Development and validation of the Accommodations and Impact Scale for Developmental Disabilities

Thesis

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Abstract

The lives of caregivers are deeply impacted by having a child with a developmental disability. To offset some of those impacts, caregivers may engage in accommodations, aiming to support the needs of their child. These accommodations and impacts fluctuate as the needs of their child change and can cumulatively affect the quality of life and well-being of caregivers. Despite this, they are not often captured during assessment of family needs or treatment planning. Thus, it is important to have a scale that can be used to evaluate how to support families of children with developmental concerns.

In the current study, the Accommodations & Impact Scale for Developmental Disabilities (AISDD) was developed and evaluated for its psychometric properties. The AISDD is a 19-item questionnaire that measures the accommodations and impacts of caring for a child with a developmental disability. A sample of 407 caregivers of youth with intellectual disability, autism spectrum disorder, or both (average age = 11.7 years; 63% males) rated their child on a pool of 30 items, along with similar measures of accommodations and impacts (Parenting Daily Hassles scale [PDH] and Caregiver Strain Questionnaire [CSQ], respectively), a measure of adaptive functioning (Adaptive Behavior Assessment System - 3rd edition), and a measure of disruptive behaviors (Nisonger Child Behavior Rating Form).

Factor analysis of the AISDD suggested a one-factor solution. Items had high factor loadings (mean = .65), and the total score was normally distributed. The scale demonstrates high internal consistency (ordinal alpha = .93) and excellent test-retest reliability (ICC = .95). AISDD scores were negatively associated with age (r = -.19), had no association with gender, and differed by diagnosis (ASD+ID > ASD only > ID only). As expected, there was a negative correlation with adaptive functioning (r = -.35) and a positive association with challenging behaviors (e.g., NCBRF subscales were all significant and ranged from Anxious/Insecure r = .22 to Hyperactive r = .57). Convergent validity with the PDH (Frequency: r = .77, Intensity: r = .69) and CSQ (r = .77) was strong. The current study fills a gap in the literature, as it provides a brief, reliable measure of caregiver accommodations and impacts that was developed to be sensitive to change over time.

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Fields of Study

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Chapter 1. Introduction

Having a child with a developmental disability (DD) influences all aspects of one's life, even the minutia of day-to-day tasks. Along with delays in developmental milestones, children with DD often experience challenges with regulating behavior and emotions as well as keeping up with tasks of independent functioning. In order to address and offset some of these concerns, caregivers will often make frequent visits to medical and specialty care, which likely leads to referral to specialized services, such as speech, physical, behavior, and occupational therapy. The provision of changes that occur in the life of a caregiver of a child with DD accumulate, leading to both day-to-day impacts as well as accommodations that aim to offset those impacts.

Impacts of having a child with a DD

Caregivers of children with DD are responsible for identifying services and appropriate schooling for their child, communicating with health care professionals, and navigating the wealth of knowledge that is presented to them as they learn about their child's disability. Indeed, raising a child with special needs confers profound changes to almost every aspect of a caregiver's life. These impacts are defined broadly as effects of raising a child with special needs. Short-term, day-to-day impacts can include staying in instead of going out because it is difficult to find a specialized babysitter, avoiding extraneous purchases because of financial constraints, and getting little sleep. Short-term caregiver impacts have often been referred to in the literature as "caregiver strain" or "caregiver burden," which mainly refer to the perceived negative effects of raising a child with special needs (Bradshaw et al., 2020; Brannan et al., 2012). Caregiver strain can be objective or subjective. Objective strain can include the observable effects on daily life, including employment, finances, and routines, whereas subjective strain refers to emotional or psychological effects. Among caregivers of children with autism spectrum disorder (ASD), high levels of both objective and subjective caregiver strain were found, especially among those with more behavioral or emotional problems (Bradshaw et al., 2020; Stuart & McGrew, 2009). Similarly, among caregivers of youth with attention deficit/hyperactivity disorder (ADHD), co-occurring disorders predicted higher levels of caregiver strain (Rockhill et al., 2013).

High levels of strain may be an indication of unmet services and needs on the part of the family (Khanna et al., 2011; McManus et al., 2011; Shivers et al., 2017). If left unaddressed, these short-term impacts can accumulate and lead to significant long-term impacts (Harper et al., 2013; Khanna et al., 2011; Shivers et al., 2017). For example, caregiver burden has continuing effects on the mental health-related quality of life (Khanna et al., 2011; Marsack-Topolewski & Church, 2019) and marital quality (Harper et al., 2013) of caregivers whose children have ASD. Despite serving as a significant predictor of long-term impact, there has been very little research to examine the short-term, day-to-day impacts of raising a child with special needs. Instead, the vast majority of the literature is focused on long-term impacts. The long-term impacts of raising a child with a DD are multi-faceted in nature. From physical to psychological to financial, impacts reveal where services and supports are needed, as well as how the lives of families have improved from caring for a child with a DD. In the following section, the literature on long-term impacts is summarized.

Mental and Physical Health

Mental health is commonly impacted in the lives of caregivers of children with special needs, such that overwhelming challenges and stressors are often reported (Gardiner et al., 2018). Caregivers of children with DD are more likely to experience depression, anxiety, and stress, especially if their child also exhibits frequent challenging behaviors, such as externalizing symptoms, self-injurious behaviors, irritability, sleep difficulties, and emotional dysregulation (Bujnowska et al., 2019; Ferguson, 2002; Gallagher et al., 2018; Hoyle et al., 2020; Neece & Chan, 2017; Singer, 2006; Valicenti-Mcdermott et al., 2015) or if parents themselves reported poor sleep quality (Gallagher et al., 2010).

Not only is mental health implicated among caregivers of young children with various forms of developmental disabilities (Masefield et al., 2020), but physical health is as well. In fact, caring for a child with a DD can be considered a chronic source of stress (or ‘wear and tear’) that cumulatively leads to the disruption of allostasis (i.e. ability of one’s body to adapt to stress; McEwen, 2006). Over time, chronic stressors contribute to a high allostatic load, which can deteriorate overall physical health, implicating the cardiovascular system, immune system, gastrointestinal tract, and central nervous system (Miodrag & Hodapp, 2011). Further, caregivers are also more likely to report bodily pain or injuries, from instances such as regularly lifting their child or being a recipient of their child’s impulsive or aggressive behaviors (Murphy et al., 2007).

Financial Impact

Cumulatively, financial constraints are a significant effect of raising a child with medical, psychological, physical, and occupational needs. Families of children with ASD and intellectual disability (ID) are more likely to report financial problems and have a caregiver quit their job due to the child’s disability (Vohra et al., 2014). Mothers, especially, were less likely to have jobs that lasted longer than five years. Even as their children aged, mothers of children with DDs were less likely to have full-time jobs than mothers of typically developing children (Parish et al., 2004). Further, the more complex the needs of the child, the more the family finances were impacted (Ouyang et al., 2014).

Resilience

Not only is it important to discuss the challenges faced by families of children with DD, but it is also important to be aware of the strengths that caregivers gain throughout the experience. Notably, raising a child with a DD can foster resilience. Families of children with DDs often report that their child fostered opportunities for personal growth, increased their sense of purpose in life, strengthened their familial bond, and expanded their social and community networks (Cho et al., 2000; Scorgie & Sobsey, 2000; Taunt & Hastings, 2002). Indeed, qualities such as compassion, tolerance, selflessness, confidence, and strength were all attributed to having a child with a DD. Parents were also better attuned to the positive aspects of raising a child and celebrated the small achievements in their lives (Cho et al., 2000; Taunt & Hastings, 2002). A new perspective encouraged them to recognize what is important in life in order to be able to make the most of each day (Taunt & Hastings, 2002). Finally, reframing their views also helped caregivers garner hope in the face of adversity (Kausar et al., 2003).

Taken together, caregiver impacts can be categorized as short-term or long-term and beneficial or challenging; this conceptualization serves to capture the multifarious effects of caring for a child with DD. These impacts are amenable to change, as caregivers learn to adjust, or *accommodate*, their behaviors to the child’s needs and thereby mitigate the challenging impacts of raising a child with a DD.

Caregiver Accommodations in DD

While impact refers to the consequences or effects of the developmental delays, accommodations refer to the strategies that caregivers employ to prevent or minimize the effects of their child’s developmental delay. Accommodations are ubiquitous in the daily lives of caregivers of children with DD. These caregiver accommodations have been defined in the literature as functional day-to-day adjustments in response to raising a child with a DD (Gallimore et al., 1989, 1993; Keogh et al., 2000). The current study conceptualizes accommodations as daily caregiver adjustments that facilitate everyday functioning of their child with a DD.

Examples of accommodations include reducing the number of demands placed on a child, assisting with or completing manageable tasks for the child, acquiescing to the child’s requests, or avoiding exposure to situations or settings that are more likely to stir instances of disruptive behavior (Maul & Singer, 2009; Storch et al., 2007). Caregiver accommodations can often be vital to the functions of day-to-day life, especially in cases where they serve to keep the child safe (e.g., constantly supervising child so they do not inadvertently or intentionally hurt themselves or their siblings) or healthy (e.g., preparing separate meals to suit their particular diet or taste). Though accommodations can be taxing on parents of children with DD, they can also be crucial for reducing stress and challenging behaviors in the short term (Kagan et al., 2017; Rovane et al., 2020; Storch et al., 2007).

While accommodations can serve as a helpful strategy for reducing short-term impacts, they may have downstream negative effects on long-term impacts. Thus, accommodations may provide insight into which families are susceptible to long-term challenging impacts than others (Piazza et al., 2014; Seltzer et al., 2004). This is crucial, as long-term physical and psychological impacts are pervasive among families of children with DD (Magaña & Smith, 2006; Minnes & Woodford, 2004), not only within parents but the entire family structure (Head & Abbeduto, 2007).

Accommodations are a continuing feature of everyday life that fluctuates in scope and intensity across the lifespan (Freedman et al., 1995; Gallimore et al., 1996), but persists in moderating the relationship between the child's characteristics and the family's daily routine (Gallimore et al., 1996). Accommodations can look very different across time and families, but common themes that emerged during interviews with caregivers of youth with DDs include providing copious structure in their child's day, adjusting the timing or the pace of activities in their day, changing work schedules, and planning almost every activity in advance (Bernheimer & Weisner, 2007; Maul & Singer, 2009). These accommodations are decided by caregivers through a trial and error process, eventually landing upon accommodations that fit the family's lifestyle and preferences (Maul & Singer, 2009). For example, some families may patronize restaurants that offer special seating arrangements suitable for their child, while other families may avoid restaurants altogether (Maul & Singer, 2009). Additionally, some families may choose to take their child to schools outside their community, while other families may not have the resources to do so (Cho et al., 2000).

In this manner, accommodations may explain why prescribed interventions and treatments are not followed through for some families. Many are unable to do so because these treatment plans do not fit into the lives of families, with accommodations already consuming so much of their physical and mental resources (Bernheimer & Weisner, 2007). While accommodations may differ across a child’s development and across families, they all share a purpose in facilitating the lives of children with special needs and minimizing the short-term challenging impacts that are a result of the disability.

Constructs Related to Accommodations

There are several constructs related to accommodations that are described in the literature. These include coping, supports, and parenting daily hassles. These constructs do not consider the extent to which the family has altered their day-to-day behaviors to facilitate the functioning of their child with DD. In the following sections, these three constructs that are relevant to accommodations are described.

Coping

Conceptually, accommodations differ from psychological coping. Coping, or positive adaptations (Daire et al., 2014), occurs when families restructure their goals (Brandstadter & Renner, 1990) and perceptions (Glidden et al., 2006; Taunt & Hastings, 2002) in response to having a child with a DD. Strategies such as these involve cognitive restructuring/reframing, and are associated with (and often vital to achieving) positive outcomes for families of children with special needs (Dyches et al., 2012; Nachshen & Minnes, 2005; Ncube et al., 2018; Seltzer et al., 2004). Accommodations differ from coping because they reflect the behavioral changes (as opposed to the cognitive modifications) that a family may engage in to best care for their child. Families who exhibit positive coping methods, including a focus on family integration, engagement, and optimism tend to be less stressed overall (Jones & Passey, 2004; Piazza et al., 2014). Further, positive reappraisal and problem-focused coping strategies predict higher subjective well-being, whereas emotion-focused strategies and escape-avoidance are associated with lower subjective well-being (Glidden et al., 2006). Coping strategies are paramount in the lives of caregivers of children with DDs, as they can lead to lower depressive and physical symptoms, greater perceived parental efficacy, and higher levels of self-acceptance (Seltzer et al., 2004; Woodman & Hauser-Cram, 2013).

Supports

Accommodations may resemble, or even encompass, supports. Supports are defined as any action or resource that enhances individual functioning (Luckasson et al., 2002) or involvement and integration in the community (Thompson et al., 2002). Both supports and accommodations can serve to bolster the level of functioning in the day-to-day lives of children with a DD (e.g., providing constant structure for child, spending more time toilet training). What differentiates supports from accommodations is that supports reflect the assistance that the individual with DD needs as part of his/her medical home. In other words, the focus of supports is to understand what form of assistance an individual may need to enhance independent functioning and considers the multitude of health care professionals who are involved in an individual’s care (e.g., speech therapist, occupational therapist, psychologist, caregiver), encompassing not only the supports provided by the caregiver, but also the day-to-day behaviors associated with having a child with a DD that could be modified or targeted with treatment. As an example, a visual schedule of a bedtime routine is considered a support, whereas spending hours getting one’s child to bed would be an accommodation. Both may function to bolster a desired behavior (sleep), but one is less sustainable for caregivers.

The support needs of individuals with DD are often extensive, ranging across various areas of functioning and can be provided anywhere from the home to school to the community (Thompson et al., 2014). Although the precise nature and extent to which supports are needed depend on the individual (Thompson et al., 2009), support needs are generally high across all domains of functioning in adults with ID in comparison with nondisabled peers (Wehmeyer et al., 2012). The Supports Intensity Scale - Children's version (Thompson et al., 2014; SIS) is a caregiver survey that assesses the nature and level of supports that youth with DDs require. However, the SIS is not specific to caregiver-provided supports but is rather focused on any support that the individual with a DD needs, whether it be provided by a teacher aide at school or a physical therapist at home. In contrast, accommodations focus solely on the role of the caregiver, encompassing not only the adjustments that caregivers make in order to provide supports, but also adjustments that may be amenable with intervention. These adjustments are referred to in the literature as "parenting daily hassles."

Daily Hassles

Parenting daily hassles refers to the minor stresses that caregivers often experience as a result of raising a child (Crnic & Booth, 1991). In addition to supports, daily hassles are also encapsulated within accommodations. Examples of both daily hassles and accommodations can include having to continuously clean up after one's child and avoiding taking one's child in public (e.g., out on errands). In contrast to daily hassles, accommodations also encompass caregiver supports (as mentioned above). In other words, daily hassles alone fail to capture other day-to-day behaviors of caregivers that facilitate the functioning of their child, such as supports. Accommodations identify both daily hassles and the supports provided by caregivers, providing a multi-faceted depiction of the types of adjustments caregivers make everyday.

The Parenting Daily Hassles is a measure of everyday parenting hassles that parents of typically developing children experience, hassles such as frequent cleaning, bathing, and dressing (Crnic & Greenberg, 1990). Because this scale was developed for caregivers of typically developing children, items reflect hassles within the context of non-clinical populations. Among parents of typically developing children, daily hassles are determinants of parental well-being and can differ as a function of parental social support (Crnic & Booth, 1991) and child externalizing behaviors (Coplan et al., 2003).

Studies that have utilized this scale on samples of caregivers of children with DD, including ASD and ADHD, have found high rates of daily hassles in comparison to typically developing counterparts (Quintero & McIntyre, 2010; Rutgers et al., 2007; Stover, 2017; Walerius et al., 2016). Further, daily hassles among caregivers of youth with ASD exceeded those of caregivers with a child with ID (Rutgers et al., 2007).

Significance, Gaps in the Literature, and Goals of the Current Study

While there are existing measures that individually assess some form of impact or accommodations, they are conceptually different from what is proposed here. Further, several of these measures are cumbersome to complete or not designed for caregivers of children with DD (especially ID). Moreover, none of the existing measures quantify *both* impact and accommodations. Given these limitations, the current study aims to develop and validate a short survey measuring both constructs. As part of these aims, the present study will validate the Accommodation & Impact Scale for DD (AISDD). This scale, along with comparison measures, will be distributed to families in order to assess its construct validity and temporal stability. It is hypothesized that 1) the AISDD will contain two factors measuring accommodations and impacts, 2) AISDD scores will positively correlate with adaptive functioning and negatively correlate with challenging behaviors, and 3) there will be moderate correlations ($r \sim .5 – .7$) with the PDH and CSQ. It is hoped that a measure of day-to-day accommodations and impact would 1) serve to predict which families are at risk for long-term challenging impacts, 2) provide an understanding of the areas in which a family would need additional services and supports, and 3) serve as a proxy for measuring the effects of treatment.

Chapter 2. Method

Participants

The current study collected data from 407 caregivers of children with DDs. According to clinician-assigned ICD diagnostic code, these children had ID (n= 161), ASD (n = 193), and co-occurring ID+ASD (n=53). By parent report, diagnoses were as follows: 139 youth with ID, 161 with ASD, 93 with ASD+ID, and 14 with neither ASD nor ID (but with other conditions such as ADHD [n=10] and epilepsy [n=3]). There was an 80% match rate between clinician- and caregiver-reported diagnosis. Because diagnoses were quite similar and for sake of simplicity, subgroups were categorized based on ICD codes.

One caregiver from each family was asked to participate in the study. In order to participate, caregivers needed to be able to read in English at a 5th grade reading level (at minimum). In addition, a diagnosis must have been made within at least one year of participation. Across the three groups, children were between the ages of 5 and 18 years of age (M_{age} = 11.7, SD = 3.9), 63% were male, and 35% were taking medications for behavioral/emotional dysregulation. Forty-nine of the caregivers completed the instrument twice at about a 2-week interval (range: 10 to 21 days; M = 12.6, SD = 2.6) to assess test-retest reliability. Demographic information for the sample is provided in Table 1.

Table 1. Demographic Information of Sample

		ID	ASD	ID+ASD	Total Sample
	N(%)	161(40%)	193(47%)	53(13%)	407
Sex	% males	50	72	72	63
Age	M(SD)	12.7(3.9)	10.5(3.6)	13.2(3.9)	11.7(3.9)
	Range	5 - 18	5 - 18	5 - 18	5 - 18
	Median	12.8	10.9	13.8	11.8
	IQR	6.4	6.5	7.3	6.4
Medications	% psychotropic medications*	25	39	51	35
Caregiver	% Biological or Adoptive Mother	83	82	87	83
Race/Ethnicity	% White	63	55	64	60
	% Black/African American	12	11	11	13
	% Hispanic/Latinx	9	7	10	10
	% Other	7	17	10	8
	% Unknown	9	10	6	9
Household Income	% 100,000 and more	50	44	57	48
	% 60,000-99,999	16	22	13	19
	% 30,000- 59,999	15	14	15	14
	% Less than 30,000	10	10	9	10
Education	% college or higher	65	65	72	66

ID = intellectual disability; ASD = autism spectrum disorder; M = mean; SD = standard deviation; IQR = interquartile range.

Study Measures

Accommodation & Impact Scale for DD (AISDD)

The Accommodation & Impact Scale for DD is a measure of day-to-day adjustments and effects of raising a child with a DD. The preliminary version of the scale contained 30 items that are rated on a 5-point scale, ranging from *Strongly Disagree* to *Strongly Agree*. With an anticipated two-factor structure, it was hypothesized that the scale be evenly split with the first 15 items measuring Accommodations and the last 15 items measuring Impact. The 30-item AISDD can be found in Appendix A.

The current version of the AISDD draws upon a previous study, in which a pool of 133 items was developed and completed by 500 caregivers of individuals with DDs (Udhnani, 2021). The sample largely consisted of individuals with moderate to severe ID (78% male), who had a mean age of 11 years (SD = 7, range = 0-46 years). This original version of the questionnaire comprised four scales: Parent Accommodation, Challenging Behaviors, Family Accommodations, and Positive Outlooks. The Challenging Behavior scale was removed because it was extraneous to the intent of the scale. The Positive Outlook subscale was discarded because item distributions were largely skewed. Items were further culled if they had high inter-correlations, skewed distributions, unclear verbiage, or an N/A response option. Next, items that were neither sensitive to change over time/intervention or applicable across various DDs were removed. The remaining items were reworded so they could be understood with a 5th grade reading level. Finally, parents provided feedback on the wording and relevance of the items. The resulting scale consisted of 30 items.

Caregiver Strain Questionnaire (CSQ)

The Caregiver Strain Questionnaire (Brannan et al., 1997) is a 21-item questionnaire that assesses stressful situations in a caregiver’s life. The scale contains three factors: objective strain, subjective externalized strain, and subjective internalized strain. The objective strain subscale measures parental perceptions of observable impacts of having a child with special needs, such as effects related to work, finances, and daily routines. The subjective internalized strain subscale reflects the caregiver’s inward feelings of sadness, fatigue, and worry about the child’s future. The subjective externalized subscale measures outward feelings, such as embarrassment, resentment, and anger. Items are rated on a 5-point scale, ranging from *not at all* to *very much a problem.*

The CSQ was developed for caregivers of children with behavioral and emotional disturbances and has proven to have acceptable psychometric properties. The three factor solution has been supported for children with behavioral and emotional disturbances (Brannan et al., 1997) and for children with ASD (Khanna et al., 2012). Among caregivers of children with behavioral and emotional disturbances, Cronbach’s alpha coefficient for the objective strain subscale was .92, .74 for the externalized subjective strain subscale, and .86 for the internalized subjective strain subscale (Brannan et al., 1997). It showed acceptable internal consistency and factor structure in samples of children with ASD (Bradshaw et al., 2020; Khanna et al., 2012). The CSQ is depicted in Appendix B.

Parent Daily Hassles Scale (PDH)

The Parent Daily Hassles Scale (Crnic & Greenberg, 1990) is a 20-item caregiver questionnaire that was developed to assess minor daily stresses experienced by caregivers during day-to-day routine childrearing tasks or interactions. The scale contains two factors (Challenging Behaviors and Parenting Tasks), with each item rated on two dimensions: frequency and intensity. The Frequency Scale is rated on a 5-point Likert scale (ranging from 1[never] to 5[constantly]. The Intensity Scale is also rated on a 5-point scale, with 1 indicating No Hassle and 5 indicating Big Hassle.

The PDH was developed with caregivers of typically developing children and children born prematurely. Chronbach's alpha for the Frequency Scale was .81 and .90 for the Intensity Scale. It has also been used with caregivers of children with DDs (Gerstein et al., 2009; Walerius et al., 2016), although its psychometric properties have yet to be evaluated in this population. The Parenting Daily Hassles scale is located in Appendix C.

Adaptive Behavior Assessment System – Third Edition (ABAS-III)

The Adaptive Behavior Assessment System – Third edition (ABAS- 3; Harrison & Oakland, 2015) is a caregiver questionnaire that assesses adaptive skills across the lifespan. Caregivers only completed the Conceptual scale of the ABAS-3, for which norm-referenced standard and scaled scores with confidence intervals and percentile ranks were generated. The Conceptual standard score was used to characterize level of functioning of the participants. The Conceptual scale assesses communication, functional academics, and self-direction. Internal consistency is very high at .98, the standard error of measurement is 1.95 for caregivers of children ages 5 to 21, and test-retest reliability was .81 (Harrison & Oakland, 2015). A copy of the ABAS-3 can be found in Appendix D.

Nisonger Child Behavior Rating Form (NCBRF)

The Nisonger Child Behavior Rating Form (NCBRF; Aman et al., 1996) is an instrument designed to assess the behaviors of children with DDs. The scale contains 76 items spread over two Positive Social subscales and six Problem Behavior subscales. Only the six Problem Behavior subscales were administered in the present study: Conduct Problems, Insecure/Anxious, Hyperactive, Self-Injury/Stereotypy, Self-Isolated/Ritualistic, and Overly Sensitive. All items are rated on a 4-point Likert scale, ranging from 0 (behavior does not occur) to 3 (behavior occurs a lot). The NCBRF has been used in a number of studies and has been shown to have acceptable psychometric properties in children with ID and children with ASD (Lecavalier et al., 2004; Norris & Lecavalier, 2011) The NCBRF can be found in Appendix E.

Demographic Form

The Demographic Form collects basic demographic information such as race/ethnicity, education, household income, and caregiver education level. It consists of an additional four items that assess the long-term adjustments of caregivers in this population, and another four items that measure some of the long-term positive impacts/outlooks from having a child with DD. These items are rated on the same five-point Likert scale as the AISDD, from Strongly Disagree to Strongly Agree. The demographic form can be found in Appendix F.

Procedures

Families were recruited through the Children's Hospital of Philadelphia recruitment registries. The registries at the Children's Hospital of Philadelphia consist of an electronic medical patient database and the Center for Autism Research registry. Participants were recruited on the basis of their child's International Classification of Diseases (ICD) code, age, and time since diagnosis. Caregivers received an email with a recruitment letter that indicated a public survey link to proceed to the study. To maintain the integrity of the sample, only those who received the study invitation were allowed to participate, and any duplicate attempts at completing the study were excluded.

Data collection occurred online through RedCap surveys. The study was anticipated to take approximately 30 minutes, but participants were allowed to save their progress and return at another time. Two validity checks were interspersed between measures. A random sub-sample of those who completed the study were invited to complete the surveys a second time, with 2 weeks between administrations. The study was approved by the institutional review boards at the Children's Hospital of Philadelphia (reviewing site) and the Ohio State University (relying site). Written informed consent was obtained from caregivers prior to survey completion.

Statistical Analyses

Demographic and clinical variables were calculated as means, standard deviations, medians with interquartile ranges (IQR), or percentages as appropriate. These findings are presented in Table 1. Data were collected from 421 participants. Preliminary data inspection led to removal of cases that 1) did not pass either of the two validity checks (n=9), 2) completed the entire study in less than 12 minutes (n= 1), 3) were duplicate attempts (n=3), or 4) were not on the CHOP medical listserv (n=1). This resulted in a final sample of 407 caregivers. From the retest sample, there were 53 caregivers who completed the instrument twice, four of whom exceeded the two-week (+/- 7 days) timeframe. The resulting retest sample consisted of 49 caregivers who completed the AISDD twice within 10-21 days of each other (M=12.6, SD = 2.6).

Validity

An exploratory factor analysis (EFA) was conducted to investigate the factor structure of the AISDD. The EFA was conducted using ordinary least squares estimation with oblique Quartimax rotation on the polychoric correlation matrix. The choice of dimensionality was guided by examination of the scree plot, a parallel analysis, and clinical meaningfulness, as suggested by Norris and Lecavalier (2010).

The convergent validity of the AISDD caregiver questionnaire was assessed using Pearson correlation coefficients with other well-established rating forms, the Caregiver Strain Questionnaire (Brannan et al., 1997) and the Parenting Daily Hassles scale (Crnic & Greenberg, 1990). A Pearson correlation coefficient between .4 and .7 was required for adequate convergent validity (Cicchetti & Sparrow, 1981).

Reliability

The internal consistency of the AISDD caregiver form was assessed with ordinal alpha coefficient, as it is the preferred method in measuring internal consistency of items with an ordinal scale (Gadermann et al., 2012; Zumbo et al., 2007). Test-retest reliability was assessed using intraclass correlation coefficients (ICCs), with a two-way random effects model and absolute agreement. An ICC estimate of .75 or greater was required for acceptable test-retest reliability. An ICC between .75 and .90 is indicative of good reliability and an ICC greater than .90 indicates excellent reliability (Koo & Li, 2016).

Associations Between Child Characteristics and AISDD scores

The association between AISDD scores and subject characteristics (e.g., age, gender, sociodemographic information, level of functioning, problem behaviors) was measured with Pearson correlations and nonparametric Independent Samples Kruskal-Wallis tests.

Chapter 3: Results

Exploratory Factor Analysis

To determine the number of factors to extract, I examined the scree plot, conducted a parallel analysis, and evaluated clinical meaningfulness of the different solutions. The scree plot, shown in Figure 1, depicted an ‘elbow’ after the first eigenvalue. Six eigenvalues were > 1.0; however, there was one dominant eigenvalue that was five times larger than the next eigenvalue. The parallel analysis suggested a 6-factor model. Based on those findings, preliminary EFAs examined the 1-, 2-, 3-, and 6-factor solutions. Only the single-factor solution made clinical sense. All other factor structures lacked clinical interpretability.

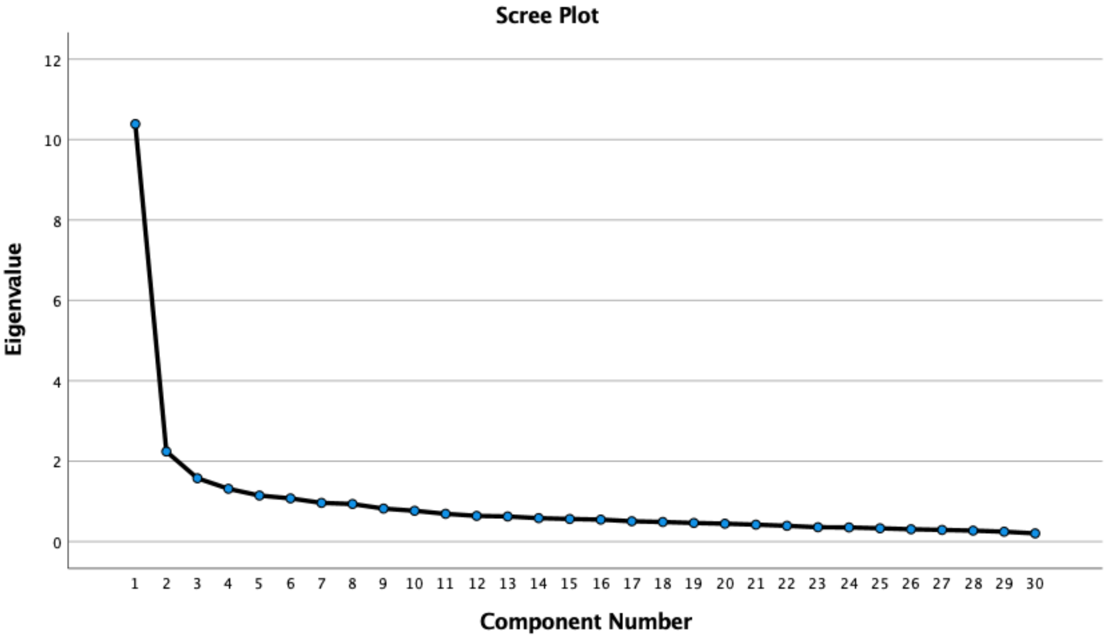

Figure 1**.** Scree plot of eigenvalues.

Item inspection

Next, item distributions and inter-item correlations were examined. Four items (items 8, 16, 21, and 28) were discarded because they had skewed distributions (skewness: 1.18, 1.31, 1.12, 1.24; kurtosis: -.73, -.76, -.92, -.86), with more than 70% of the sample either agreeing or disagreeing with the statements. Inter-item correlations were considered too high if they exceeded 2.5 SDs from the mean inter-correlation. One item (item 25) met this criterion and was discarded.

Items were then examined for lower factor loadings (below .45), lower test-retest reliability (ICC below .8), and higher correlated residuals (above +/- .30). Seven items did not meet the loading cutoff (items 3, 5, 7, 8, 12, 15, and 18), three items had lower test-retest reliability (items 3, 15, and 28), and no correlated residuals exceeded +/- .30.

Altogether, 11 items were removed, which resulted in a 19-item, 1-factor scale. Factor loadings of the final model, along with mean ratings for each item, appear in Table 2. The final list of items is in Appendix G.

Table 2. Final Factor Structure for the Accommodations & Impact Scale for Developmental Disabilities

AISDD item[a]		Factor Loading	ICC test-retest reliability	Mean item rating
1.	Give in to avoid meltdowns	.477	.86	2.79
2.	Avoid buying nice things	.620	.84	2.55
4.	Constantly supervise child	.525	.89	3.66
6.	Act quickly	.537	.81	3.22
9.	Avoid taking child places	.674	.93	2.82
10.	Planning for outings	.744	.83	3.48
11.	Leave outings early	.824	.90	2.86
13.	Persuade for simple things	.561	.76	3.35
14.	Extreme safety measures	.636	.80	3.53
17.	Have less fun time	.719	.87	3.44
19.	Difficult to soothe child	.657	.76	2.75
20.	Guessing why upset	.551	.83	3.22
22.	Less attention to family	.687	.84	3.10
23.	Finding caretaker	.717	.87	3.73
24.	Energy levels	.653	.91	2.95
26.	Bedtime is draining	.581	.86	2.61
27.	Less time for myself	.797	.76	3.54
29.	Days are hard	.741	.86	3.65
30.	Child hurts self or others	.572	.77	2.62
Test Average		.646	.839	3.18

[a] Summary of item phrasing.

Final Model

Another EFA was conducted on the final solution, which consisted of 1 factor and 19 items. The mean factor loading on the 19-item scale was .65, and the mean AISDD sum score for the entire sample was 59.9 (SD = 14.9; range = 22 – 93; see Table 3). The distribution of total scores for this new version can be found in Figure 2. All further analyses were conducted using the new 19-item AISDD scale.

Table 3. AISDD and adaptive functioning scores.

		ID	ASD	ID+ASD	Total Sample
AISDD Mean Sum Score	M(SD)	55.5(14.0)	61.0(15.3)	69.2(11.4)	60.0(14.9)
	Range	22 - 91	24 – 93	46 – 93	22 - 93
	Median	58	61	70	61
	IQR	21	22	12	21
ABAS-3 Conceptual Scale	M(SD)	63.4(13.8)	76.6(15.8)	56.7(11.5)	68.8(16.4)
	Range	47 – 108	47 - 120	47 - 108	47 – 120
	Median	59	77	54	67
	IQR	22	21	10	27

ID = intellectual disability; ASD = autism spectrum disorder; M = mean; SD = standard deviation; IQR = interquartile range.

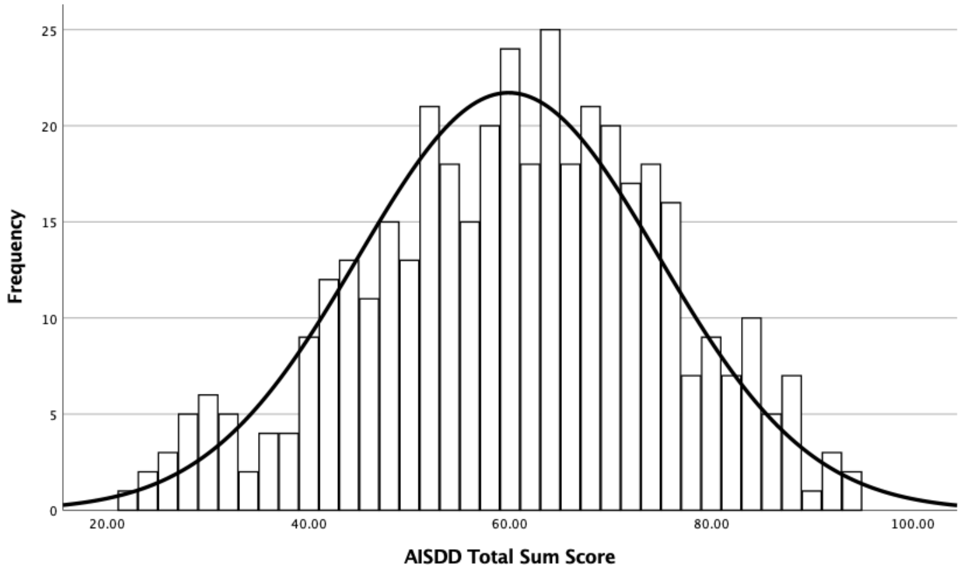

Figure 2. Distribution of AISDD Total Sum Score across whole sample.

Internal consistency

Using polychoric correlations, ordinal alpha coefficient was used to calculate internal consistency. Internal consistency for the AISDD was excellent, with an ordinal alpha coefficient of .93. The scale also had a mean inter-item correlation of .42.

Test-retest reliability

Test-retest reliability, measured with ICCs, on the Total Sum Score of the 19-item AISDD (n=49) was excellent at .95 (p<.001). Temporal stability for all individual item ratings was significant at the p<.001 level. Sixty-one percent of the retested sample had ID and 39% had

ASD. Sixty-five percent was male, and the average age was 12.3 years (SD = 3.6). The retest sample had a higher proportion of youth with ID than the main (Time 1) sample (61% v. 40%; Z = -3.08, p = .002). However, the proportion of males (63% v. 64%; Z= -.17, p>.05) and the mean age (t(400) = -1.23, p>.05) were both comparable across test and retest samples.

Association with demographic and clinical characteristics

Correlations with demographic and clinical characteristics are found in Table 4. In terms of demographic characteristics, Pearson correlations revealed a weak, albeit significant, inverse relationship between age and the 19-item AISDD total score (r = -.19, p<.001). In contrast, there were no significant differences in AISDD scores by either gender ($\chi^2(3) = 3.33$, p>.05) or household income ($\chi^2(4) = 6.31$, p>.05).

In terms of clinical characteristics, nonparametric Independent-Samples Kruskal-Wallis tests revealed differences in AISDD scores by clinician diagnosis ($\chi^2(2) = 36.98$, p<.001), such that ID only (M = 55.5, SD = 14.0) < ASD only (M = 61.0, SD = 15.3) < ASD+ID (M = 69.2, SD = 11.4). Further, the AISDD had a moderate negative correlation with the ABAS Conceptual Standard Score (r = -.35, p<.001). All three of the scaled scores of the Conceptual domain demonstrated similar associations with the AISDD which were significant at the p<.01 level: Communication = -.33, Functional Academics = -.27, Self-Direction = -.38. Post-hoc analyses were conducted to compare the lower and upper quartiles of the Conceptual Standard Score on the Total Score of the AISDD. It revealed that individuals with the lowest adaptive functioning had significantly higher AISDD scores (M = 65.4, SD = 13.3) than those with the highest adaptive functioning (M = 52.9, SD = 15.2) in the sample (t[222] = 6.6, p<.001). This difference was associated with a large effect size of d = .88 (Cohen, 1969).

Of the six NCBRF sum scores, the scale with the strongest association with the AISDD was the Hyperactive scale (r = .57), while the weakest association was with the Insecure/Anxious scale (r = .22). All correlations were significant at the $p<.001$ level. These correlations are listed in Table 4.

AISDD scores also differed by use of psychotropic medications. Those taking medications scored higher (M = 66.3, SD = 13.3) than those not taking medications (M = 55.8, SD = 14.8; t(363) = 6.78, $p<.001$). This difference had a large effect size of d = .74.

Table 4. Correlations with clinical characteristics

	AISDD total Sum Score
Child age	-.191*
ABAS Conceptual Standard Score	-.348*
ABAS Communication Scaled Score	-.332*
ABAS Functional Academics Scaled Score	-.271*
ABAS Self-Direction Scaled Score	-.383*
NCBRF Conduct Problems Sum Score	.507*
NCBRF Insecure/Anxious Sum Score	.224*
NCBRF Hyperactive Sum Score	.568*
NCBRF Self-Injury/Stereotypy Sum Score	.435*
NCBRF Self-Isolated/Ritualistic Sum Score	. 312*
NCBRF Overly Sensitive Sum Score	.429*

* indicates correlation is significant at the .01 level

Convergent Validity

Convergent validity was supported with strong Pearson correlations between the AISDD, PDH, and CSQ. Table 5 presents the correlations between these measures. The correlations between the 19-item AISDD and the PDH Sum of Frequency and Intensity scores were strong at .77 and .69 (respectively). The correlation between the AISDD Sum Score and the CSQ Global Sum Score was similar, at .77. However, when separated by CSQ subscale, findings reveal disparate correlations between types of impacts: AISDD's association with the Objective Strain Score was highest at $r = .79$, very strong with the CSQ Subjective Internalized Strain Score ($r = .71$), and lowest with the Subjective Externalized Strain Score ($r = .45$). All of these correlations were significant at the $p<.001$ level and met criteria for excellent convergent validity (Cicchetti & Sparrow, 1981).

Table 5. Correlation matrix of study measures

	AISDD total Sum Score	PDH Sum of Frequency Score	PDH Sum Intensity Score	CSQ Global Sum Score	CSQ Objective Strain Score	CSQ Subjective Internalized Strain Score
AISDD total Sum Score	--					
PDH Sum of Frequency Score	.767*	--				
PDH Sum Intensity Score	.693*	.888*	--			
CSQ Global Sum Score	.768*	.706*	.702*	--		
CSQ Objective Strain Score	.790*	.727*	.698*	.912*	--	
CSQ Subjective Internalized Strain Score	.712*	.634*	.626*	.923*	.794*	--
CSQ Subjective Externalized Strain Score	.448*	.439*	.481*	.752*	.520*	.552*

AISDD = Accommodations & Impact Scale for Developmental Disabilities; CSQ = Caregiver Strain Questionnaire; PDH = Parenting Daily Hassles. * indicates the correlation is significant at the p < .001 level (two-tailed).

Chapter 4: Discussion

Overview of Findings

This paper presents the development and preliminary validation of the AISDD, a unidimensional 19-item measure of accommodations and impacts of caring for a child with DDs. The AISDD has excellent internal consistency and test-retest reliability. Scores on the AISDD were normally distributed, decreased with age, and were not related to child gender or household income. However, they differed by diagnosis, such that accommodations were highest for those in the co-occurring ID+ASD group and lowest for those in the ID only group. Accommodations also differed by level of adaptive functioning and challenging behaviors, such that higher accommodations were associated with lower adaptive functioning and greater challenging behaviors. Finally, the AISDD showed excellent convergent validity with similar measures of accommodations (PDH) and impacts (CSQ). These findings support the use of the AISDD as a valid and reliable tool for measuring accommodations among caregivers of individuals with DDs.

The AISDD is the first measure of accommodations and impacts to be specifically designed for DDs. It is short and easy to administer and score, and items were developed to be sensitive to change over time. As such, the AISDD may serve as a measure of family-level outcomes or effects of intervention and can be useful in addressing the needs of both the child and the family.

Factor Solution & Reliability

The original 30-item AISDD underwent a series of preliminary steps to result in its final structure, including 1) EFAs to examine potential factor solutions and 2) inspection of items for high inter-correlations, skewed distributions, low loadings, or low ICCs. Results of the various EFAs revealed that the 1-factor solution had the highest loadings and the most clinical meaningfulness. In this case, the most parsimonious model allowed for ease of interpretation and scoring. In addition, inspection of items led to the removal of 11 items. Together, these resulted in a unidimensional, 19-item scale.

This single factor solution contrasts to the hypothesized two-subscale model (Accommodations and Impacts). Although the literature on accommodations (Bernheimer & Weisner, 2007; Gallimore et al., 1996; Mas et al., 2016) is separate from the literature on impacts (Murphy et al., 2007; Piazza et al., 2014), caregiver responses in the current study did not discern the two. This suggests an overlap in the way accommodations and impacts are conceptualized by caregivers. What is conceptualized as impacts in the literature could be construed as accommodations among caregivers. For example, caregivers may not interpret the item ‘I get less sleep than I would like to’ as an impact, but an accommodation they make to get other tasks completed. As another example, they may interpret having less time for oneself as an accommodation to be able to spend more time with their child. Perhaps it is difficult to disentangle the two because they are inextricably linked. The final instrument includes items from the two hypothesized factors, as results of the factor analysis suggested they may represent the same construct.

In terms of reliability of the final scale, both internal consistency and test-retest reliability were excellent. Test-retest reliability of the AISDD (ICC = .95) was comparable to the CSQ (Global Strain Score: .92) and PDH (Frequency: .95, Intensity: .94), when tested on the current sample. The AISDD's test-retest reliability was higher than another commonly used, well-validated measure, the Parenting Stress Index – 4th edition (Abidin, 2012), which has an ICC of .82 for the Difficult Child scale and .71 for the Parental Distress scale. A high test-retest reliability is not only important for measuring stability in scores, but, given the tool's granularity in capturing day-to-day caregiver challenges, it may also indicate that the measure could be sensitive to change over time (McCrae et al., 2011). A measure's ability to detect true change is only possible when it can prove to remain stable in the face of no change. Because all items were devised with the intent of being sensitive to change over time, this finding supports the utility of the AISDD as a potential outcome measure.

Association with demographic and clinical variables

Of the demographic variables examined, only one stood out as correlated with AISDD scores. Older age was associated with lower AISDD scores, although this relationship was weak (r = -.19). This finding is somewhat consistent with Gallimore et al. (1996), who interviewed 93 caregivers of children with developmental delays about their accommodations at three time points: ages 3, 7, and 11. They found that accommodation *intensities* decreased between ages 7 and 11, while accommodation *types* increased between ages 3 and 11.

Other demographic variables examined, gender and household income, were not associated with AISDD scores. To date, there have been no other studies to our knowledge that have evaluated the relationship between gender and accommodations. This finding may challenge some of the underlying notions the field has about females with DDs. One such notion is that females have fewer behavioral and social problems (Mandy et al., 2012). This may be true, but the lack of differences in scores in the current study may suggest a level of need in females that is going undetected in studies that fail to consider the caregivers' role in supporting their child.

With regard to household income, no difference in accommodations was found. In contrast, Gallimore et al. (1996) found a significant correlation between SES and accommodation intensity at ages 3 ($r = .51, p < .03$) and 7 ($r = .57, p = .05$) but not 11 ($r = .56, p > .05$). However, their interview included assessment for financial accommodations that confound with SES (e.g., an accommodation highlighted from their interview, "mother is not working or reduces hours for child," is an accommodation that families with a higher SES will be more likely to make). This may explain the discrepant findings, since the AISDD does not contain items that involve financial accommodations (in order to remain broadly applicable to all strata of SES).

As expected, there was a negative relationship between the AISDD and adaptive behavior. Post-hoc analyses revealed that individuals with the lowest adaptive functioning had significantly higher AISDD scores than those with the highest adaptive functioning in the sample. A similar relationship was observed by Feldman et al. (2019), who found that greater accommodations of restricted and repetitive behaviors (RRBs) were associated with lower adaptive functioning in ASD. In this study, they used the Family Accommodation Scale – RRBs, a tool designed to measure caregiver accommodations specifically for RRBs, a core feature of ASD. As adaptive functioning of the sample of children with ASD improved, family accommodations of RRBs decreased. These findings align with our hypothesis that levels of accommodations would differ as a function of the developmental needs of the child (Booth-LaForce & Kelly, 2004; Diamond & Kontos, 2004).

Caregivers are largely responsible for providing opportunities to bolster child adaptive functioning (Estes et al., 2019). Thus, they accommodate by engaging in behaviors that compensate for a child's reduced independent living skills (e.g., cleaning up after them) at the same time as expending great effort to teach such new skills. As children gain more independent living skills, they require less accommodations from their caregivers to provide support and involve fewer daily hassles. Additionally, greater adaptive functioning leads to reduced caregiver stress (Estes et al., 2019), although Beck et al. (2004) found no predictive relationship. This may further illustrate the inter-connectedness between caregiver stress/burden (impact) and daily hassles and supports (accommodation).

The relationship between the AISDD and the NCBRF was significantly positive, with high levels of problem behavior associated with high accommodations. This finding aligns with studies that have found a strong significant correlation between challenging behaviors in DDs and family accommodations across childhood (Keogh et al., 2000; Koller et al., 2021). In fact, in a sample of 102 caregivers who were asked about their day-to-day routines, many reported their child's challenging behavior (e.g., frequent tantrums) as a common cause for accommodations (Bernheimer & Weisner, 2007), such as greater effort and time spent on childcare and supervision. Similarly, accommodation of RRBs increased as disruptive behaviors increased in a sample of 90 children ages 2-9 years ($M = 5.7$, $SD = 1.6$) with ASD living in Israel ($r = .34$, $p<.001$). As challenging behaviors increase, not only do caregiver accommodations increase, but so does caregiver stress (Beck et al., 2004; Huang et al., 2014; Lecavalier et al., 2006; Zaidman-

Zait et al., 2014), again highlighting the relationship between accommodations and impacts among caregivers of children with DDs.

Further, level of accommodations captured by the AISDD also differed as a function of type of challenging behaviors, as the relationship was strongest for the Hyperactive scale and weakest for the Insecure/Anxious scale. Much of the literature on accommodations focus on children with externalizing behaviors (Keogh et al., 2000; Koller et al., 2021) or internalizing problems (Lebowitz et al., 2013; Storch et al., 2015), but not both. This paper provides a first instance of evaluating accommodations in both.

Finally, AISDD scores were lowest for those with ID only and highest for those with co-occurring ASD+ID. These findings fit with the literature that has reported higher caregiver daily hassles, behavioral and emotional dysregulation, and caregiver stress in ASD than ID (Brereton et al., 2006; Esteves et al., 2021; Matson & Rivet, 2008; Rutgers et al., 2007; Vaz et al., 2021). In addition, AISDD scores were significantly higher among those taking psychotropic medications than those who were not (d = .74). Together, these findings suggest that as severity of symptoms increase, accommodations increase – a finding consistent with the literature in accommodations of anxiety (Storch et al., 2015), OCD (Storch et al., 2007), and RRBs (Feldman et al., 2019). To date, studies of accommodations in DDs either focus exclusively on ASD (Adams & Emerson, 2020; Feldman et al., 2019) or an undifferentiated sample of various DDs and developmental delays (Bernheimer & Weisner, 2007; Cho et al., 2000; Keogh et al., 2000). Thus, this study provides a first examination of how DD diagnoses can impact caregiver accommodations.

Convergent Validity

Finally, convergent validity was measured between the AISDD and two measures: the PDH (a measure of daily hassles) and the CSQ (a measure of caregiver burden). The AISDD showed evidence of strong convergent validity with both measures. High convergent validity between these measures could be, in part, because of the way the AISDD was developed. In the pilot study, during which the AISDD was developed, items were pruned if they were not sensitive to change over time or if they were not broadly applicable to individuals across all levels of DD. For example, items such as ‘My child may never be toilet trained’ and ‘I worry about who will take care of my child as I get older’ were removed because they mainly apply to families of children with severe or profound ID and may be less sensitive to change. Consequently, the remaining items addressed behavioral and emotional dysregulation (e.g., ‘I “give in” to my child to avoid meltdowns’), as they are more prevalent across DDs (Mazzucchelli & Sanders, 2011) and can be susceptible to change with treatment (Chisholm et al., 2016; Kaat & Lecavalier, 2013).

As a result, the item content of the AISDD overlaps considerably with that of the PDH and CSQ, as these two measures were developed for young children and children with behavioral and emotion disturbances, respectively. High convergent validity with the PDH and the CSQ does not indicate that the AISDD is redundant, though, for several reasons. First, despite having such high correlations, not all variance was accounted for by the CSQ and PDH. The highest correlation coefficient found, r = .77, reflects only 59% shared variance with the CSQ Global Sum Score and PDH Sum of Frequency Score. This leaves 41% of variance left unaccounted for by the CSQ and PDH, suggesting that the AISDD is contributing novel information than what is captured by these measures. Second, convergence between the measures may differ with age, as developmental profiles of individuals with DDs evolve over time. Since the PDH was designed for caregivers of young children, some items may be less appropriate among adolescents and young adults with DDs, although this has yet to be examined. Third, use of the AISDD is advantageous, as it is shorter than the PDH and CSQ combined, was developed to be sensitive to change over time, and is suitable for a wide age range of individuals with DDs.

While strong correlations were demonstrated with most of the subscales of the PDH and CSQ, there was one exception: a weak correlation between the AISDD and the CSQ Subjective Externalized Strain Score. This finding was not surprising, as that subscale captures caregivers' outward feelings of anger, embarrassment, and resentment – impacts the AISDD was not designed to measure. The other scales of the CSQ overlap more with the AISDD because they capture more relevant impacts, such as disruptions to daily routines and work (Objective Strain) and inward feelings of worry and fatigue (Internalized Strain). Overall, the AISDD seems to be capturing some aspects of accommodations and impacts, as measured by these scales, while capturing some of its own unique variance.

Limitations and Future Directions

Several limitations exist in the present study. The sample was not representative based on household income or education. Although there was no relationship found between household income and AISDD scores, the sample may have lacked enough variance to detect a relationship. In addition, while other measures subtype accommodations by intensity and type, the AISDD does not. However, it is unclear whether this level of specificity is clinically meaningful, or if it creates additional burden on caregivers by creating more items to rate. Further, in using a large medical care system such as CHOP, there was great variability in the way DDs were diagnosed, and by whom. However, even with the lack of standardization in diagnostic practice and provider, the sample was still representative of the population of youth with DDs on clinical characteristics. It is unclear how variability in the diagnostic process could have influenced the sample attained. Finally, removal of items that were neither sensitive to change nor applicable across DDs precluded the ability to capture accommodations that are specific to severe presentations of DDs. Consequently, the AISDD may not be measuring accommodations to the same extent within these families.

To address these limitations, future work should aim to sample caregivers of children across all strata of SES, examine whether measuring accommodations by type and intensity will add clinical utility, ascertain how diagnosis of children with the DDs was made, and further investigate the accommodations specific to individuals with severe presentations of DDs. In addition to that, following up on the current study, future research should confirm the factor structure with a confirmatory factor analysis on a new sample of youth with DDs. Next, studies should examine whether convergence between the AISDD, CSQ, and PDH differs with age. In addition, including a typically developing sample could allow for a comparison of accommodations between groups. Finally, as accommodations can and do change over the course of a child’s life (Bernheimer & Weisner, 2007), a crucial next step is to attain longitudinal data on this measure among families of children with DDs, to evaluate how AISDD scores change over time or with treatment. In doing so, it is hoped that the AISDD could provide insight into how the field can support families of youth with DDs.

Clinical Importance and Implications

The present study evaluates one of the first questionnaires of caregiver accommodations developed for youth with DDs. Findings reveal that the AISDD shows promise as a valid and reliable tool for this population, as it demonstrated excellent convergent validity, internal consistency, test-retest reliability, and correlations with relevant clinical characteristics.

While there are other existing measures of accommodations (e.g., PDH, Family Accommodation Scale – RRBs, Family Adjustment Measure; Daire et al., 2014), they were either not developed for DDs (thus, fail to capture DD-specific accommodations) or do not consider the global changes caregivers make across DDs. Similarly, while there are other measures of caregiver impacts, such as those that measure caregiver stress and strain (CSQ, Parenting Stress Index, Parental Stress Scale [Berry & Jones, 1995]), the AISDD differs from these measures because it is shorter and captures the day-to-day impacts that could be modified with treatment. Thus, the present study introduces a novel measure that converges with similar existing measures while also contributing its own unique variance.

The study has many other strengths, namely recruiting a large, representative sample of children with DDs. The sample consisted of 407 caregivers of children with DDs, with a normal distribution of age (M = 11.7, SD = 3.9) and adaptive functioning (M = 68.8, SD = 16.4). In addition, the sample consisted of a representative distribution of gender (63% male; Loomes et al., 2017; Patrick et al., 2021), diagnoses (47% ASD; (Anderson et al., 2019; Redfield et al., 2020; Zeidan et al., 2022), and use of psychotropic medications (35%; Rosenberg et al., 2010). The sample exceeded recommendations by Velicer and Fava (1987) to attain 150 participants, given a minimum loading of .40 and 10 items per factor. The current study also used a closed hospital registry to recruit caregivers of children with a clinician-assigned diagnosis of a DD, rather than recruiting publicly online. Along with that, validity checks were placed throughout the surveys, and cases were removed if they failed either of the checks. Because oversight of survey completion was not possible with an online study, cases were also removed if they completed the entire study in less than 12 minutes. Together, all of these steps helped to ensure integrity in the data that was collected.

The AISDD shows great promise in its ability to predict which families may be at risk for greater long-term challenging impacts and which areas they may need additional services or supports in. Moreover, as caregiver accommodations are the first to fluctuate with the needs of the child, the AISDD may sensitively capture changes that broadband measures of behaviors and cognition cannot, thus serving as a clinically useful tool for measuring the effects of intervention.

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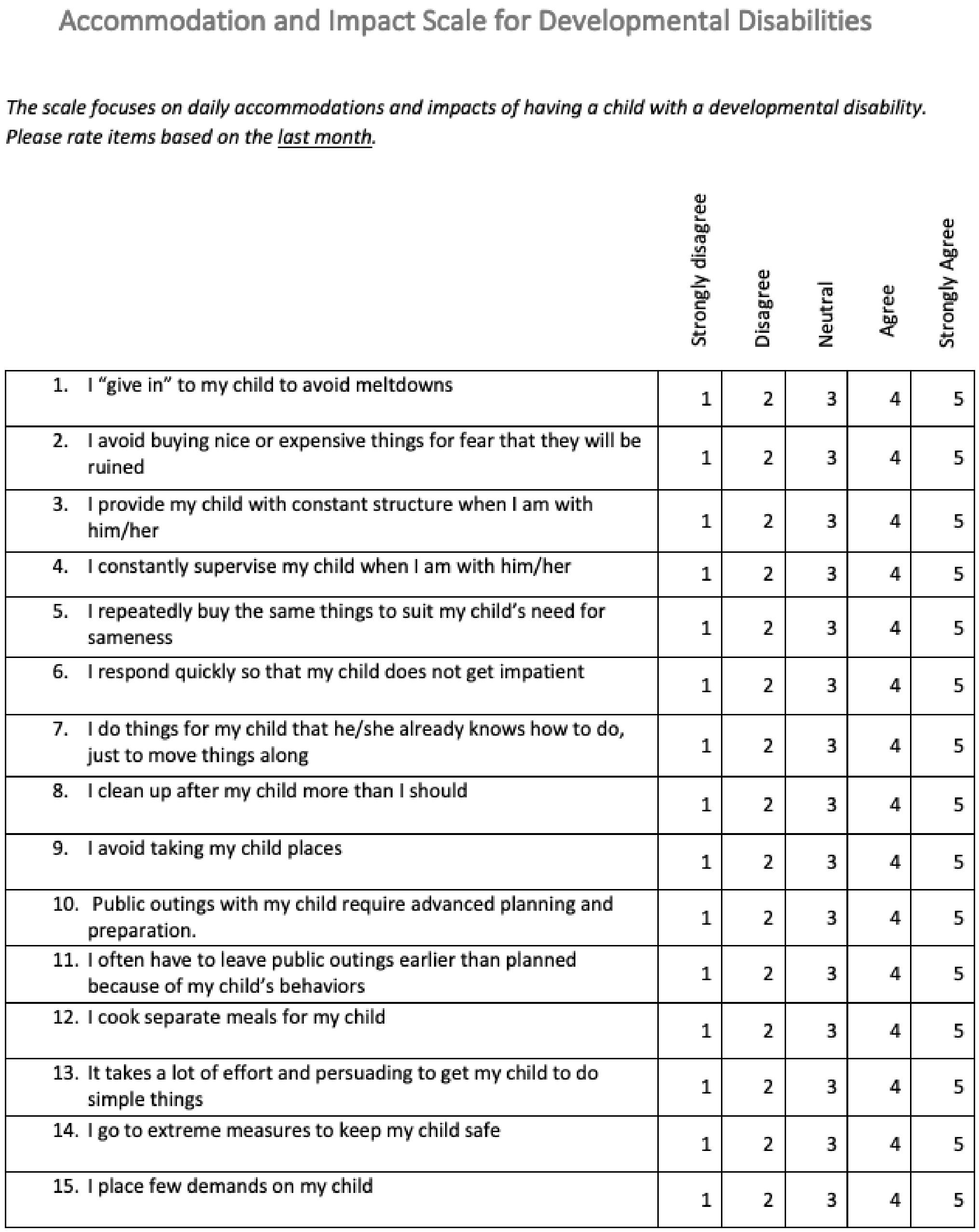
Appendix A. Original 30 items of the Accommodation and Impact Scale for DDs.



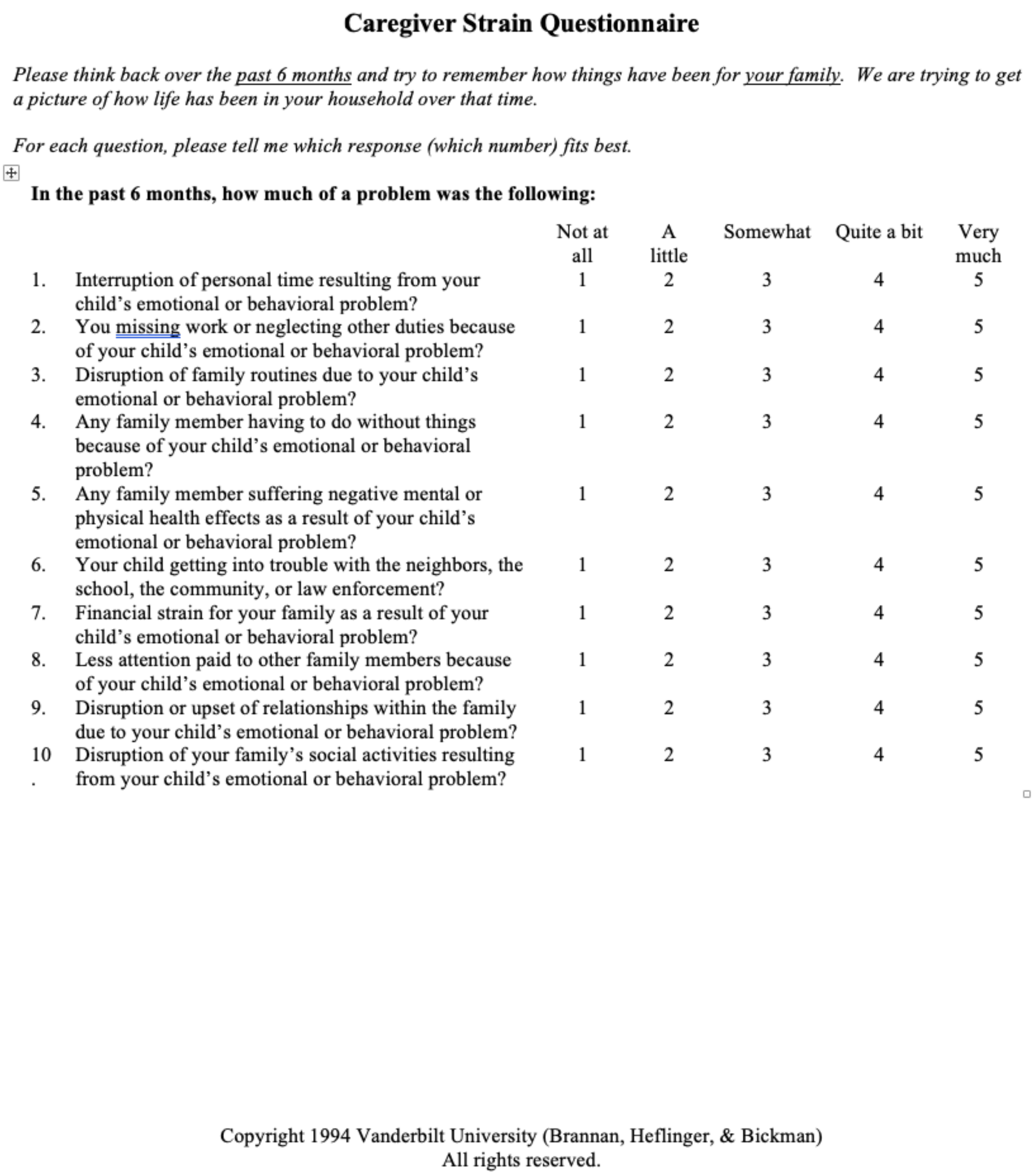
Accommodation and Impact Scale for Developmental Disabilities

The scale focuses on daily accommodations and impacts of having a child with a developmental disability. Please rate items based on the last month.

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
1. I "give in" to my child to avoid meltdowns	1	2	3	4	5
2. I avoid buying nice or expensive things for fear that they will be ruined	1	2	3	4	5
3. I provide my child with constant structure when I am with him/her	1	2	3	4	5
4. I constantly supervise my child when I am with him/her	1	2	3	4	5
5. I repeatedly buy the same things to suit my child's need for sameness	1	2	3	4	5
6. I respond quickly so that my child does not get impatient	1	2	3	4	5
7. I do things for my child that he/she already knows how to do, just to move things along	1	2	3	4	5
8. I clean up after my child more than I should	1	2	3	4	5
9. I avoid taking my child places	1	2	3	4	5
10. Public outings with my child require advanced planning and preparation.	1	2	3	4	5
11. I often have to leave public outings earlier than planned because of my child's behaviors	1	2	3	4	5
12. I cook separate meals for my child	1	2	3	4	5
13. It takes a lot of effort and persuading to get my child to do simple things	1	2	3	4	5
14. I go to extreme measures to keep my child safe	1	2	3	4	5
15. I place few demands on my child	1	2	3	4	5

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
16. I get less sleep than I would like to	1	2	3	4	5
17. I have less fun time with family and friends than I would like	1	2	3	4	5
18. I do not buy the things I want because finances are tight	1	2	3	4	5
19. It is difficult to soothe my child	1	2	3	4	5
20. I am often guessing why my child is upset	1	2	3	4	5
21. My life/schedule is built around my child's schedule	1	2	3	4	5
22. I feel I am not giving the rest of my family adequate attention	1	2	3	4	5
23. It is difficult to find a caretaker/babysitter who understands my child's needs	1	2	3	4	5
24. I find it challenging to keep up with my child's energy levels	1	2	3	4	5
25. My child's daily routine leaves me tired	1	2	3	4	5
26. Trying to get my child to sleep is draining	1	2	3	4	5
27. It is hard to find time for myself because of the needs of my child	1	2	3	4	5
28. I feel alone when others around me do not understand what it is like to care for my child	1	2	3	4	5
29. My days are challenging	1	2	3	4	5
30. I worry that my child will hurt him/herself or others	1	2	3	4	5

Appendix B. Caregiver Strain Questionnaire



Caregiver Strain Questionnaire

Please think back over the past 6 months and try to remember how things have been for your family. We are trying to get a picture of how life has been in your household over that time.

For each question, please tell me which response (which number) fits best.

In the past 6 months, how much of a problem was the following:

		Not at all	A little	Somewhat	Quite a bit	Very much
1.	Interruption of personal time resulting from your child's emotional or behavioral problem?	1	2	3	4	5
2.	You missing work or neglecting other duties because of your child's emotional or behavioral problem?	1	2	3	4	5
3.	Disruption of family routines due to your child's emotional or behavioral problem?	1	2	3	4	5
4.	Any family member having to do without things because of your child's emotional or behavioral problem?	1	2	3	4	5
5.	Any family member suffering negative mental or physical health effects as a result of your child's emotional or behavioral problem?	1	2	3	4	5
6.	Your child getting into trouble with the neighbors, the school, the community, or law enforcement?	1	2	3	4	5
7.	Financial strain for your family as a result of your child's emotional or behavioral problem?	1	2	3	4	5
8.	Less attention paid to other family members because of your child's emotional or behavioral problem?	1	2	3	4	5
9.	Disruption or upset of relationships within the family due to your child's emotional or behavioral problem?	1	2	3	4	5
10.	Disruption of your family's social activities resulting from your child's emotional or behavioral problem?	1	2	3	4	5

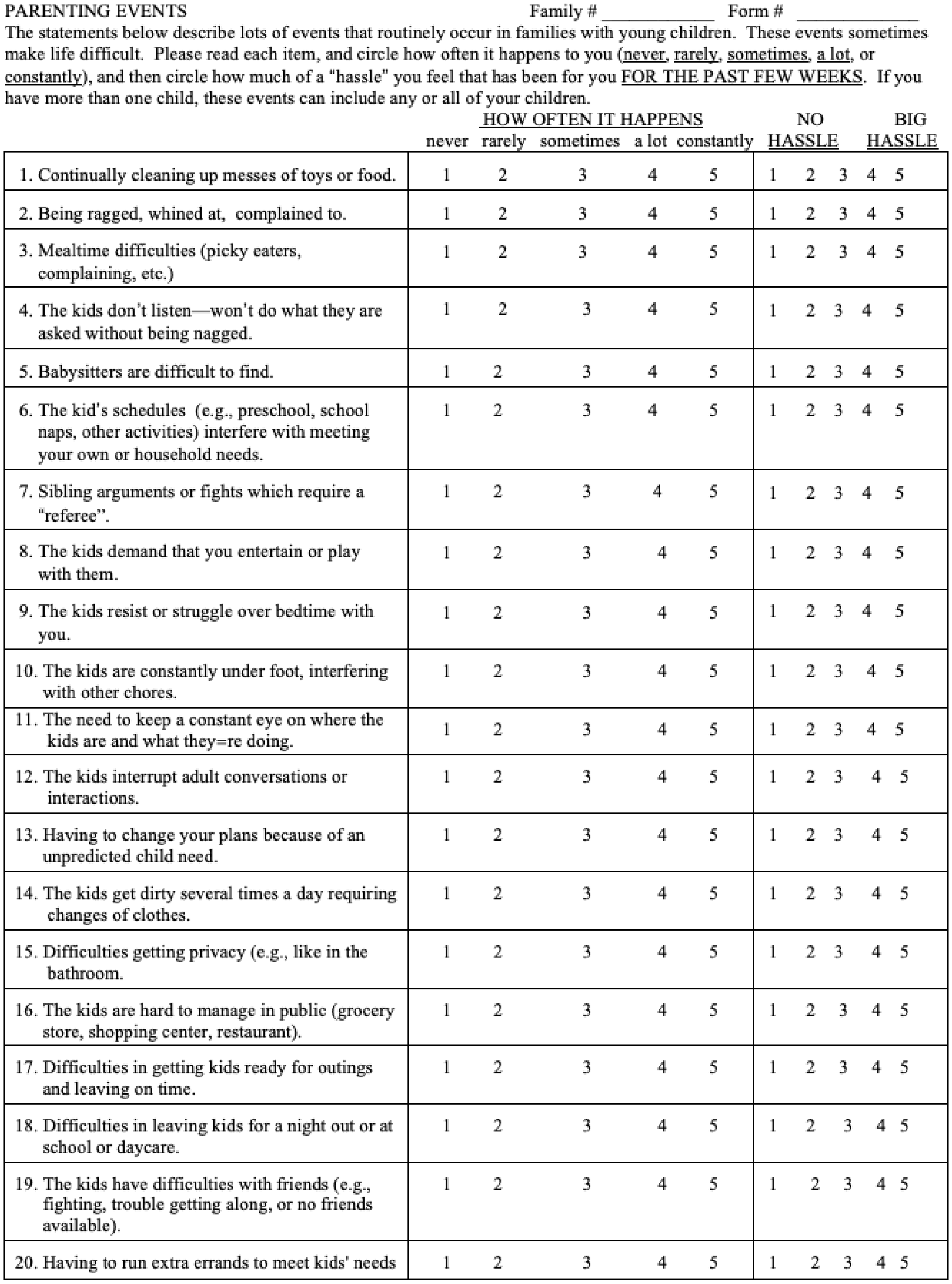
In this section, please continue to look back and try to remember how <u>you</u> have felt during the <u>past 6 months</u>.

For each question, please tell me which response (which number) fits best.

In the past 6 months:

		Not at all	A little	Somewhat	Quite a bit	Very much
11.	How isolated did you feel as a result of your child's emotional or behavioral problem?	1	2	3	4	5
12.	How sad or unhappy did you feel as a result of your child's emotional or behavioral problem?	1	2	3	4	5
13.	How embarrassed did you feel about your child's emotional or behavioral problem?	1	2	3	4	5
14.	How well did you relate to your child?	1	2	3	4	5
15.	How angry did you feel toward your child?	1	2	3	4	5
16.	How worried did you feel about your child's future?	1	2	3	4	5
17.	How worried did you feel about your family's future?	1	2	3	4	5
18.	How guilty did you feel about your child's emotional or behavioral problem?	1	2	3	4	5
19.	How resentful did you feel toward your child?	1	2	3	4	5
20.	How tired or strained did you feel as a result of your child's emotional or behavioral problem?	1	2	3	4	5
21.	In general, how much of a toll has your child's emotional or behavioral problem taken on your family?	1	2	3	4	5

Appendix C. The Parenting Daily Hassles Scale



PARENTING EVENTS Family # ____________ Form # ____________

The statements below describe lots of events that routinely occur in families with young children. These events sometimes make life difficult. Please read each item, and circle how often it happens to you (never, rarely, sometimes, a lot, or constantly), and then circle how much of a "hassle" you feel that has been for you FOR THE PAST FEW WEEKS. If you have more than one child, these events can include any or all of your children.

	HOW OFTEN IT HAPPENS					NO				BIG
	never	rarely	sometimes	a lot	constantly	HASSLE				HASSLE
1. Continually cleaning up messes of toys or food.	1	2	3	4	5	1	2	3	4	5
2. Being ragged, whined at, complained to.	1	2	3	4	5	1	2	3	4	5
3. Mealtime difficulties (picky eaters, complaining, etc.)	1	2	3	4	5	1	2	3	4	5
4. The kids don't listen—won't do what they are asked without being nagged.	1	2	3	4	5	1	2	3	4	5
5. Babysitters are difficult to find.	1	2	3	4	5	1	2	3	4	5
6. The kid's schedules (e.g., preschool, school naps, other activities) interfere with meeting your own or household needs.	1	2	3	4	5	1	2	3	4	5
7. Sibling arguments or fights which require a "referee".	1	2	3	4	5	1	2	3	4	5
8. The kids demand that you entertain or play with them.	1	2	3	4	5	1	2	3	4	5
9. The kids resist or struggle over bedtime with you.	1	2	3	4	5	1	2	3	4	5
10. The kids are constantly under foot, interfering with other chores.	1	2	3	4	5	1	2	3	4	5
11. The need to keep a constant eye on where the kids are and what they=re doing.	1	2	3	4	5	1	2	3	4	5
12. The kids interrupt adult conversations or interactions.	1	2	3	4	5	1	2	3	4	5
13. Having to change your plans because of an unpredicted child need.	1	2	3	4	5	1	2	3	4	5
14. The kids get dirty several times a day requiring changes of clothes.	1	2	3	4	5	1	2	3	4	5
15. Difficulties getting privacy (e.g., like in the bathroom.	1	2	3	4	5	1	2	3	4	5
16. The kids are hard to manage in public (grocery store, shopping center, restaurant).	1	2	3	4	5	1	2	3	4	5
17. Difficulties in getting kids ready for outings and leaving on time.	1	2	3	4	5	1	2	3	4	5
18. Difficulties in leaving kids for a night out or at school or daycare.	1	2	3	4	5	1	2	3	4	5
19. The kids have difficulties with friends (e.g., fighting, trouble getting along, or no friends available).	1	2	3	4	5	1	2	3	4	5
20. Having to run extra errands to meet kids' needs	1	2	3	4	5	1	2	3	4	5

PARENTING DAILY HASSLES
Measure and Manual

The Parenting Daily Hassle (PDH) measure was initially created to assess minor daily stresses experienced by most parents in routine interactions with their children and in routine tasks involving childrearing. As presently composed, the PDH has 20 items, each of which is rated along two major dimensions: (1) the frequency with which the event occurs and (2) the intensity or degree of "hassle" the parent perceives the event to be. The Frequency Scale was constructed to provide a more objective marker of the frequency with which these events occur within families. The Intensity Scale was developed to assess the parent's subjective appraisal of the significance of the event. Generally, the PDH is quick to complete (5 - 8 minutes) and has been well received by parents. Specific information on the PDH can be found in Crnic, K. A. & Greenberg, M. T. (1990). Minor Parenting Stresses With Young Children. Child Development, 61, 1628-1637.

The measure can be scored in two distinct ways. First, the two major Scale scores can be constructed. The FREQUENCY SCALE can be constructed by summing the frequency ratings across all 20 items, for which never = 1, rarely = 2, sometimes = 3, a lot = 4, and constantly = 5. Frequency Scale scores could range from 20 to 100. Internal consistency alpha=s for the Frequency scale have ranged from .80 to .89 in three separate data sets. The INTENSITY SCALE can be constructed by summing the hassle ratings across the 20 items of the measure. The possible range of score is 20 to 100. Internal consistency alpha=s for the Intensity Scale have ranged from .89 to .93 in three separate data sets. The Frequency and Intensity Scales are also typically highly correlated with one another, averaging a r = .75.

It is also possible to score the measure in relation to two separate factors that were derived from an initial factor analysis reported in the 1990 Child Development paper. These factors are the (1) Challenging Behavior Factor and (2) the Parenting Tasks Factor. The factors are created only from the Intensity Scale, and represent the sums of ratings from each item comprising the factor. The items that comprise these factors are as follows:

(1) Challenging Behavior: Items = 2, 4, 8, 9, 11, 12, 16

(2) Parenting Tasks: Items = 1, 6, 7, 10, 13, 14, 17, 20

Supporting information for these factors is available in the 1990 CD paper. Because, however, this factor structure was derived from a single study with a relatively small sample size, replication is necessary before these can be considered reliable. Nevertheless, the factor scores can be used for comparative purposes with the findings reported in the 1990 CD paper.

Finally, it should be noted that the instructions provide a time frame for the parent to respond within. The time frame should be set by the individual investigator according to the purposes of the study. We have used a range from "over the past several days" to "the past six months". Differences in the performance of the measure across varying time frames has not been determined as yet, although our initial attempts to compare scores across time frames suggest there is fair consistency. This remains, however, an interesting empirical question.

There is no charge for using this measure, and we encourage use by other investigators. We ask only that findings be shared with us so that we can keep abreast of how the measure is performing and under what conditions. Thank you for this consideration.

Please direct inquiries or reports to:

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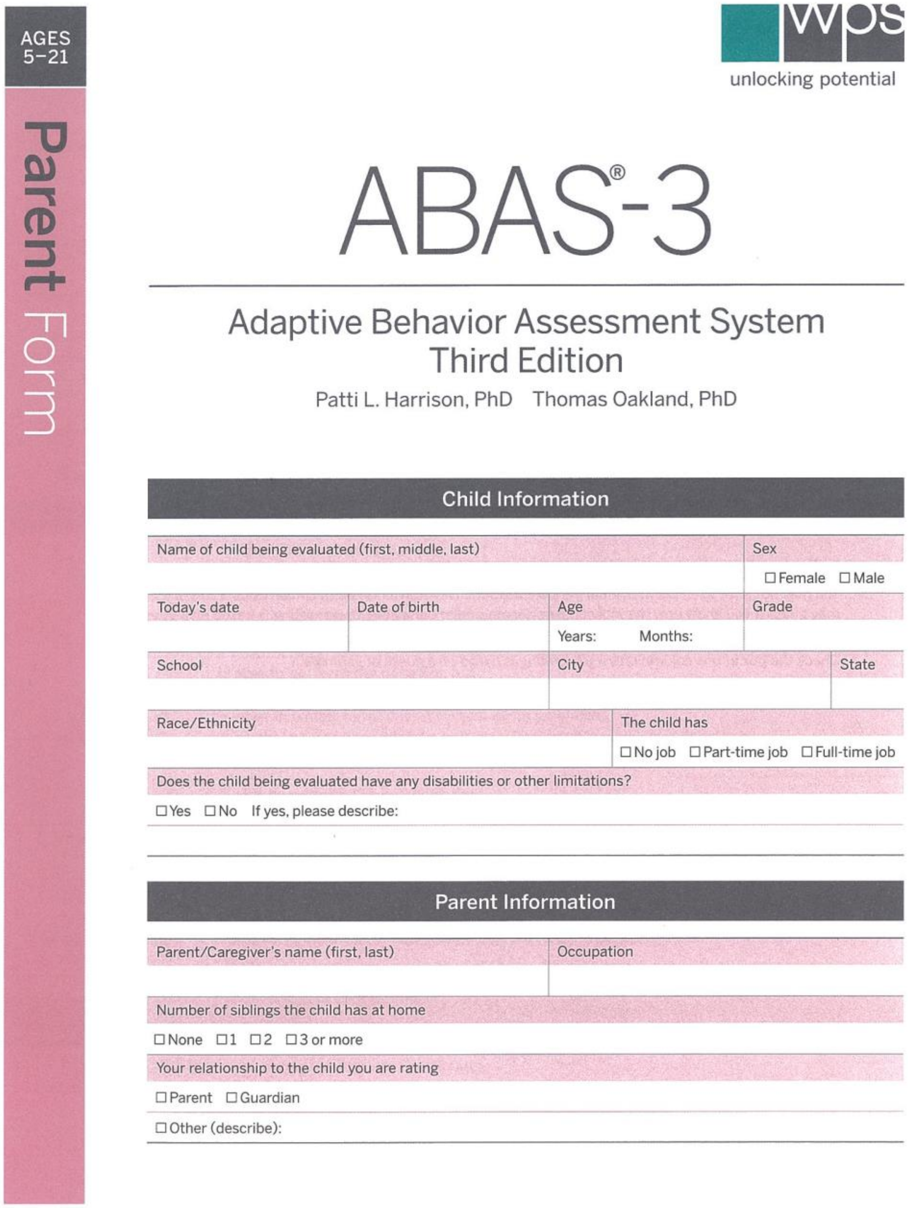
Department of Psychology
Arizona State University
Tempe, AZ 85287
(480) 965-3061
email: keith.crnic@asu.edu

Appendix D. The Adaptive Behavior Assessment System – III



AGES
5–21

Parent Form

wps
unlocking potential

ABAS®-3

Adaptive Behavior Assessment System
Third Edition

Patti L. Harrison, PhD   Thomas Oakland, PhD

Child Information

Name of child being evaluated (first, middle, last)			Sex ☐ Female ☐ Male
Today's date	Date of birth	Age Years: Months:	Grade
School		City	State
Race/Ethnicity		The child has ☐ No job ☐ Part-time job ☐ Full-time job	

Does the child being evaluated have any disabilities or other limitations?

☐ Yes ☐ No If yes, please describe:

Parent Information

Parent/Caregiver's name (first, last)	Occupation

Number of siblings the child has at home

☐ None ☐ 1 ☐ 2 ☐ 3 or more

Your relationship to the child you are rating

☐ Parent ☐ Guardian

☐ Other (describe):

Communication

	BEHAVIOR RATINGS				
	Ability	Frequency			
	Is not able	Never (or almost never) when needed	Sometimes when needed	Always (or almost always) when needed	Check **ONLY** if you GUESSED
1. Says the names of other people (for example, "Mama," "Daddy," or names of friends).	0	1	2	3	☐
2. Shakes head or says "Yes" or "No" in response to a simple question (for example, "Do you want something to drink?").	0	1	2	3	☐
3. Says "Hello" and "Good-bye" to others.	0	1	2	3	☐
4. Names 20 or more familiar objects.	0	1	2	3	☐
5. Tells parents, friends, or others about his or her favorite activities.	0	1	2	3	☐
6. Uses sentences with a noun and verb.	0	1	2	3	☐
7. Answers the telephone by saying "Hello."	0	1	2	3	☐
8. Speaks clearly and distinctly.	0	1	2	3	☐
9. Looks at other people's faces when they are talking to him or her.	0	1	2	3	☐
10. Listens closely for at least 5 minutes when people talk.	0	1	2	3	☐
11. Nods or smiles to encourage others when they are talking.	0	1	2	3	☐
12. Says irregular plural nouns correctly (for example, says "feet" instead of "foots" and "men" instead of "mans").	0	1	2	3	☐
13. Follows parent's or caregiver's verbal instructions when completing tasks or participating in activities (for example, a household chore or new game).	0	1	2	3	☐
14. Gives verbal instructions to others that involve two or more steps or activities.	0	1	2	3	☐
15. States his or her telephone number.	0	1	2	3	☐
16. Participates in conversations without talking too much or too little.	0	1	2	3	☐
17. Starts conversations on topics of interest to others.	0	1	2	3	☐
18. Discusses a topic for at least 3 minutes.	0	1	2	3	☐
19. Refrains from repeating what he or she says over and over again.	0	1	2	3	☐
20. States his or her home address, including zip code.	0	1	2	3	☐
21. Distinguishes truthful from exaggerated claims by friends, advertisers, or others.	0	1	2	3	☐
22. Talks about realistic future educational or career goals.	0	1	2	3	☐
23. Answers complex questions that require careful thought and opinion (for example, questions about politics or current events).	0	1	2	3	☐
24. Talks with others about complex topics for at least 10 minutes (for example, about politics or current events).	0	1	2	3	☐

FOR EXAMINER USE ONLY	**Raw total**	/ 72	
		Total guessed	

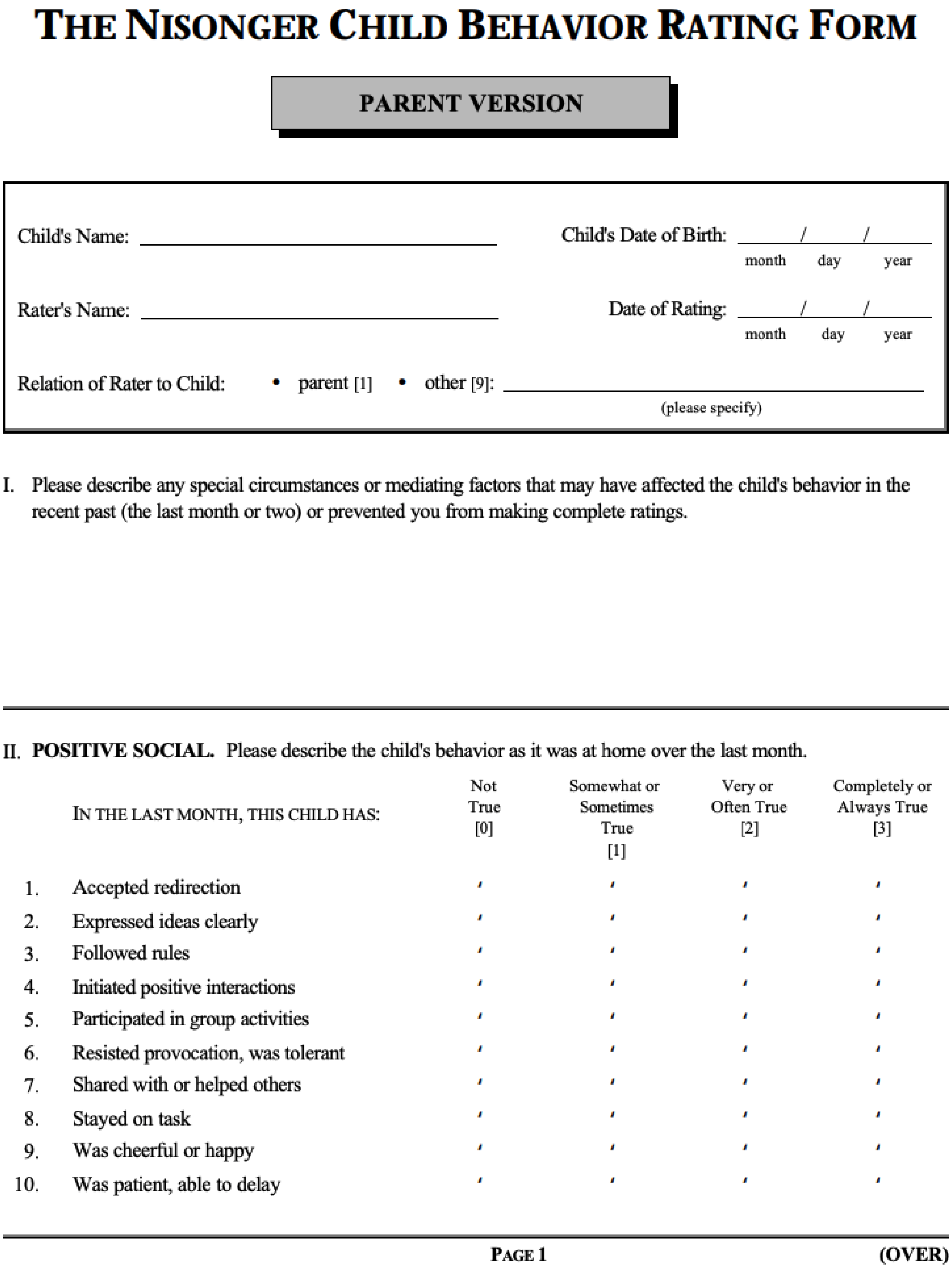
Functional Academics

		BEHAVIOR RATINGS			
	Ability	Frequency			
	Is not able	Never (or almost never) when needed	Sometimes when needed	Always (or almost always) when needed	Check **ONLY** if you GUESSED
1. Writes or prints his or her first and last name.	0	1	2	3	☐
2. Reads his or her name when printed.	0	1	2	3	☐
3. States the days of the week in order.	0	1	2	3	☐
4. Reads and obeys common signs (for example, Do Not Enter, Exit, Stop).	0	1	2	3	☐
5. Answers simple questions about a story read to him or her.	0	1	2	3	☐
6. Keeps score correctly when playing games.	0	1	2	3	☐
7. Locates important dates on a calendar (for example, birthdays or holidays).	0	1	2	3	☐
8. Tells time correctly, using a watch or a clock with hands.	0	1	2	3	☐
9. Reads menus at restaurants.	0	1	2	3	☐
10. Writes his or her address, including zip code.	0	1	2	3	☐
11. Measures length and height.	0	1	2	3	☐
12. Gives a clerk the necessary amount of money when buying items.	0	1	2	3	☐
13. Writes and sends letters, personal notes, or emails.	0	1	2	3	☐
14. Follows a favorite interest or current event by reading about it in newspapers, books, or other materials, or on the Internet.	0	1	2	3	☐
15. Uses printed or Internet resources to find information (for example, in dictionaries and encyclopedias).	0	1	2	3	☐
16. Uses lists and reminders to remember important things.	0	1	2	3	☐
17. Records dates and times for appointments and deadlines.	0	1	2	3	☐
18. Checks for correct change after buying an item.	0	1	2	3	☐
19. Reads and follows instructions for assembling new purchases.	0	1	2	3	☐
20. Reads labels before purchasing products for important information about size, weight, and directions for use.	0	1	2	3	☐
21. Checks the accuracy of charges before paying a bill.	0	1	2	3	☐
22. Budgets money to cover expenses for at least 1 week.	0	1	2	3	☐
23. Completes written forms to apply for jobs.	0	1	2	3	☐
FOR EXAMINER USE ONLY	**Raw total**			/ 69	
				Total guessed	

Self-Direction

	BEHAVIOR RATINGS				
	Ability	Frequency			
	Is not able	Never (or almost never) when needed	Sometimes when needed	Always (or almost always) when needed	Check **ONLY** if you GUESSED
1. Works independently and asks for help only when necessary.	0	1	2	3	☐
2. Stands still when needed, without fidgeting or moving around.	0	1	2	3	☐
3. Works on one home or school activity for at least 15 minutes without reminders.	0	1	2	3	☐
4. Controls temper when disagreeing with friends.	0	1	2	3	☐
5. Refrains from telling a lie to escape punishment.	0	1	2	3	☐
6. Completes tasks that need to be done, even those that are not enjoyable.	0	1	2	3	☐
7. Controls disappointment when a favorite activity is canceled.	0	1	2	3	☐
8. Stops a fun activity, without complaining, when told that time is up.	0	1	2	3	☐
9. Controls feelings when not getting his or her own way.	0	1	2	3	☐
10. Starts a household chore at once when told to do so.	0	1	2	3	☐
11. Keeps working on hard tasks without becoming discouraged, quitting, or needing reminders.	0	1	2	3	☐
12. Refuses when another person asks him or her to do something foolish.	0	1	2	3	☐
13. Makes schoolwork a priority over leisure activities.	0	1	2	3	☐
14. Routinely arrives at places on time.	0	1	2	3	☐
15. Avoids behavior that could embarrass or bring shame to self or family.	0	1	2	3	☐
16. Completes large home or school projects on time.	0	1	2	3	☐
17. Works on one home or school activity for at least 1 hour without being reminded or redirected.	0	1	2	3	☐
18. Limits time playing computer games or other nonproductive activities.	0	1	2	3	☐
19. When leaving home, informs others of destination and return time.	0	1	2	3	☐
20. Returns on time when asked to be back in 1 hour.	0	1	2	3	☐
21. Gathers all supplies needed before beginning a cleaning or maintenance project at home.	0	1	2	3	☐
22. Calls family or others when he or she will be late (for example, in returning home, attending a social event, or arriving for an appointment).	0	1	2	3	☐
23. Plans ahead to allow enough time to complete big projects.	0	1	2	3	☐
24. Makes important decisions only after careful consideration, without rushing.	0	1	2	3	☐
25. Plans home projects in logical steps.	0	1	2	3	☐
FOR EXAMINER USE ONLY **Raw total**				/ 75	
				Total guessed	

Appendix E. Nisonger Child Behavior Rating Form



THE NISONGER CHILD BEHAVIOR RATING FORM

PARENT VERSION

Child's Name: ______________________________ Child's Date of Birth: ____/____/____ (month day year)

Rater's Name: ______________________________ Date of Rating: ____/____/____ (month day year)

Relation of Rater to Child: • parent [1] • other [9]: ______________________________ (please specify)

I. Please describe any special circumstances or mediating factors that may have affected the child's behavior in the recent past (the last month or two) or prevented you from making complete ratings.

II. **POSITIVE SOCIAL.** Please describe the child's behavior as it was at home over the last month.

	IN THE LAST MONTH, THIS CHILD HAS:	Not True [0]	Somewhat or Sometimes True [1]	Very or Often True [2]	Completely or Always True [3]
1.	Accepted redirection	☐	☐	☐	☐
2.	Expressed ideas clearly	☐	☐	☐	☐
3.	Followed rules	☐	☐	☐	☐
4.	Initiated positive interactions	☐	☐	☐	☐
5.	Participated in group activities	☐	☐	☐	☐
6.	Resisted provocation, was tolerant	☐	☐	☐	☐
7.	Shared with or helped others	☐	☐	☐	☐
8.	Stayed on task	☐	☐	☐	☐
9.	Was cheerful or happy	☐	☐	☐	☐
10.	Was patient, able to delay	☐	☐	☐	☐

PAGE 1 (OVER)

III. **PROBLEM BEHAVIOR.** For each item that describes the child's behavior as it was over the last month, circle the:

0.... if the behavior **did not** occur or **was not a problem**
1.... if the behavior occurred **occasionally** or was a **mild problem**
2.... if the behavior occurred **quite often** or was a **moderate problem**
3.... if the behavior occurred **a lot** or was a **severe problem**

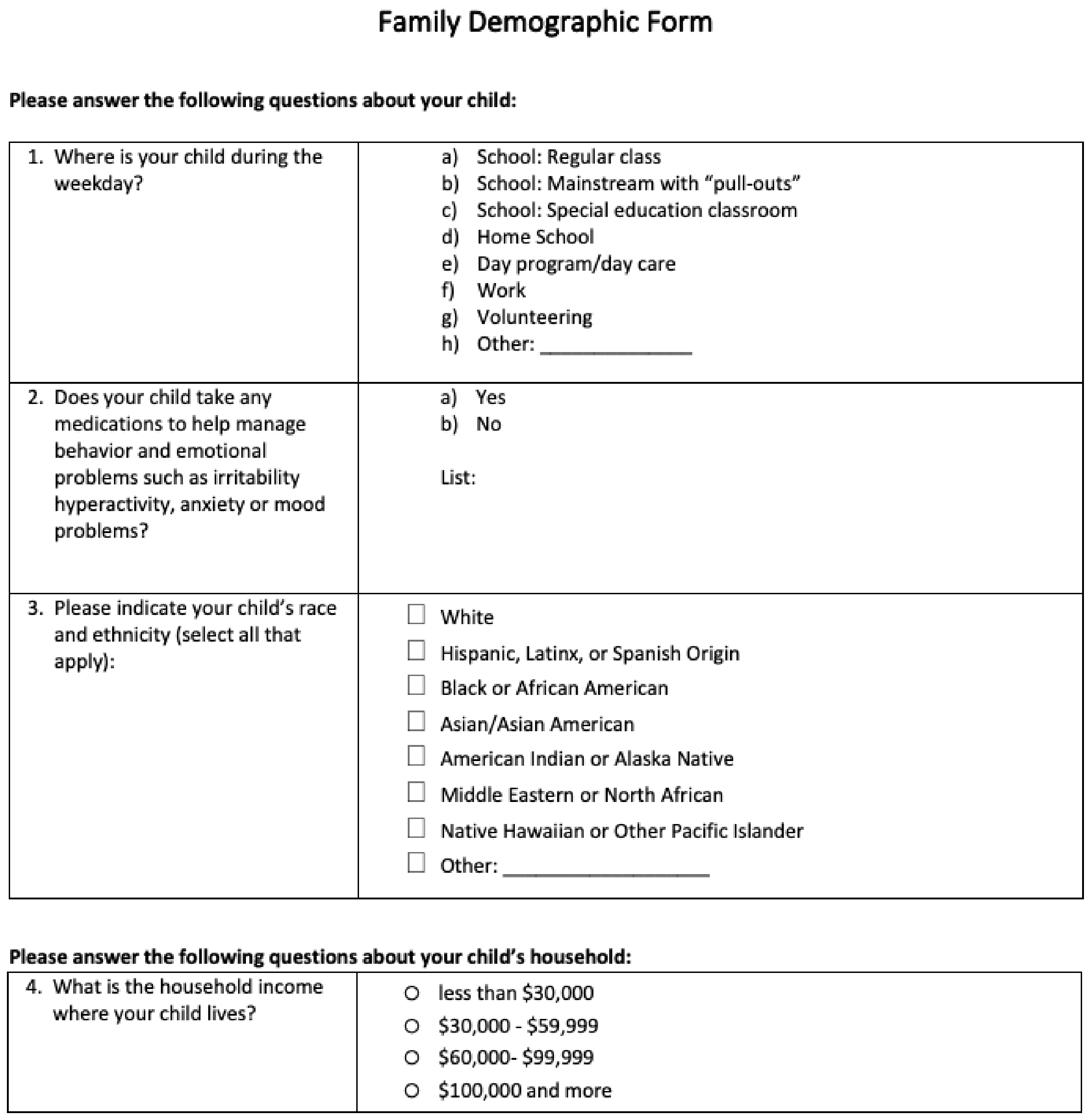
For each problem that occurred, circle only the score that best describes the behavior.

PLEASE DO NOT SKIP ANY QUESTIONS. IF YOU DO NOT KNOW THE ANSWER OR HAVE NOT HAD A CHANCE TO OBSERVE THE CHILD FOR A GIVEN TIME, CIRCLE THE ZERO.

1. Apathetic or unmotivated 0 1 2 3
2. Argues with parents, teachers, or other adults 0 1 2 3
3. Clings to adults, too dependent 0 1 2 3
4. Cruelty or meanness to others 0 1 2 3
5. Crying, tearful episodes 0 1 2 3
6. Hits or slaps own head, neck, hands, or other body parts 0 1 2 3
7. Defiant, challenges adult authority 0 1 2 3
8. Knowingly destroys property 0 1 2 3
9. Difficulty concentrating 0 1 2 3
10. Disobedient 0 1 2 3
11. Rocks body or head back and forth repetitively 0 1 2 3
12. Doesn't feel guilty after misbehaving 0 1 2 3
13. Easily distracted 0 1 2 3
14. Easily frustrated 0 1 2 3
15. Overly sensitive; feelings easily hurt 0 1 2 3
16. Exaggerates abilities or achievements 0 1 2 3
17. Explosive, easily angered 0 1 2 3
18. Has rituals such as head rolling or floor pacing 0 1 2 3
19. Fails to finish things he/she starts 0 1 2 3
20. Feelings easily hurt 0 1 2 3
21. Feels others are against him/her 0 1 2 3
22. Harms self by scratching skin or pulling hair 0 1 2 3
23. Feels worthless or inferior 0 1 2 3
24. Fidgets, wiggles, or squirms 0 1 2 3
25. Shy around others; bashful 0 1 2 3
26. Gets in physical fights 0 1 2 3
27. Irritable 0 1 2 3
28. Repeatedly flaps or waves hands, fingers or objects (such as pieces of string) 0 1 2 3
29. Isolates self from others 0 1 2 3
30. Lying or cheating 0 1 2 3
31. Nervous or tense 0 1 2 3
32. Gouges self, puts things in ears, nose, etc., or eats inedible things 0 1 2 3
33. Overactive, doesn't sit still 0 1 2 3
34. Overly anxious to please others 0 1 2 3
35. Overly excited, exuberant 0 1 2 3
36. Physically attacks people 0 1 2 3
37. Refuses to talk 0 1 2 3
38. Repeats the same sound, word, or phrase over and over 0 1 2 3
39. Restless, high energy level 0 1 2 3
40. Runs away from adults, teachers, or other authority figures 0 1 2 3
41. Says no one likes him/her 0 1 2 3
42. Secretive, keeps things to self 0 1 2 3
43. Repeatedly bites self hard enough to leave tooth marks or break skin 0 1 2 3
44. Self-conscious or easily embarrassed 0 1 2 3
45. Shifts rapidly from topic to topic when talking 0 1 2 3
46. Short attention span 0 1 2 3
47. Shy or timid behavior 0 1 2 3
48. Steals 0 1 2 3
49. Odd repetitive behaviors (e.g., stares, grimaces, rigid postures) 0 1 2 3
50. Stubborn, has to do things own way 0 1 2 3
51. Sudden changes in mood 0 1 2 3
52. Sulks, is silent and moody 0 1 2 3
53. Physically harms or hurts self on purpose 0 1 2 3
54. Talks back to teacher, parents, or other adults 0 1 2 3
55. Talks too much or too loud 0 1 2 3
56. Temper tantrums 0 1 2 3
57. Threatens people 0 1 2 3
58. Threatens to harm self 0 1 2 3
59. Engages in meaningless, repetitive body movements 0 1 2 3
60. Too fearful or anxious 0 1 2 3
61. Underactive, slow 0 1 2 3
62. Unhappy or sad 0 1 2 3
63. Violates rules 0 1 2 3
64. Withdrawn, uninvolved with others 0 1 2 3
65. Worrying 0 1 2 3
66. Argues with other children or peers 0 1 2 3

Developed by M. G. Aman, M. J. Tassé, J. Rojahn, and D. Hammer, 1995.

Appendix F. Family Demographic Form



Family Demographic Form

Please answer the following questions about your child:

1. Where is your child during the weekday?	a) School: Regular class b) School: Mainstream with "pull-outs" c) School: Special education classroom d) Home School e) Day program/day care f) Work g) Volunteering h) Other: ______________
2. Does your child take any medications to help manage behavior and emotional problems such as irritability hyperactivity, anxiety or mood problems?	a) Yes b) No List:
3. Please indicate your child's race and ethnicity (select all that apply):	☐ White ☐ Hispanic, Latinx, or Spanish Origin ☐ Black or African American ☐ Asian/Asian American ☐ American Indian or Alaska Native ☐ Middle Eastern or North African ☐ Native Hawaiian or Other Pacific Islander ☐ Other: ___________________

Please answer the following questions about your child's household:

4. What is the household income where your child lives?	○ less than $30,000 ○ $30,000 - $59,999 ○ $60,000- $99,999 ○ $100,000 and more

Please answer the following questions about yourself (Caregiver):

5. What is your relationship to the child:	○ Biological Mother ○ Biological Father ○ Step Mother ○ Step Father	○ Adoptive Mother ○ Adoptive Father ○ Grandparent ○ Legal Guardian ○ Other: __________
6. What is <u>your</u> highest degree or level of school completed:	○ Less than college degree ○ College degree or higher	

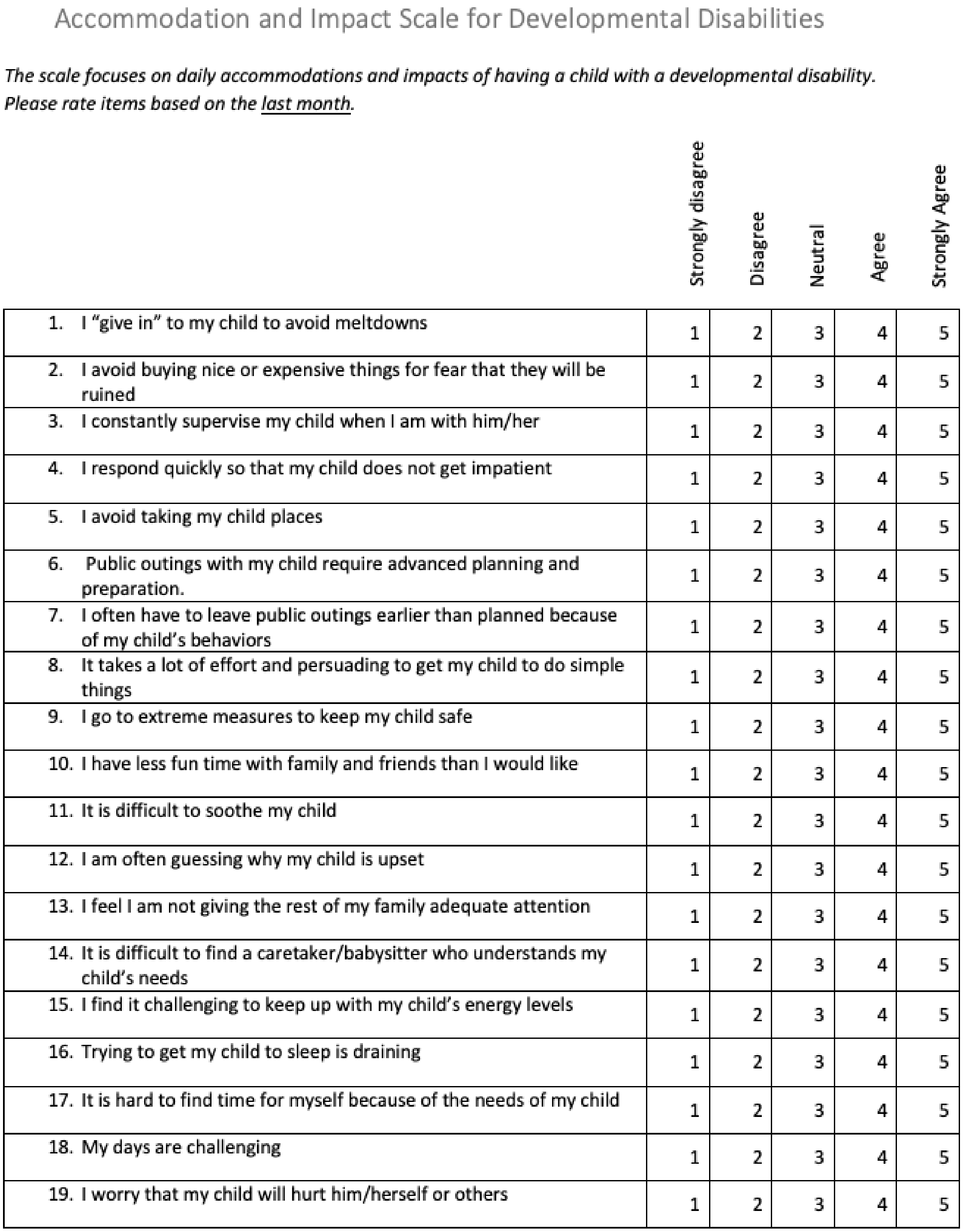
Please rate each statement based on how strongly you agree or disagree with these statements:

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
1. Since having my child, I have struggled more with my mental health	1	2	3	4	5
2. Since having my child, I am unsatisfied with the way my career path has changed.	1	2	3	4	5
3. I worry about whether my child will get the support he/she needs as he/she gets older	1	2	3	4	5
4. I did not imagine my life to be this challenging	1	2	3	4	5

Please rate each statement based on how strongly you agree or disagree with these statements:

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
1. My child's disability brought our family closer together	1	2	3	4	5
2. Overall, I am doing well	1	2	3	4	5
3. I appreciate the moments my child and I spend together	1	2	3	4	5
4. I have found new purpose surrounding my child's disability	1	2	3	4	5
5. I celebrate and appreciate small milestones in my child's life	1	2	3	4	5

Appendix G. Final 19 items of the AISDD



Accommodation and Impact Scale for Developmental Disabilities

The scale focuses on daily accommodations and impacts of having a child with a developmental disability. Please rate items based on the last month.

	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
1. I "give in" to my child to avoid meltdowns	1	2	3	4	5
2. I avoid buying nice or expensive things for fear that they will be ruined	1	2	3	4	5
3. I constantly supervise my child when I am with him/her	1	2	3	4	5
4. I respond quickly so that my child does not get impatient	1	2	3	4	5
5. I avoid taking my child places	1	2	3	4	5
6. Public outings with my child require advanced planning and preparation.	1	2	3	4	5
7. I often have to leave public outings earlier than planned because of my child's behaviors	1	2	3	4	5
8. It takes a lot of effort and persuading to get my child to do simple things	1	2	3	4	5
9. I go to extreme measures to keep my child safe	1	2	3	4	5
10. I have less fun time with family and friends than I would like	1	2	3	4	5
11. It is difficult to soothe my child	1	2	3	4	5
12. I am often guessing why my child is upset	1	2	3	4	5
13. I feel I am not giving the rest of my family adequate attention	1	2	3	4	5
14. It is difficult to find a caretaker/babysitter who understands my child's needs	1	2	3	4	5
15. I find it challenging to keep up with my child's energy levels	1	2	3	4	5
16. Trying to get my child to sleep is draining	1	2	3	4	5
17. It is hard to find time for myself because of the needs of my child	1	2	3	4	5
18. My days are challenging	1	2	3	4	5
19. I worry that my child will hurt him/herself or others	1	2	3	4	5