therapists, and any other professional whose expertise may be beneficial.

2. Fieldwork Agency Profile

Background. This agency began in 2014 as part of a larger institution, with aims of providing quality outpatient care for individuals with autism and neurodevelopmental disorder. This center utilizes a multidisciplinary approach to care by conducting comprehensive diagnostic assessments as well as providing individualized, evidence-based interventions and treatments for patients and their family members across the lifespan. The center is federally funded with some funds through private foundations, while various grants fund the center’s integrative research program. Over the years, the agency has taken the latest methods of research to continuously build on their understanding of ASD and NDDs. A member of this agency has stated:

> One of the most unique things about [this agency] is that anyone who comes to us looking for clinical services, gets asked to participate in our research studies which further allows us to aggregate people and follow them longitudinally.

With the success of this agency having national and international recognition, many organizations from around the world are looking to produce a similar service style for their patients. The multidisciplinary team at this agency includes a team of experts in psychiatry, psychology, neurology, pediatrics, genetics, social work, speech therapy, behavioral therapy, clinical researchers, volunteers, as well as collaborative efforts with other medical and psychiatric professionals. Aside from diagnostic assessment, parental education and group treatments are also provided. The following table (Table 1) is a non-exhaustive list of the wide range of services* offered at this agency:

Table 1

List of Services

Multidisciplinary Services	**Multidisciplinary Services (Types)**	**Individual Treatment Services**	**Group Treatment Services**
1. Comprehensive Diagnostic Evaluation 2. Psychological and Behavioral Services 3. Group Treatment Services 4. Medical Services 5. Parent Education and Support 6. Medication Management 7. Research 8. Advocacy 9. Speech and Language Services	**Comprehensive Diagnostic Evaluation:** *ADOS-2, ADI-R,* various cognitive testing measures **Psychological/Behavioral Services:** Structured Teaching (TEACCH), Cognitive Behavior Therapy, Applied Behavioral Analysis: Pivotal Response Treatment, Early Start Denver Model **Research:** investigator-led behavioral studies, multi-site studies, online survey studies, repository/databank studies, and longitudinal follow-up studies **Advocacy:** advocacy for all family members, attendance at community events, lectures, research presentations, family resource fairs, clinician spotlight talks, etc.	Behavioral Activation Therapy Individual CBT Individual Behavioral Treatment Intensive Behavioral Treatment Medication Management Speech Therapy	**For Teens and Young Adults in Transition:** Transitioning Together **Parent group training series:** First Steps (0-6 Years) First Steps (7+ Years) Parent Mindfulness Group **PEERS social skills group series:** Preschool PEERS Teen PEERS Young Adult PEERS **Other groups for school age/adolescents:** Facing Your Fears Depression Group Unstuck and On Target School-Age Social Skills Group Enhancing Independence

Note. Most of the services are adapted from various evidence-based practices.

3. Methods

Aim, Objectives, Question

Aim. The aim of this study was to explore and highlight the impacts a diagnosis of autism or other neurodevelopmental disorder has on the life of the caregiver, while focusing on the impacts on the family unit. By observing how autism or other NDDs shape a day in the life of the caregiver, we could develop measures and clinical services that are not only personalized for the child with autism, but for the family as well.

Objectives. The first objective was to thoroughly read and analyze the caregiver responses to one specific open-ended response question from a six-question caregiver survey. The second objective was to code each valid response using a developed codebook to identify main themes (e.g. concerns) from the caregivers' written answers. The third objective was to utilize our findings to either devise new forms of care that address these concerns or produce evidence-based suggestions that address these concerns in existing interventions and services.

Question. The Caregiver Questionnaire Pre-Intake Form (Appendix C) consisted of six open-ended questions. Our study solely focused on caregiver responses to question number four, which asked, "*What effects has your son/daughter had on other aspects of your life? (Marriage, family relations, social relations, work situation, etc.)*"

Study Design

Qualitative Survey. The Caregiver Questionnaire was administered to parents and other types of caregivers of children scheduled for initial intake visits at the center. They were given a chance to complete this questionnaire online via a Qualtrics survey link two weeks prior to their clinic intake visit. Caregivers filling out the survey were allowed to answer any and all questions with no restrictions. Once responses to this survey were submitted, qualitative data was aggregated for each of the six questions on the Caregiver Questionnaire. The focus of this current study was solely on one of the six questions. After the development of the final codebook, relevant codes were assigned to caregiver's responses to question number four. The codes were analyzed using R (version 3.0.3; https://cran.r-project.org) where the quantitative results were generated.

Participants

Target population. For our study, we used the term 'caregiver' to describe anyone who is directly responsible in caring for a child displaying concerning behaviors, habits, etc. Caregivers can refer to parents, adoptive parents, grandparents, siblings, and even a parent's significant other (not otherwise related to the diagnosed individual), among many others. Caregiver's seen at this agency came through either a self-referral or a physician referral. The questionnaire is completed for clinical assessment purposes and research consent is obtained in order to enter the patient's clinical data into the center's databank study. The caregiver responses were derived from families who agreed and provided required research consent to participate in the databank study. Of note, the Caregiver Questionnaire was administered before the clinic intake appointment and included visits that were either for *assessment* or *treatment*. Caregivers seeking *treatment* for their child had an existing diagnosis either from the same institution or another institution. Whereas, caregivers seeking an *assessment* appointment most likely had a child with behavioral concerns and were seeking a diagnosis following their completion of assessment appointments. After the completion of the assessment appointments, diagnoses were discussed with the caregiver during a 'feedback' appointment. From here, clinician(s) will then suggest the best course for treatment services.

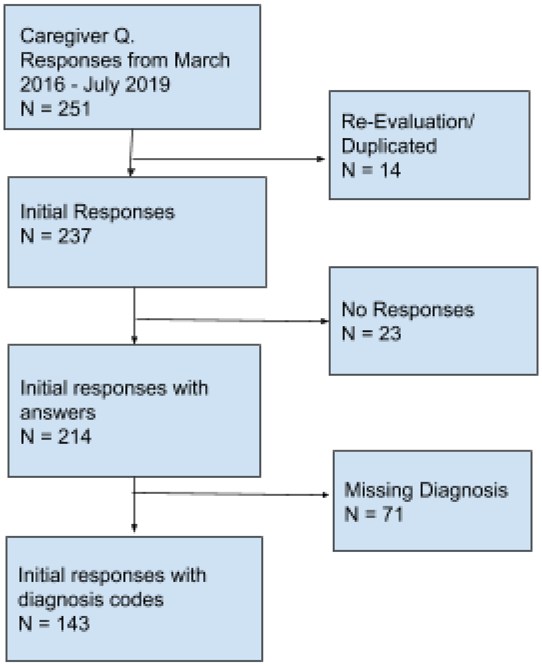
Data Collection Procedures

Study procedures. This study and all human subject research performed at this center were IRB approved by UCSF. In addition, parental consent for youth under 18 years and adult consent for individuals over 18 years of age were obtained in order to enroll and enter a research study. The Caregiver Questionnaire (Appendix C) was created in order to collect an open-ended sense of caregiver thoughts on behavioral concerns, or things they believe their child is doing well, and general thoughts for why they have decided to seek out clinical services at the center. This Caregiver Questionnaire was administered via the online Qualtrics survey platform and was asked to be filled out two weeks prior to the patient's initial intake appointment at the center as part of a *pre-intake* caregiver-report questionnaire packet. The questionnaire contains a total of six open-ended questions, with our focus being on question number four, that is, "*What effects has your son/daughter had on other aspects of your life? (Marriage, family relations, social relations, work situation, etc)?*" This allowed caregivers up to two weeks to submit responses prior to coming in for any assessment services. The questionnaire was completed for clinical assessment purposes and research consent was obtained in order to enter the patient's clinical data into the center's databank study. The caregiver responses were derived from families who agreed and provided required research consent to participate in the databank study. Researchers at the center have IRB approval to use patient's clinical data that has been entered into the databank, for research purposes, such as with our current qualitative analysis study.

Data inclusion criteria. The 143 caregiver responses utilized in this study were received between March 2016 to July 2019. Families were also given this questionnaire (with some adjustments to the questions) at any re-evaluation appointments (typically 6 months to 1 year post-initial intake) as a way to track change in caregiver perspectives after patient's may have been given a diagnosis and/or their families decided to seek out treatment services. We began with 251 caregiver responses. However, for the purposes of this study we only included responses collected prior to the initial intake appointment date to maintain consistency and for this reason, we excluded 14 respondents from re-evaluation appointments. Additionally, we excluded 23 respondents who provided no response to question number four within the Caregiver Questionnaire. From the remaining 214 respondents, 71 had a missing diagnosis (i.e. patients who were still on the waitlist to be seen at this agency, or diagnosis information was not recorded on the appropriate form and/or due to limitations and lack of access to physical patient charts, we were unable to obtain this information) leaving us with a total of 143 to input for quantitative analysis. Caregiver responses to this question varied from single sentences to multiple paragraphs

Figure 1

Data analysis criteria flowchart



Diagnosis codes. Diagnosis codes were assigned for patients based on clinician 'best estimate' diagnosis using DSM-5 criteria. Qualified healthcare professionals make the 'best estimate' diagnosis typically once patients complete their multi-day clinical assessment appointments, created by the multidisciplinary team at the agency.

Qualitative data.

Phase One Coding Strategy. We observed a multi-step coding strategy to obtain thorough results. All 251 caregiver responses were compiled onto Microsoft Excel with unique study ID numbers to allow researchers to identify patient demographics and read over data times. From the 251 responses, we excluded 14 respondents from the re-evaluation appointments and 23 with no responses. We were left with 214 caregiver responses, including those with a missing diagnosis, which we utilized for the qualitative analysis portion.

No patient names were used during this study and coders were blinded to the diagnoses of the patients. Two researchers independently read and analyzed the caregiver's responses creating separate codebooks. The researchers aimed to capture the main effects or "themes" of all responses labeled as the "Rough Domains."

Phase Two Coding Strategy. We compiled the individual "Rough Domain" codebooks into one codebook separated by six main clusters, 0-2 subdomains for each cluster and controlled for valence, or tone of the response. Coding for the tone is a way to capture the caregivers' feelings towards the experience through the response to the question, that will ultimately allow for appropriate interventions and services to be suggested; these were identified by negative (N), positive (P), and neutral (E) codes.

Phase Three Coding Strategy. After input from colleagues and extensive discussion, we modified the codebook to expand the 'clusters' and 'subdomains' to individual codes numbered

1-46 and a final codebook was developed (Appendix D). The final codebook consisted of 46 codes, 10 major clusters, and three codes describing the valence of the response: negative (N), positive (P), and neutral (E). Both researchers coded the first 25 responses individually and achieved a 0.74 kappa value for reliability, with a 95% agreement on the valence of the overall response. After establishing interrater reliability, codes were split with one researcher coding response numbers 25 to 60 and the second researcher coding response numbers 61 to 251. If the responses listed several effects that were independent of each other, coders assigned multiple codes. However, each phrase was coded only one. If there was a phrase with several effects that were dependent on each other, we coded them as one code separated by a decimal. For example, a caregiver specifically feeling stress regarding their child’s behavior was coded as 1.7; 1 being the code for stress, and 7 being the code for child's behavior.

Quantitative data.

Data analysis. Once all responses were assigned appropriate codes, the 143 valid responses (Figure 1) were extracted from Microsoft Excel and input into R (version 3.0.3; https://cran.r-project.org). From this, five bar graphs were generated (Appendix E). Graph 1 looked at frequency of DSM-V diagnosis comparisons, graphs 2 and 3 looked at the overall tone of caregiver responses (negative, positive, neutral) in both ASD diagnosed children and non-ASD spectrum children with another NDD, respectively. Graphs 4 and 5 compared the frequency of the 10 clustered themes by percentage between ASD and non-ASD individuals, respectively.

4. Results

Participants

Caregiver demographics. The questionnaire was aimed for caregivers directly responsible for caring for an individual displaying concerning behaviors among other things, to further evaluate the overall effects on the caregiver's life. The term caregiver can take many forms ranging from biological or adoptive parents to siblings and grandparents. The data suggested that respondents for this Caregiver Questionnaire consisted primarily of biological parents. Other relationships included: nanny, adoptive parent, sister, agency/domestic helper, mother by means of sperm and egg donation, significant other of parent, and grandparent.

Patient demographics. Agency patients (children), for which the Caregiver Questionnaire was completed about, were aged between 2-17 years old. For the purposes of this study, the patients were separated by type of diagnosis: ASD diagnosis and non-ASD spectrum diagnosis (those with an ASD diagnosis not on the spectrum, but have another NDD diagnosis).

Themes

"Themes" refer to the primary effects or impact, both positive and negative, that the child has had on the caregiver's life, as described in the caregiver response to question number four, "*What effects has your son/daughter had on other aspects of your life?*" A total of ten themes were defined in our codebook: career, child's well-being, family, marriage, non-specific (miscellaneous), parent health, parenting, relationship, services, and social/daily life. These themes are best exemplified in Table 3 below, with direct quotes from the caregiver questionnaire. The relevance of the themes slightly differed between caregivers of individuals with an ASD diagnosis and in individuals with a non-ASD spectrum diagnosis, however the top three themes were consistent (Appendix F) and ranked; family life was the most affected aspect of a caregiver's life as a result of their child's behavior, followed by social/daily life, and then career.

Family life. Caregivers mentioned *family life* as the top most affected part of their life both positively and negatively. Negative codes included: divided attention between siblings with more focus being given on the diagnosed child, effect on the siblings behavior, stress and worry for the child in the family, a sense of wanting to maintaining normalcy and balance within the household, decrease time and interaction family members, or there is a general lack of understanding from sibling/other family members. Positive codes included: siblings [positive] understanding of diagnosis (being advocates for the child), siblings become more mature as a result of the diagnosis, a general positive impact on the sibling, increased time and interaction between the family, or the diagnosis has in some way enriched the lives of the family members.

Social and daily life. Social life was the second most affected part of a caregivers life. This included caregivers avoiding public places and meeting people, avoiding or changing planned activities, finding a strong support system as a result of the diagnosis, financial burden, feelings of social isolation, daily life/schedule changes, or other social life changes.

Career. Effects on career was the third most affected part of a caregivers life. Caring for a child with behavioral disturbances can require a lot of time and present many challenges when balancing external responsibilities. As a result, many caregivers expressed effects on their career. This included general career changes and challenges (e.g. cutting back on hours, leaving a job, or not taking a promotion), job flexibility (e.g. thankful that the workplace is flexible in understanding child care responsibilities, or shifted careers as a result of a child's diagnosis.

Parenting. Effects on parenting included parenting skills (e.g. doubtful of caregivers own skillset to being able to provide for the child), parenting burden: advocacy, supervision, protection (e.g. feelings that the caregiver has to constantly advocate, supervise, or protect their child), parents feeling a lack of understanding on the diagnosis, or parents feeling an appreciation of the diagnosis.

Parent health. Many caregivers felt extraneous effects on their health. This included stress, worry, exhaustion, sleep challenges, other mental health/emotional issues, and other physical health issues. Some other issues included depression, anxiety, single parent stress and weight challenges.

Marriage. Effects on marriage included parenting conflict (e.g. differing on how to discipline the child), general strain on the relationship between two partners, and a decrease in quality time spent between the two partners (e.g. life revolves around the child, no one-on-one time).

Services. Services for a child with behavioral issues can pose unique challenges as well. This includes numerous appointments, ineffective services, appropriate babysitter services (i.e. ASD experienced babysitter services), appropriate respite care worker services.

Relationship. Caregivers experienced a loss of previous relationships, or formed new relationships, or a lack of understanding from friends. This includes for example, family or friends being unable to understand the behavioral disturbances of the child leading to loss of relationship over time or gaining new friendships with caregivers whom they share similar experiences with.

Child well-being. Many caregivers associated their well-being with aspects of their child's well-being. This included the child’s level of independence and the child’s behavior. For instance, the caregiver expresses concern about their child’s future and whether or not the child could maintain a job, relationship, or any level of independence without the support of the caregiver, or feelings of exhaustion as a result of the child’s behavior and habits (e.g. screaming, running, can’t put the child to sleep).

Non-specific. This includes the caregivers describing *everything* or *nothing* being affected in their lives as a direct result of their child's behavior.

Overall feelings towards the diagnosis. The valence of the caregiver responses showed the same patterns regardless of the diagnosis (Appendix G). These responses were categorized by negative (N), positive (P) and neutral (E) feelings in both responses by caregivers of individuals with an ASD diagnosis and non-ASD spectrum diagnosis. An overwhelming majority expressed negative impacts on various aspects of their life, followed by neutral feelings, and then positive feelings.

Table 3

Significant themes and quotes from caregiver questionnaire

Theme	Illustrative Quote
Career	*Positive theme* “Since returning to work I have taken a very different, but still fulfilling, career trajectory that I had prior to her diagnosis...” *Negative theme* “I quit my successful tech career to take care of my daughter to give her the services that she needed.”
Child’s well-being	*Negative theme* “We have had a difficult time getting [him] through high school. We worry that he will not be able to be independent someday.”
Family	*Positive theme* “She completes us. [She] is the favorite for her grand-parents being the youngest member of our

	extended family. I am never bored of her. All my time is for her and I feel that her arrival has brought lots of love, stability and good luck to our life.” *Negative theme* “I think the constant battles (sibling rivalry that may be intensified by his autism) are having a negative effect on our daughter who is 8.”
Marriage	*Negative theme* “She is getting worse and can't imagine what her life will be like with all her current behavior problems. These issues make my husband and I fight, whereas we normally would not.”
Non-specific	“Everything is effected”, “Nothing”
Parent Health	*Negative theme* “I feel constantly stressed with her behaviors. I also am beginning to feel depressed...”
Parenting	*Positive theme* “I spend more time helping her navigate her world and understand ours, by doing this I am privileged to see things from a different angle.” *Negative theme* “As my son has shown increasing symptoms of autism and developmental delays, parenting him has become more and more time consuming.”
Relationship	*Positive theme* “Have connected with parents with kids with differences. Have made a few good friends as a result of families who see [him] for who he is.” *Negative theme* “it's hard to give much to each other (my husband and myself) because we are so emotionally spent. We try to go on date nights at least once or twice a month to connect with each other.”
Services	*Negative theme* “it is extremely difficult to find appropriate babysitting that would not hinder Dominic's behavior progress and skills”

Social/Daily life	*Positive theme* “I feel lucky to have a strong support system, at work and home, that I have had limited issues arise from [his] condition.” *Negative theme* “We avoided social situations and birthday parties and he wore out people who had been friends.”

5. Discussion

Behavioral disturbances, as experienced in an ASD or NDD diagnosis, can have serious implications on the life of the individual experiencing them, as well as the family members of the individual. Individuals with autism are more likely to have comorbidities such as depression, anxiety, stress, and other NDDs (Lai et al., 2019) and present additional unique challenges to caregivers. These unique challenges can be expressed through the variability of the autism experience. One semi-structured interview study captures this with the quote, “There is no normal; what is normal? You could get fifty kids with the same diagnosis and they are all completely different” (Cage, Bird, & Pellicano, 2016). Interventions and treatment plans that support a wide range of developmental behaviors that provide skills to be maintained across the lifespan while supporting the entire family would be beneficial (Hodgetts, Zwaigenbaum, & Nicholas, 2014).

Our study strategically analyzed qualitative data from a caregiver questionnaire survey that aimed to look at the various effects of a child's behavior on the caregiver’s life. Our codebook defined 46 individual codes underlining the main effects found in caregiver responses. We then aggregated data into ten main themes: family, career, child’s well-being, marriage, non-specific (miscellaneous), parent health, parenting, relationship, services, and social/daily life. We input our findings into R (version 3.0.3; https://cran.r-project.org) and generated various graphs comparing findings of two groups: caregivers of individuals with either an ASD or non-ASD spectrum disorder diagnosis. Our findings (Appendix F) presented the same top three themes among caregivers of individuals with ASD and caregivers of individuals with a non-ASD spectrum diagnosis: impacts on family life, social life, and career. This section will elaborate further on the interpretation of our findings, implications for practice and recommendations, and the strengths and limitations.

Interpretation of Findings

Themes.

Family life. As mentioned previously, behavioral disturbances had the most prominent effect on the caregivers' family life, which included effects on the sibling(s) of the child as well. Understandably the variability in the concerns is dependent upon the individual and family dynamic. Caregivers stated that there was an increase of stress and worry for the child in the family as it relates to the child's behavior and independence. Many caregivers voiced concerns on the high level of caregiver dependency, causing further stressors on the child's future in the "real world" as it pertains to maintaining relationships, careers, or even cooking meals for themselves among many other things. In contrast, some caregivers felt positive outcomes in their lives as a result of the child's behavior/diagnosis. Many felt that their lives were "enriched" or changed for the better as their love for their child was something they would not take for granted. Others mentioned seeing their family members more as a result of the diagnosis, where they otherwise would not.

Caregivers consistently expressed concern for the sibling of the diagnosed child ranging from effects on the siblings behavior as a result of unequal divided attention between them to increasing maturity in the sibling as a result of caring for the diagnosed child. Within a family unit, children spend a large majority (if not most) of their time with their siblings unless they are an only child. Given this, behavioral disturbances of one child are likely to have an effect to some degree on the other child. Additionally, caregivers stated the siblings' feelings of anger and resentment towards the child with a diagnosis could be a direct result of the sibling's lack of understanding about the diagnosis. As mentioned in the literature review section, family members of individuals with ASD play a key role in delivering interventions (Richdale & Tennison, 2017) and should be thoroughly involved with understanding the diagnosis and treatment planning.

Social and daily life. Social and daily life was the second most affected aspect of a caregiver's life. Caring for a child with ASD, NDD, or general behavioral disturbances can take up a lot of time and resources over the lifespan. There is a possibility of significant financial burden and psychological impact on the family unit. Factors that contribute to this include ASD-experienced babysitters, paying out-of-pocket for therapy related to the child and self, and feelings of social isolation. Although many of these hardships are recognized among caregivers and families with neurotypical (not displaying autistic or atypical neurological behaviors) children as well, these hardships are likely to be higher in vulnerable populations such as families of individuals with behavioral concerns, for example.

As caregivers try to reduce behavioral outbursts in their child by avoiding meeting people, going in public, avoiding outings, or any other form of stimulation, caregivers become increasingly isolated and develop feelings of loneliness. These feelings become more recognizable with the absence of a strong social-emotional support system. These feelings might be more apparent in single parent households. Hence, it would be important to advocate for workshops or services that allow caregivers and families to recognize these social and daily life changes to gain a better understanding on how to help themselves and ultimately better help their child.

Aside from financial burden, feelings of social isolation, avoiding outings, events and people, the caregivers day-to-day routine could be remarkably altered as a result of caring for their child showcasing the behavioral concerns. Generally, caregivers pointed out how disparate their lives would have been had their child not been in their life. Many caregivers mentioned their everyday life revolving around their child as a result of unpredictability in moods and behaviors. Everyday life consists of marriage life, social life, and career. While negative social and daily life changes are the majority, positive changes are also present as mentioned earlier in this paper; caregivers and family members might view the autism experience for example, as a life-changing one which challenges their priorities, causing the family unit to have a shift in perspective and live in a way they haven’t before.

Career. For these families, sacrifices in everyday life have been clearly evident, with no exception to careers. Caregivers often sacrifice their careers to care for the child with an ASD or NDD diagnosis. Our study findings exhibited career as being the third most affected aspect of a caregivers life. Some positive instances in caregiver careers were mentioned, but the majority mentioned negative experiences. Most responses mentioned either cutting back on work hours to properly care for their child (shifting from full-time to part-time), quitting their job to be a stay at home parent, or struggling with reliability issues as a result of an unpredictable personal schedule. Many responses mentioned feeling “grateful”, “thankful”, and “lucky” to have an understanding and/or flexible workplace that accommodates to their lifestyle. A few caregivers mentioned a positive shift in their careers as a result of caring for their child, such as heading in a new career direction that they wouldn’t otherwise and finding a new meaning in it.

Other themes. Other themes were widely displayed among caregiver responses as well. Many caregivers felt a strain on their own well-being as a result of caring for the child. These mental and physical health concerns mainly consisted of stress and worry, but feelings of anxiety, depression, sleeping challenges and exhaustion were present. Feelings of resentment towards self as associated with judging one's own parenting skills was common as well as resentment towards their child. Mental and physical health concerns were many times associated with other themes such as parenting burden and parenting skills. Some caregivers voiced feelings of guilt in not being the “best” parent they could be.

A handful of responses categorized under non-specific mentioned no changes in their life, or possibly everything was changed. Marriage and relationships were heavily impacted. Only one caregiver response was coded with a positive overall tone, as she mentioned being closer to her husband as a result of the child, whereas prior to the child's birth, they were on the verge of divorce. The majority of the responses in this theme, like others, displayed negative impacts. Many parents came across parenting conflicts with differences on how to discipline the child with behavioral concerns. One parent might feel that they know their son/daughter better than their partner, and that the partner might not understand them or the situation as well as they presumed. Lack of quality time with spouse, decrease in time spent with family, a general lack of understanding from friends and family was common. Caregivers felt that many of their family and friends gradually lost touch with them as they failed to recognize or support them in their hardships with their children. The various responses showcased the way in which families chose to cope with a significant stressor.

Implications for Practice & Recommendations

Using the Transactional Model of Stress and Coping to Understand Caregiver Responses. The Transactional Model of Stress and Coping (TSC; Lazarus & Folkman, 1984) (Table 2 & Figure 2) helped us understand how a caregiver might choose to have a positive experience versus a negative one, in relation to the effects of significant behavioral disturbances on the caregivers' life. The TSC model suggests that primary and secondary appraisal (judgement) stages are made in deciding whether an event is relevant to us and whether or not we have the resources to battle this event. If not, we diverge to various coping mechanisms, both positive and negative.

Utilizing Quantitative Measures. Our study primarily utilized qualitative data to then create a standardized quantitative measure (the codebook) to specifically explore themes in caregiver responses expanding on caregiver stress. A secondary quantitative measure to expand on our codebook findings would be beneficial in understanding a family's strengths and weaknesses as it relates to caring for a child with an ASD or NDD diagnosis. With this, we could advocate for interventions promoting family empowerment for families of children with ASD or a NDD diagnosis. Ideally, these interventions would create learning opportunities for families, environmental modification to promote growth and education, and advocacy. One such measure could be the Family Empowerment Scale (FES).

The FES (Appendix H) is a 34-item scale developed to measure empowerment (regarding family, services, community) within families with children with emotional, behavioral, and/or developmental challenges and how caregivers may feel about his or her situation as indicated by one's behavior, knowledge, and attitude. Ideally, the FES would be modified to include factors or themes that reflect the most affected aspects of a caregivers life as per our findings.

This includes questions regarding family (focusing on caregiver and sibling stress), career, and social/daily life. A modified FES (Appendix I) expands on our understanding of the complexities of being the caregiver experience and can be an impactful framework in developing theory-based interventions to further promote positive outcomes.

The Caregiver Questionnaire allowed caregivers to convey their experiences in an open-ended format where responses varied from sentences to paragraphs, from which we developed a standardized codebook. With a standardized quantitative measure such as the FES, we can expand on our findings with a strengths-based approach. By working with clinical professionals and families in various settings (e.g. in the home, research settings, clinical practices) to set goals, identify problems and strategies we can identify a family's strengths (i.e. knowledge, resources, skills) and maximize their use of coping techniques and resources.

Strengths and Limitations

Strengths. After the development of our codebook, we proceeded to code the qualitative data while blinding ourselves from demographic information and diagnosis code. Additionally, the online data collection method eliminated clinical oversight during the completion of the questionnaire which allowed caregivers to answer the questions without implicit bias from physicians and other healthcare providers. The experiences of a family unit with a family member that has an ASD or NDD diagnosis are highly variable. The Caregiver Questionnaire allowed for respondents to share their true thoughts, feelings, and emotions towards the questions and their personal experiences. While most quantitative measures only address impact on caregivers with pre-determined domains, the measures in our study were driven by caregiver's responses'. Therefore, we were able to identify domains (e.g. career, relationship strain, parental health) that were not addressed in other existing questionnaires (e.g. Family Empowerment Scale is limited to impact on the caregivers' lives and not the whole family. Parenting Sense of Competence is available to measure parents' stress).

Limitations. While there are many strengths with having a qualitative analysis study design, limitations are present as well. The qualitative data available to us was up to the interpretation of the reader and therefore lacked objectivity and presented possible implicit bias as both researchers read through the responses. This was combated with the use of the kappa value to measure inter-reliability between the coding team. The qualitative data findings were difficult to analyze and generalize, as many responses fit into multiple themes and categories. An example of this is a caregiver mentioning a direct impact on the sibling of the child displaying behavioral concerns, with the sibling displaying signs of maturity. While this statement could be implied as a negative or positive theme, it is entirely dependent on the context of the statement. For the purposes of this study, all the responses that shared this code expressed this as a positive change in their life and therefore was coded as a positive theme. Another major limitation of our study is that we did not control for factors such as age, sex, IQ, co-morbidities, and SES status, which can manipulate the impact of the diagnoses.

Conclusion

Our findings shed a spotlight on the various effects a child's behavior has on the life of the caregiver and family unit. This was made evident through our codebook findings to the question "*What effects has your son/daughter had on other aspects of your life? (Marriage, family relations, social relations, work situation, etc.)"* particularly on family life, social life, and career. While individual experiences varied from family to family, the themes were consistent throughout the data. Additional research and services could utilize quantitative measures that expand on caregiver perceptions of their difficulties through a strengths perspective; this would help clinicians to help families identify various positive measures of their parenting, psychological well-being, social-emotional support, and more. Ultimately, caregivers and families members would be equipped with the tools and resources to maintain these skills over the lifespan. If families do not have the support or resources to help the child with ASD needs, efforts become delayed and quality of life is hindered for both the child and the family unit of the child. Autistic children see the world through a different lens. For a caregiver and family unit, caring for a child with autism or another NDD has various effects on the lives of everybody involved. Caregiver stress negatively affects caregiver health and well-being, limits the attention caregivers can provide to other relationships in their life, interferes with effective parenting skills, and counteracts the effects of interventions and clinical services. In order to address caregiver and family stress, we should consider the individual family dynamic when providing future interventions, clinical services, and healthcare burdens. Caregiver stressors and demands outweigh ASD-related resources available to them. Caregivers should ideally utilize all resources available to them, seek social support and mental health treatment for themselves, and find positive meaning in their diagnosis. By doing so, care dynamic can drastically be changed for the better.

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Appendices

Appendix A

Identified Prevalence of Autism Spectrum Disorder

CDC's Autism and Developmental Disabilities Monitoring Network (ADDM) combines data from all 11 sites of their sites (Arizona, Arkansas, Colorado, Georgia, Maryland, Minnesota, Missouri, New Jersey, North Carolina, Tennessee, and Wisconsin) to show the increase in prevalence throughout years 2000-2016.

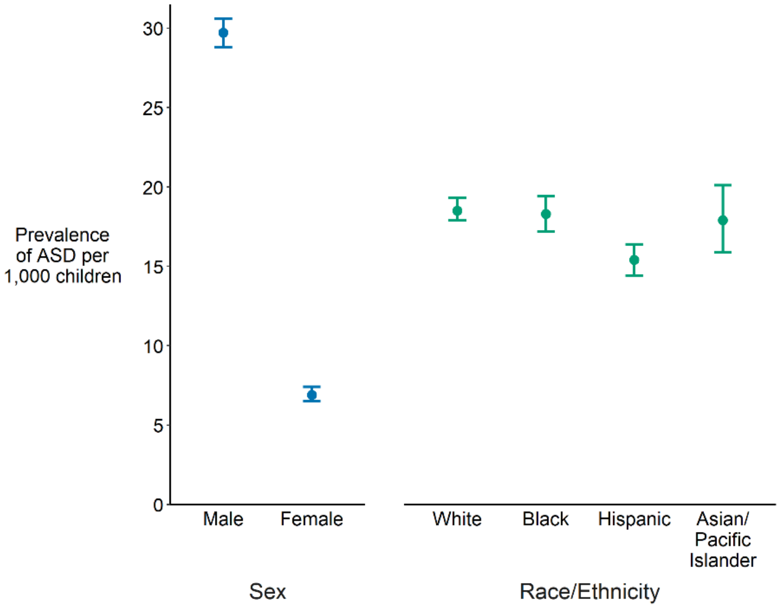
Identified Prevalence of Autism Spectrum Disorder

ADDM Network 2000-2016 Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Combined Prevalence per 1,000 Children (Range Across ADDM Sites)	This is about 1 in X children...
2000	1992	6	6.7 (4.5-9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88
2010	2002	11	14.7 (5.7-21.9)	1 in 68
2012	2004	11	14.5 (8.2-24.6)	1 in 69
2014	2006	11	16.8 (13.1-29.3)	1 in 59
2016	2008	11	18.5 (18.0-19.1)	1 in 54

Appendix B

Prevalence of autism spectrum disorder showing a large discrepancy in diagnosis between males and females. Among race and ethnicities, Latinos are shown as having the lowest prevalence in ASD as compared to whites, blacks, and asian/pacific islanders, primarily because of the low testing rates.

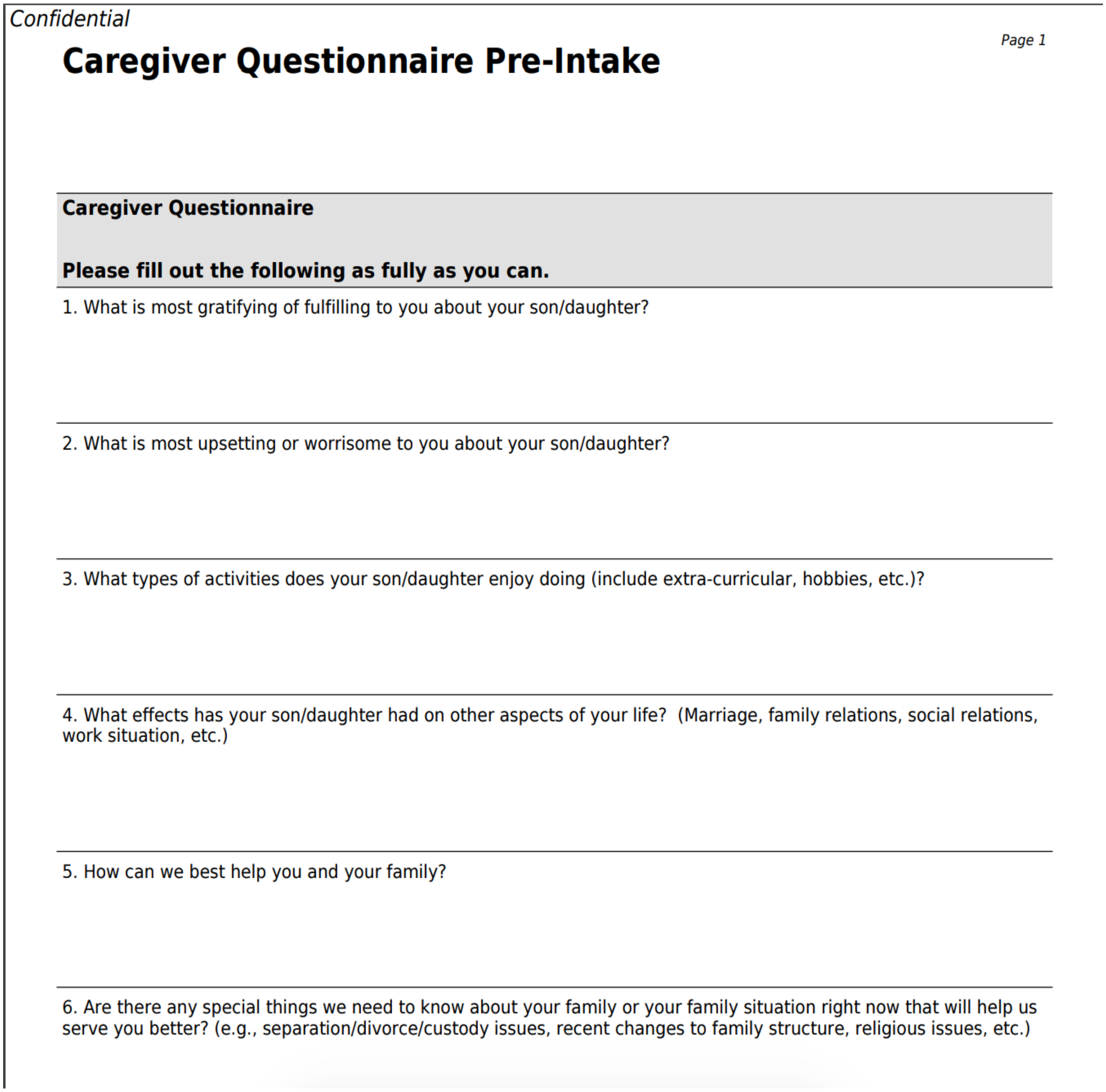


Prevalence of autism spectrum disorder per 1,000 children aged 8 years, by sex and race/ethnicity

Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2016

Appendix C

Caregiver Questionnaire Pre-Intake Form



Confidential

Page 1

Caregiver Questionnaire Pre-Intake

Caregiver Questionnaire

Please fill out the following as fully as you can.

1. What is most gratifying of fulfilling to you about your son/daughter?

2. What is most upsetting or worrisome to you about your son/daughter?

3. What types of activities does your son/daughter enjoy doing (include extra-curricular, hobbies, etc.)?

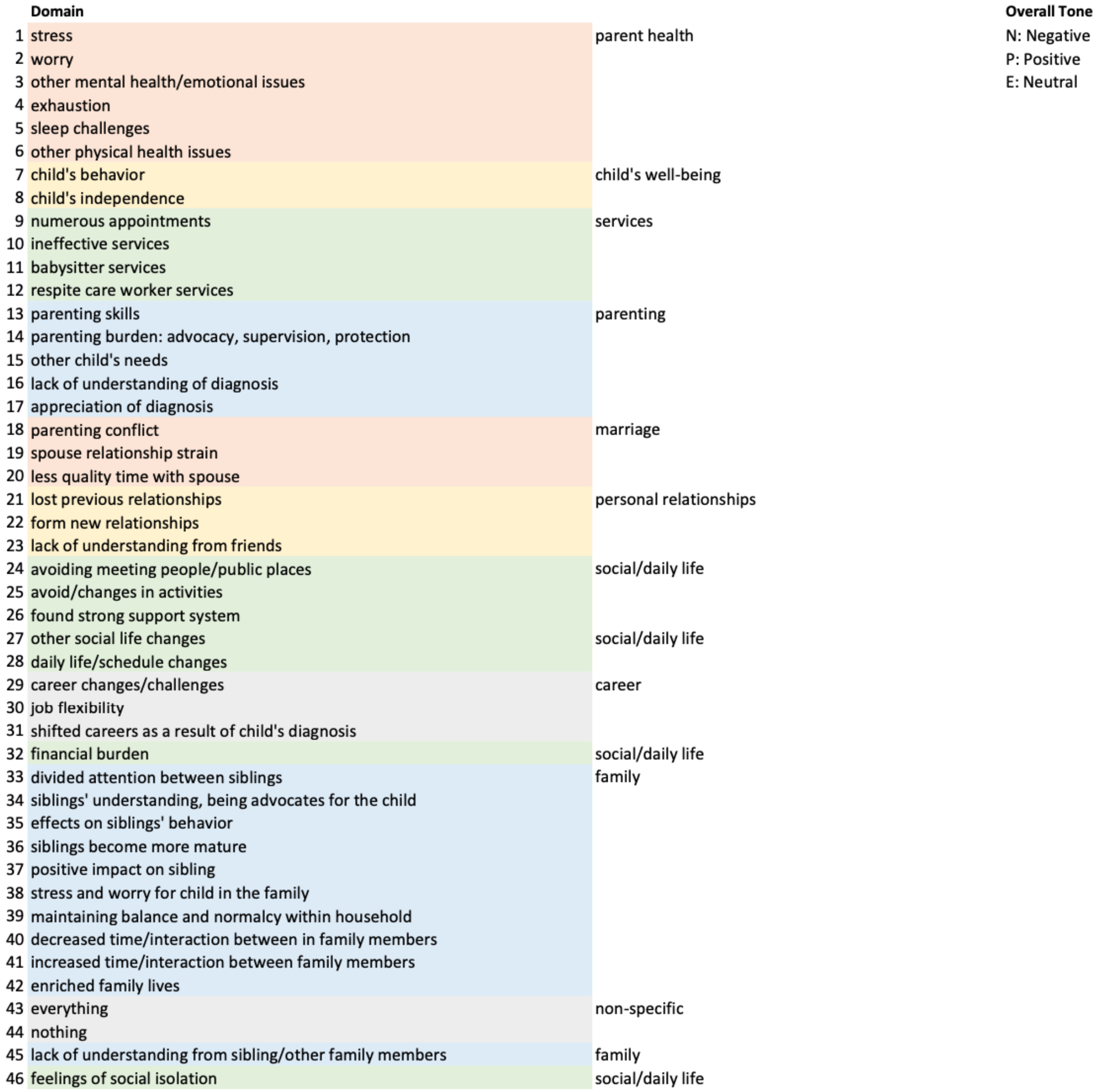
4. What effects has your son/daughter had on other aspects of your life? (Marriage, family relations, social relations, work situation, etc.)

5. How can we best help you and your family?

6. Are there any special things we need to know about your family or your family situation right now that will help us serve you better? (e.g., separation/divorce/custody issues, recent changes to family structure, religious issues, etc.)

Appendix D

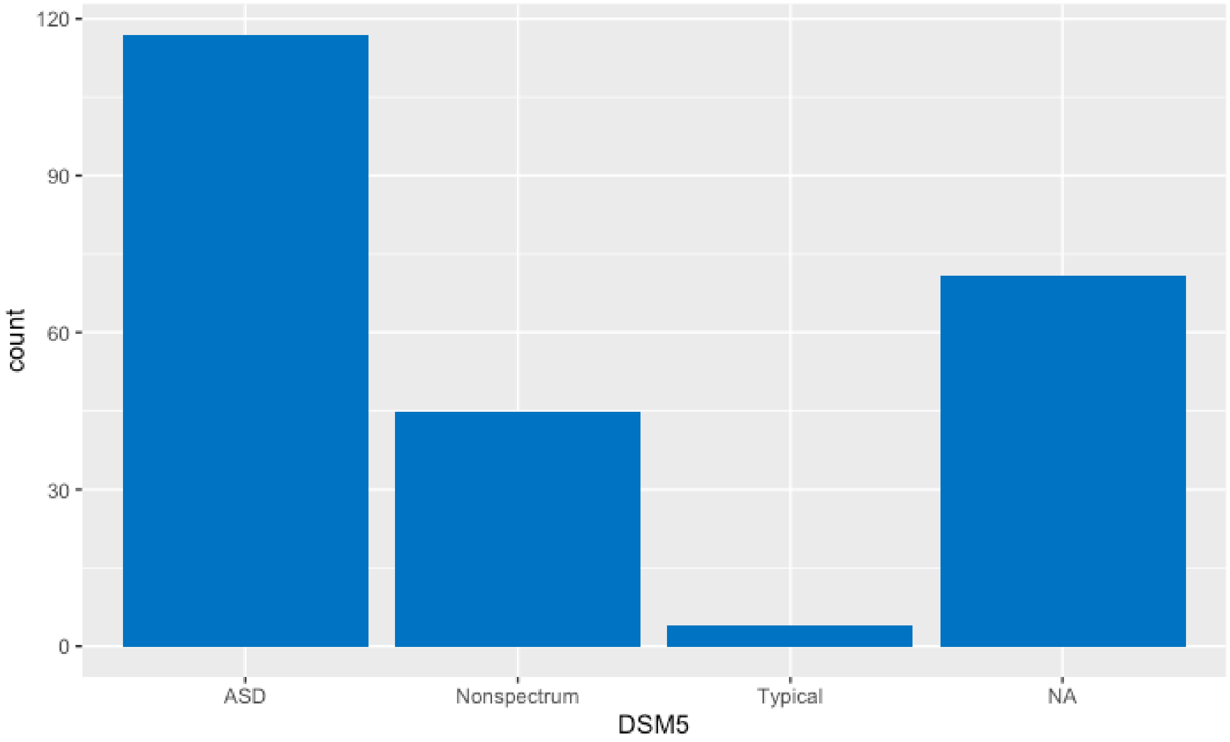
Final Codebook



	Domain		Overall Tone
1	stress	parent health	N: Negative
2	worry		P: Positive
3	other mental health/emotional issues		E: Neutral
4	exhaustion		
5	sleep challenges		
6	other physical health issues		
7	child's behavior	child's well-being	
8	child's independence		
9	numerous appointments	services	
10	ineffective services		
11	babysitter services		
12	respite care worker services		
13	parenting skills	parenting	
14	parenting burden: advocacy, supervision, protection		
15	other child's needs		
16	lack of understanding of diagnosis		
17	appreciation of diagnosis		
18	parenting conflict	marriage	
19	spouse relationship strain		
20	less quality time with spouse		
21	lost previous relationships	personal relationships	
22	form new relationships		
23	lack of understanding from friends		
24	avoiding meeting people/public places	social/daily life	
25	avoid/changes in activities		
26	found strong support system		
27	other social life changes	social/daily life	
28	daily life/schedule changes		
29	career changes/challenges	career	
30	job flexibility		
31	shifted careers as a result of child's diagnosis		
32	financial burden	social/daily life	
33	divided attention between siblings	family	
34	siblings' understanding, being advocates for the child		
35	effects on siblings' behavior		
36	siblings become more mature		
37	positive impact on sibling		
38	stress and worry for child in the family		
39	maintaining balance and normalcy within household		
40	decreased time/interaction between in family members		
41	increased time/interaction between family members		
42	enriched family lives		
43	everything	non-specific	
44	nothing		
45	lack of understanding from sibling/other family members	family	
46	feelings of social isolation	social/daily life	

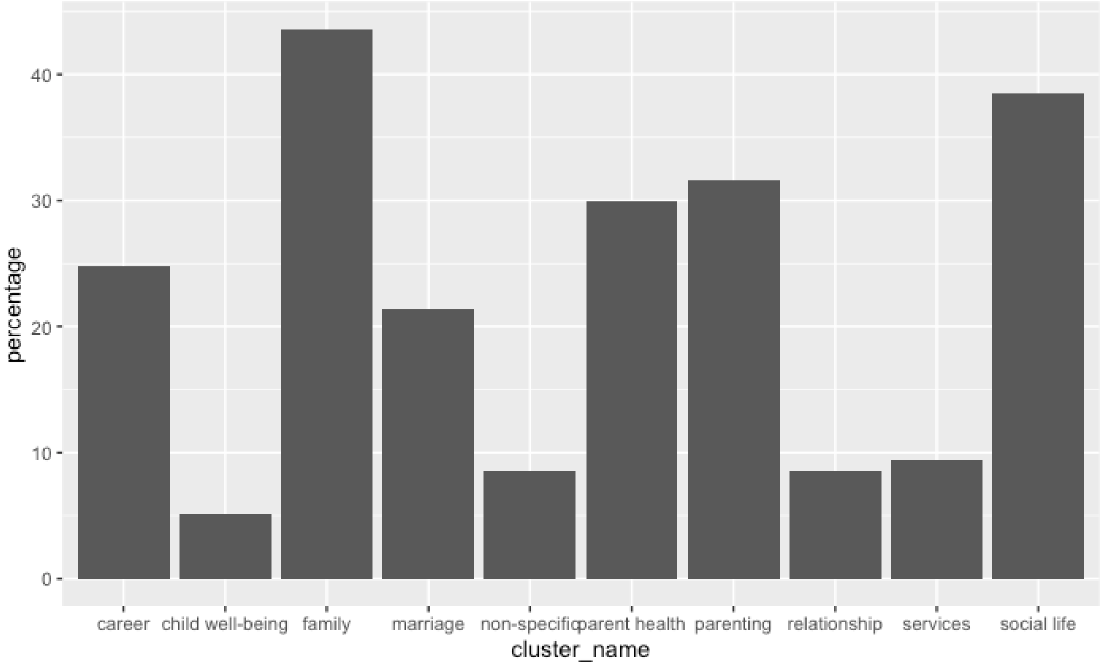
Appendix E

Frequency of DSM-V diagnosis codes in patients

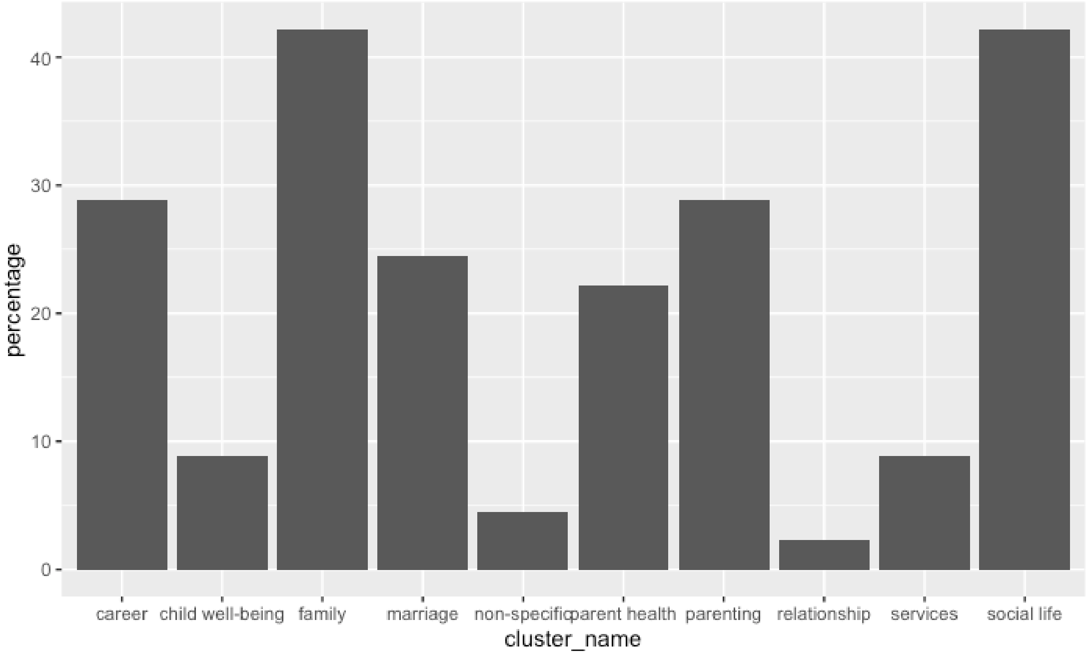


Appendix F

Frequency of themes in caregiver responses in ASD-diagnosed individuals and non-ASD spectrum diagnosed individuals



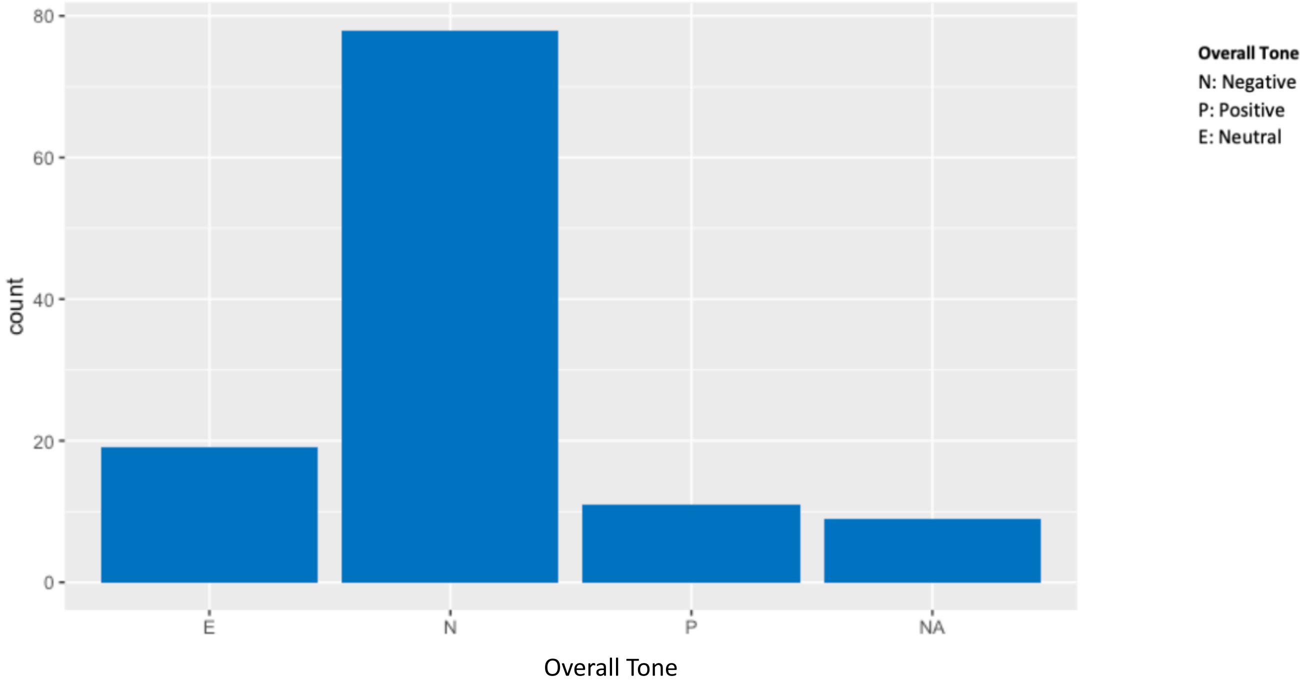
ASD-diagnosed individual



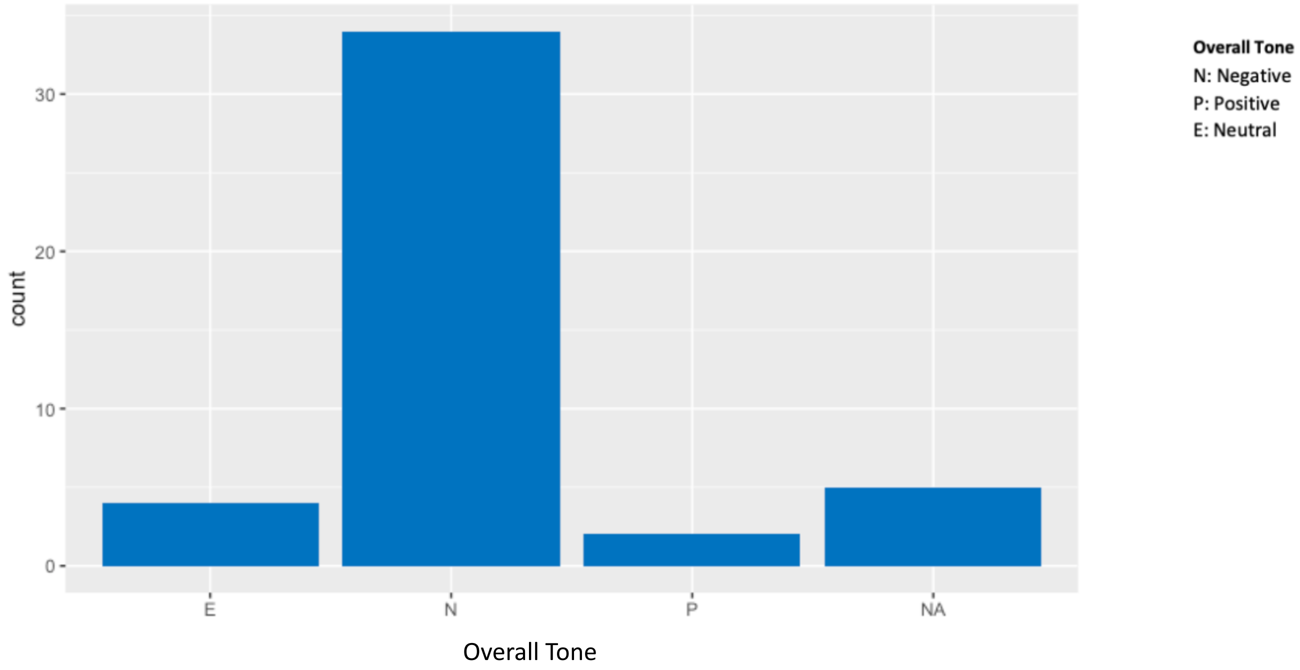
Non-ASD spectrum diagnosed individual

Appendix G

Frequency of feelings of positivity, negativity, or neutrality in overall caregiver responses in ASD-diagnosed individuals and non-ASD spectrum diagnosed individuals



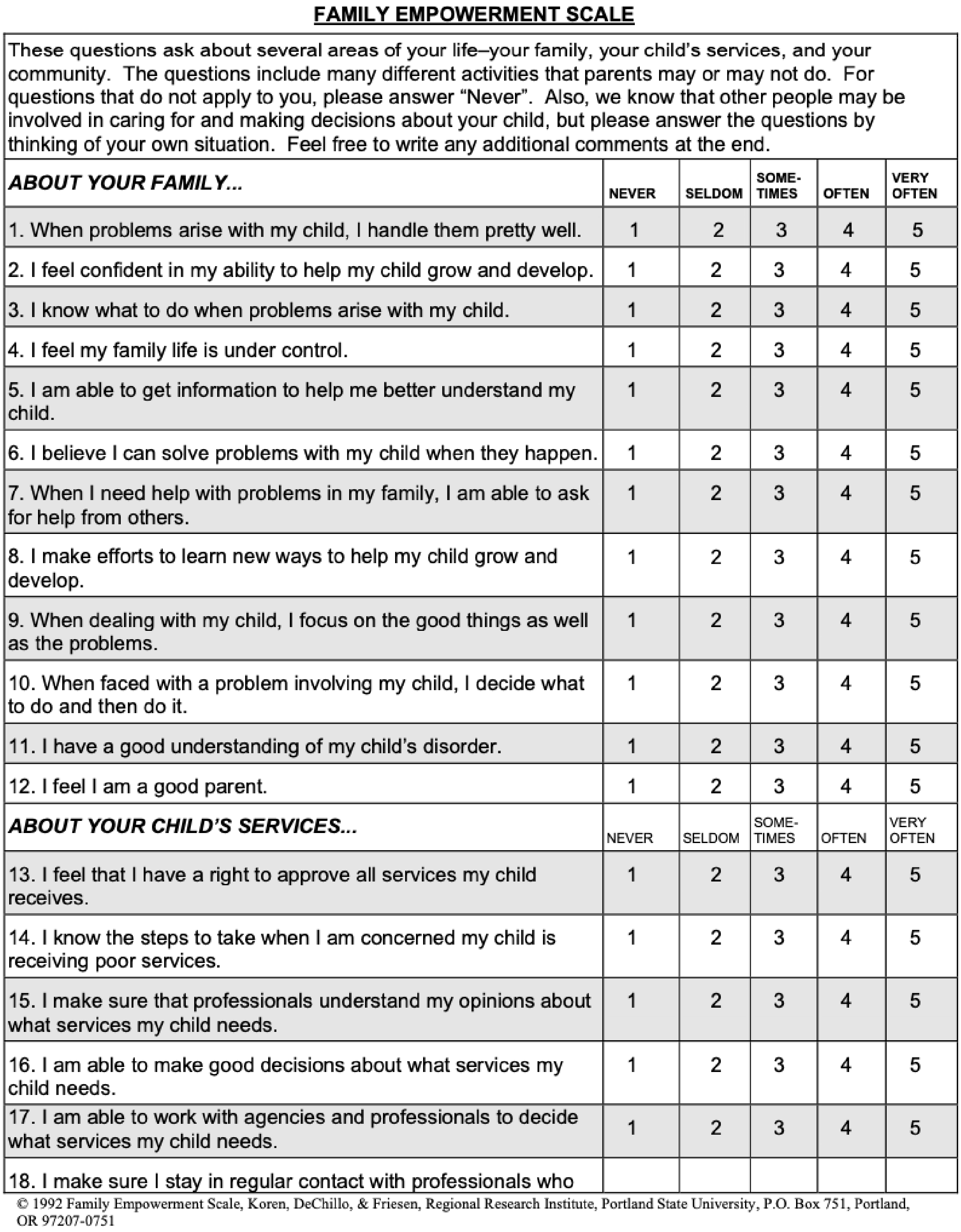
ASD-diagnosed individual



Non-ASD spectrum diagnosed individual

Appendix H

Family Empowerment Scale and Scoring



FAMILY EMPOWERMENT SCALE

These questions ask about several areas of your life–your family, your child's services, and your community. The questions include many different activities that parents may or may not do. For questions that do not apply to you, please answer "Never". Also, we know that other people may be involved in caring for and making decisions about your child, but please answer the questions by thinking of your own situation. Feel free to write any additional comments at the end.

ABOUT YOUR FAMILY...	NEVER	SELDOM	SOME-TIMES	OFTEN	VERY OFTEN
1. When problems arise with my child, I handle them pretty well.	1	2	3	4	5
2. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
3. I know what to do when problems arise with my child.	1	2	3	4	5
4. I feel my family life is under control.	1	2	3	4	5
5. I am able to get information to help me better understand my child.	1	2	3	4	5
6. I believe I can solve problems with my child when they happen.	1	2	3	4	5
7. When I need help with problems in my family, I am able to ask for help from others.	1	2	3	4	5
8. I make efforts to learn new ways to help my child grow and develop.	1	2	3	4	5
9. When dealing with my child, I focus on the good things as well as the problems.	1	2	3	4	5
10. When faced with a problem involving my child, I decide what to do and then do it.	1	2	3	4	5
11. I have a good understanding of my child's disorder.	1	2	3	4	5
12. I feel I am a good parent.	1	2	3	4	5
ABOUT YOUR CHILD'S SERVICES...	NEVER	SELDOM	SOME-TIMES	OFTEN	VERY OFTEN
13. I feel that I have a right to approve all services my child receives.	1	2	3	4	5
14. I know the steps to take when I am concerned my child is receiving poor services.	1	2	3	4	5
15. I make sure that professionals understand my opinions about what services my child needs.	1	2	3	4	5
16. I am able to make good decisions about what services my child needs.	1	2	3	4	5
17. I am able to work with agencies and professionals to decide what services my child needs.	1	2	3	4	5
18. I make sure I stay in regular contact with professionals who					

are providing services to my child.	1	2	3	4	5
19. My opinion is just as important as professionals' opinions in deciding what services my child needs.	1	2	3	4	5
20. I tell professionals what I think about services being provided to my child.	1	2	3	4	5
21. I know what services my child needs.	1	2	3	4	5
22. When necessary, I take the initiative in looking for services for my child and family.	1	2	3	4	5
23. I have a good understanding of the service system that my child is involved in.	1	2	3	4	5
24. Professionals should ask me what services I want for my child.	1	2	3	4	5
ABOUT YOUR INVOLVEMENT IN THE COMMUNITY...	NEVER	SELDOM	SOME-TIMES	OFTEN	VERY OFTEN
25. I feel I can have a part in improving services for children in my community.	1	2	3	4	5
26. I get in touch with my legislators when important bills or issues concerning children are pending.	1	2	3	4	5
27. I understand how the service system for children is organized.	1	2	3	4	5
28. I have ideas about the ideal service system for children.	1	2	3	4	5
29. I help other families get the services they need.	1	2	3	4	5
30. I believe that other parents and I can have an influence on services for children.	1	2	3	4	5
31. I tell people in agencies and government how services for children can be improved.	1	2	3	4	5
32. I know how to get agency administrators or legislators to listen to me.	1	2	3	4	5
33. I know what the rights of parents and children are under the special education laws.	1	2	3	4	5
34. I feel that my knowledge and experience as a parent can be used to improve services for children and families.	1	2	3	4	5

COMMENTS____

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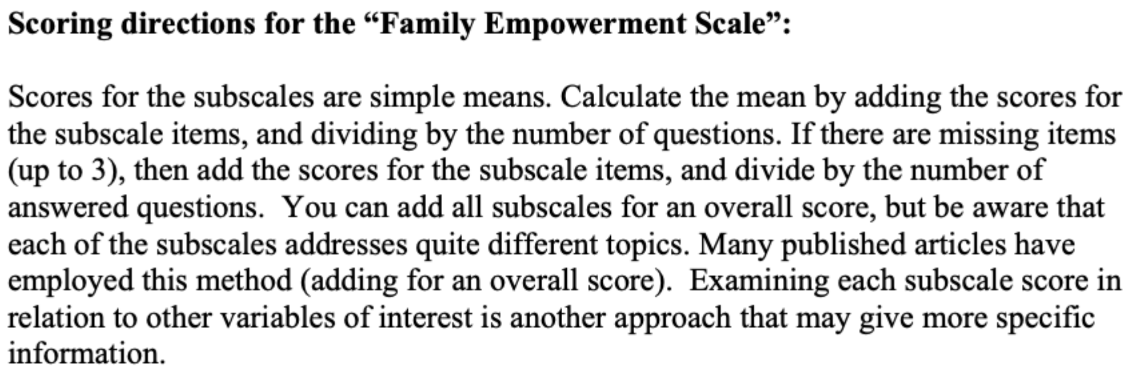

Scoring directions for the "Family Empowerment Scale":

Scores for the subscales are simple means. Calculate the mean by adding the scores for the subscale items, and dividing by the number of questions. If there are missing items (up to 3), then add the scores for the subscale items, and divide by the number of answered questions. You can add all subscales for an overall score, but be aware that each of the subscales addresses quite different topics. Many published articles have employed this method (adding for an overall score). Examining each subscale score in relation to other variables of interest is another approach that may give more specific information.

Appendix I

Modified FES for caregivers of children with ASD, NDD, or other behavioral disturbances

ABOUT YOUR FAMILY…	**NEVER**	**SELDOM**	**SOME-TIMES**	**OFTEN**	**VERY OFTEN**
1. When problems arise with my child, I handle them pretty well.	1	2	3	4	5
2. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
3. I know what to do when problems arise with my child.	1	2	3	4	5
4. I feel as if my family life is under control.	1	2	3	4	5
5. My child's sibling feels equally supported.	1	2	3	4	5
6. My child's sibling has an understanding of the diagnosis.	1	2	3	4	5
7. When I need help from others in my family, I am able to ask for help.	1	2	3	4	5
8. My family and I make efforts to learn new ways to help my child grow and develop	1	2	3	4	5
9. When dealing with my child, I focus on the good things as well as the problems.	1	2	3	4	5
10. My family has a good understanding of my child's diagnosis.	1	2	3	4	5
11. I have a good understanding of my child's diagnosis.	1	2	3	4	5

12. I feel like I am a good parent.	1	2	3	4	5
ABOUT YOUR SOCIAL/DAILY LIFE…	**NEVER**	**SELDOM**	**SOME-TIMES**	**OFTEN**	**VERY OFTEN**
1. I have someone I can talk to about my stress and worries.	1	2	3	4	5
2. I am able to maintain my personal relationships.	1	2	3	4	5
3. I have hobbies and interests that I maintain.	1	2	3	4	5
4. I am able to maintain my personal health, mental and physical.	1	2	3	4	5
5. I have a strong financial support system.	1	2	3	4	5
6. I am friends with other parents and families that share similar experiences as myself.	1	2	3	4	5
7. My friends understand me and my child’s behavior.	1	2	3	4	5
ABOUT YOUR CAREER	**NEVER**	**SELDOM**	**SOME-TIMES**	**OFTEN**	**VERY OFTEN**
8. I feel supported at my workplace in regards to my child’s needs.	1	2	3	4	5
9. My workplace is understanding of my parenting schedule and duties.	1	2	3	4	5
10. My workplace is flexible with my schedule	1	2	3	4	5
11. I have been able to consistently maintain my hours at work.	1	2	3	4	5

12. I have never felt that I would be judged at my workplace because of my child’s needs.	1	2	3	4	5

COMMENTS:

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