



Development and Preliminary Validation of the Accommodations & Impact Scale for Developmental Disabilities

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Abstract

The lives of caregivers can be deeply impacted by having a child with a developmental disability (DD). To offset those impacts, caregivers may engage in accommodations, or strategies to bolster everyday functioning. The nature and extent of these accommodations can provide insight into how the family is doing and what supports are needed from a family-centered perspective. This paper presents the development and preliminary validation of the Accommodations & Impact Scale for Developmental Disabilities (AISDD). The AISDD is a rating scale that measures day-to-day accommodations and impacts of raising a child with a DD. A sample of 407 caregivers of youth with DDs ($M_{\text{age}} = 11.7$ years; 63% males) completed the AISDD, along with measures of caregiver strain, daily challenges, child adaptive behavior, and behavior and emotional regulation. The AISDD is a unidimensional, 19-item scale with excellent internal consistency (ordinal $\alpha = .93$) and test–retest ($ICC = .95$) reliability. Scores were normally distributed and sensitive to age ($r = -.19$), diagnosis ($ASD + ID > ASD > ID$), adaptive functioning ($r = -.35$), and challenging behaviors ($r = .57$). Finally, the AISDD showed excellent convergent validity with similar measures of accommodations and impacts. These findings support the use of the AISDD as a valid and reliable tool for measuring accommodations among caregivers of individuals with DDs. This measure shows promise in its ability to identify which families may need additional support for their children.

Keywords Developmental disabilities · Survey design · Psychometrics · Caregiver accommodations · Family-centered care · Caregiver impacts

Introduction

Impacts of Having a Child with a Developmental Disability

Raising a child with special needs can lead to significant changes to many aspects of a caregiver’s life that are different from caregivers of children without developmental disabilities (DDs). Short-term, day-to-day impacts can include fewer outings because of difficulties finding a specialized babysitter, disability related expenses that result in financial stress, or getting little sleep because of the child’s own sleep difficulties. Short-term caregiver impacts have often

been referred to in the literature as “caregiver strain” or “caregiver burden,” which mainly refer to the additional stress and challenges of raising a child with a DD over and above general child rearing (Bradshaw et al., 2020; Brannan et al., 2012). High levels of caregiver strain have been reported in caregivers of children with autism spectrum disorder (ASD; Bradshaw et al., 2020) and Attention Deficit/Hyperactivity Disorder (ADHD; Rockhill et al., 2013). Caregiver strain increases when children have co-occurring behavior and emotional problems (Rockhill et al., 2013).

High levels of strain may be an indication of unmet services and needs on the part of the whole family (Khanna 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) and marital quality (Harper et al., 2013) of caregivers whose children have ASD. This in turn could impact the child’s outcome.

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Despite serving as a significant predictor of long-term impact, there has been very little research examining 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 and can include mental health problems such as depression and anxiety (Masefield et al., 2020), physical health concerns (Miodrag & Hodapp, 2011), financial challenges (Ouyang et al., 2014), as well as positive effects such as resilience (Taunt & Hastings, 2002).

Caregiver Accommodations in DD

Accommodations can be 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; Mas et al., 2016). 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 some 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 (Storch et al., 2007).

While accommodations may reduce short-term impacts, they may sometimes have downstream negative effects if they are occurring instead of needed interventions, or if they come at a significant cost to the caregiver or family. Thus, current accommodations may provide insight into which families are susceptible to long-term challenging impacts and signal an opportunity to provide additional support (Piazza et al., 2014). This is crucial, as long-term physical and psychological impacts are pervasive among families of children with DD (Magaña & Smith, 2006), 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 caregiver work schedules, and planning almost every activity in advance (Bernheimer & Weisner, 2007; Maul & Singer, 2009). These accommodations are used 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.

Existing Measures of Accommodations and Impacts in the Literature

Several measures examine constructs similar to caregiver accommodations and impacts. First, the Family Accommodations Interview is a semi-structured caregiver interview that assesses challenges in maintaining the family's daily routines and how their child's developmental delays impact them (Gallimore et al., 1996). Next, the Family Adjustment Measure assesses positive adjustment, such as seeking social and family support and developing positive coping skills (Daire et al., 2014). Additionally, the Family Accommodation Scale for Restricted and Repetitive Behaviors (FAS-RRB) measures family accommodation of RRBs in children with ASD (Feldman et al., 2019). Finally, the Parenting Daily Hassles scale (PDH) is a measure of day-to-day hassles that caregivers experience in their daily routine (Crnic & Greenberg, 1990).

Measures of caregiver impacts include the Parenting and Family Adjustment Scales, an outcome measure of parents' coping skills and quality of parent-child relationship

(Sanders et al., 2014). The Family Impact Questionnaire is a 50-item survey of parents' perceptions of the impact their child has on the family and parents' well-being (Donenberg & Baker, 1993). Finally, the Caregiver Strain Questionnaire (CSQ) is a measure of perceived external (e.g., work, finances, routines) and internal (e.g., stress, worrying) impacts (Brannan et al., 1997).

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

While there are existing measures that assess some form of impact or accommodations, they are either time-consuming (e.g., Family Accommodation Interview, Family Impact Questionnaire) or capture only one facet of accommodations or impacts (e.g., Family Adjustment Measure: positive accommodations, FAS-RRB: accommodation of RRBs). Given these limitations, the current study aims to develop and validate a brief survey of short-term accommodations and impacts to be used for DDs. As part of these aims, the present study will validate the Accommodation & Impact Scale for DD (AISDD). This scale, along with comparison measures, was distributed to families in order to assess its construct validity and temporal stability. It was hypothesized that 1) the AISDD would contain two factors measuring accommodations and impacts, 2) AISDD scores positively correlate with adaptive functioning and negatively correlate with challenging behaviors, and 3) there would be moderate correlations ($r \sim 0.5\text{--}0.7$) with the PDH and CSQ, two measures of accommodations and impacts, respectively.

It is our hope that a measure of day-to-day accommodations and impact would (1) serve to identify families 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.

Method

Participants

Participants were recruited from large clinical and research databases at the Children's Hospital of Philadelphia, through which caregivers of individuals between ages 5–18 years with International Classification of Diseases (ICD) codes corresponding to intellectual disability (ID), ASD, or a co-occurring presentation (ID+ASD) were contacted with an email solicitation about the study. Four hundred seven caregivers completed the AISDD and accompanying measures. Demographic information for the sample is provided in Table 1.

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 were 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 current version of the AISDD draws upon a previous study, in which an initial pool of 133 items was developed. During the development of the first draft of the AISDD, items were gathered from various sources: (1) previously collected caregiver interviews, in which parents reported on the daily challenges of raising a child with special needs, (2) a review of the literature on accommodations and impacts, and (3) examination of existing measures. Initial feedback on the items was provided by two expert clinicians and 10 caregivers of children with DDs. The survey was then administered to and rated by 500 caregivers of individuals with DDs, whose responses were analyzed with descriptive statistics and an exploratory factor analysis. This led to the removal of 103 items for the following reasons: skewed distributions, high inter-correlations, unclear verbiage, and/or insensitivity to change over time. The remaining items were reworded so they could be understood with a 5th grade reading level. Finally, five parents were selected to provide 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 internalized strain, and subjective externalized 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. It was hypothesized that the former two scales of the CSQ will have a strong association with the AISDD. 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

Table 1 Demographic information of sample

	ID	ASD	ID + ASD	Total Sample
Sex				
N(%)	161 (40%)	193 (47%)	53 (13%)	407
% 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
Children in home				
% 1 child	23	20	21	21
% 2–3 children	57	66	64	62
% ≥ 4 children	20	14	15	16

ID intellectual disability, ASD autism spectrum disorder, M mean, SD standard deviation, IQR interquartile range

psychometric properties in samples of children with ASD (Bradshaw et al., 2020; Khanna et al., 2012).

Parenting Daily Hassles Scale (PDH)

The Parenting 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. Both dimensions are rated on a 5-point Likert scale (Frequency: 1[never] to 5[constantly]; Hassle: 1[No Hassle] to 5[Big Hassle]). It was hypothesized that all factors and dimensions of the PDH would be strongly correlated with the AISDD. The PDH was developed with caregivers of typically developing children and children born prematurely. Chronbach's alpha for the Frequency Scale was

0.81 and 0.90 for the Intensity Scale. It has also been used with caregivers of children with DDs (Walerius et al., 2016), although its psychometric properties have yet to be evaluated in this population.

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, which assesses communication, functional academics, and self-direction. Internal consistency is 0.98 and test–retest reliability is 0.81 (Harrison & Oakland, 2015).

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. 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 acceptable psychometric properties in children with ID and children with ASD (Lecavalier et al., 2004; Norris & Lecavalier, 2011).

Demographic Form

The Demographic Form collects basic demographic information such as race/ethnicity, education, household income, and caregiver education level.

Procedures

The research study was approved by the Institutional Review Board. Families were recruited through the Children's Hospital of Philadelphia recruitment registries. Participants were recruited on the basis of their child's ICD code, age, and time since diagnosis. 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. Participants completed an informed consent form online and received a \$10 e-gift card for completing the surveys. Data collection occurred online through RedCap surveys. 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 two weeks between administrations.

Statistical Analyses

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 was assessed using Pearson correlation coefficients with all scales of the CSQ and PDH. A Pearson correlation coefficient between 0.4 and 0.7 was required for adequate convergent validity (Cicchetti & Sparrow, 1981).

Reliability

The internal consistency of the AISDD caregiver form was assessed with ordinal alpha coefficient. Test–retest reliability was assessed using intraclass correlation coefficients (ICCs), with a two-way random effects model and absolute agreement. An ICC estimate of 0.75 or greater was required for acceptable test–retest reliability. An ICC between 0.75 and 0.90 is indicative of good reliability and an ICC greater than 0.90 indicates excellent reliability (Koo & Li, 2016).

Associations Between Child Characteristics and AISDD Scores

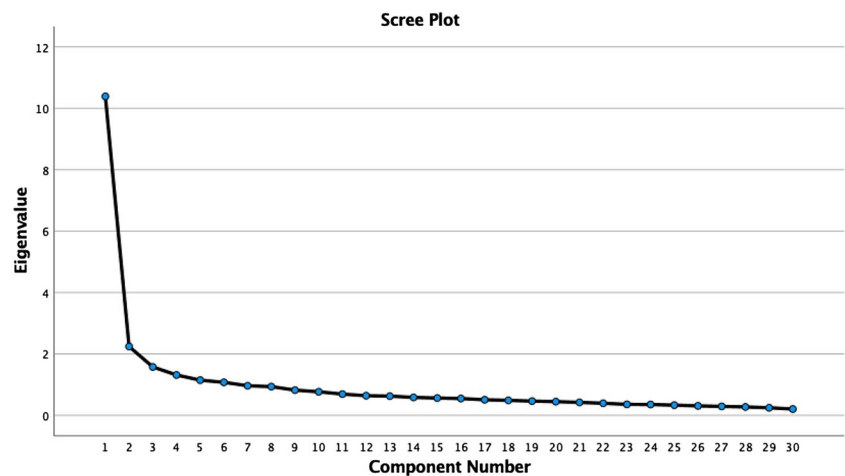
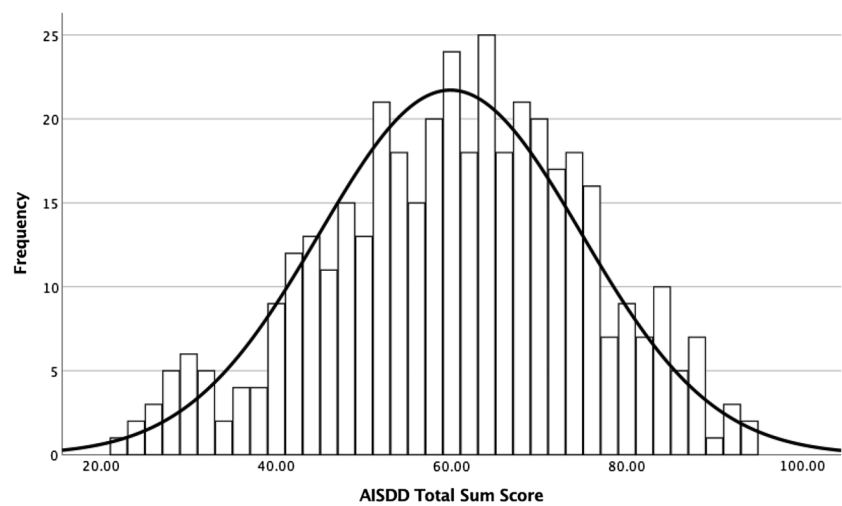
The association between AISDD scores and subject characteristics (e.g., age, sex, sociodemographic information, level of functioning, problem behaviors) was measured with Pearson correlations and nonparametric Independent Samples Kruskal–Wallis tests.

Results

Item and Factor Analysis

An iterative approach was used to reduce the number of items and to understand the structure underlying retained items. First, an EFA was conducted with the original pool of 30 items. The scree plot, shown in Fig. 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 was clinically meaningful. All other factor structures lacked clinical interpretability.

Next, item distributions and inter-item correlations were examined. A total of eleven items were discarded on the basis of having skewed distributions ($n = 4$), high inter-item correlations (i.e., exceeding 2.5 SDs from mean inter-correlation; $n = 1$), factor loadings below 0.45 ($n = 7$), or low test–retest reliability of $ICC < 0.8$ ($n = 3$). Another EFA was conducted on the final 19 items and confirmed the single-solution. The mean factor loading on the 19-item scale was 0.65, and the mean AISDD sum score for the entire sample was 59.9 ($SD = 14.9$; range = 22–93). The distribution of total scores for the AISDD can be found in Fig. 2. All further analyses were conducted using the 19-item AISDD 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 1.

Fig. 1 Scree plot of eigenvalues**Fig. 2** Distribution of AISDD Total Sum Score across whole sample. $M = 60$, $SD = 15$, range = 22–93

Reliability

Internal consistency for the AISDD was excellent, with an ordinal alpha coefficient of 0.93. The scale also had a mean inter-item correlation of 0.42. Test–retest reliability (range 10 to 21 days; $M = 12.6$, $SD = 2.6$), measured with ICCs, on the Total Sum Score of the 19-item AISDD ($n = 49$) was also excellent at 0.95 ($p < 0.001$). Temporal stability for all individual item ratings was significant at the $p < 0.001$ 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%; $Z = -3.08$, $p = 0.002$). However, the proportion of males (63% v. 64%; $Z = -0.17$, $p > 0.05$) and the mean age ($t(400) = -1.23$, $p > 0.05$) were both comparable across test and retest samples.

Association with Demographic and Clinical Characteristics

Correlations with demographic and clinical characteristics are found in Table 3. There was a small negative relationship between age and the 19-item AISDD total score ($r = -0.19$, $p < 0.001$). In contrast, there were no significant differences in AISDD scores by either sex ($\chi^2(3) = 3.33$, $p > 0.05$) or household income ($\chi^2(4) = 6.31$, $p > 0.05$).

In terms of clinical characteristics, nonparametric Independent-Samples Kruskal–Wallis tests revealed differences in AISDD scores by clinician diagnosis ($\chi^2(2) = 36.98$, $p < 0.001$), 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 ($r = -0.35$, $p < 0.001$). 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

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
3. Constantly supervise child	.525	.89	3.66
4. Act quickly	.537	.81	3.22
5. Avoid taking child places	.674	.93	2.82
6. Planning for outings	.744	.83	3.48
7. Leave outings early	.824	.90	2.86
8. Persuade for simple things	.561	.76	3.35
9. Extreme safety measures	.636	.80	3.53
10. Have less fun time	.719	.87	3.44
11. Difficult to soothe child	.657	.76	2.75
12. Guessing why upset	.551	.83	3.22
13. Less attention to family	.687	.84	3.10
14. Finding caretaker	.717	.87	3.73
15. Energy levels	.653	.91	2.95
16. Bedtime is draining	.581	.86	2.61
17. Less time for myself	.797	.76	3.54
18. Days are hard	.741	.86	3.65
19. Child hurts self or others	.572	.77	2.62
20. Test Average	.646	.84	3.18

^aSummary of item phrasing

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 ($t[222] = 6.6$, $p < 0.001$). This difference was associated with a large effect size of $d = 0.88$ (Cohen, 1969).

Of the six NCBRF sum scores, the scale with the strongest association with the AISDD was the Hyperactive scale ($r = 0.57$, $p < 0.01$), while the weakest association was with the Insecure/Anxious scale ($r = 0.22$, $p < 0.01$). These correlations are listed in Table 3. 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 ($M = 55.8$, $SD = 14.8$; $t(363) = 6.78$, $p < 0.001$). This difference had a large effect size of $d = 0.74$.

Convergent Validity

Convergent validity was supported with strong Pearson correlations between the AISDD, PDH, and CSQ. Table 4 presents the correlations between these measures. The

Table 3 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

correlations between the 19-item AISDD and the PDH Sum of Frequency and Intensity scores were strong at 0.77 and 0.69 (respectively). The correlation between the AISDD Sum Score and the CSQ Global Sum Score was similar, at 0.77. All of these correlations were significant at the $p < 0.001$ level and met criteria for excellent convergent validity (Cicchetti & Sparrow, 1981).

Discussion

The current study describes the preliminary validation of a new, unidimensional measure of accommodations in caregivers of individuals with DDs.

Factor Solution & Reliability

Through an iterative process, factor and item analysis of a pool of 30 items led to a unidimensional, 19-item scale. This single factor solution contrasts to the hypothesized two-subscale model (Accommodations and Impacts). This finding reveals overlap in the two hypothesized subscales, such that only one latent construct is sufficient to represent items from both domains. Impacts may also be interpreted as accommodations, and vice versa. 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.

In terms of reliability of the final scale, both internal consistency and test–retest reliability were excellent. Test–retest reliability of the AISDD ($ICC = 0.95$) was comparable to the CSQ (Global Strain Score: 0.92) and PDH (Frequency: 0.95,

Table 4 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)

Intensity: 0.94), when tested on the current sample. 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 will be sensitive to change over time (McCrae et al., 2011).

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 ($r = -0.19$). 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, sex 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 sex 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 ($r = 0.51$, $p < 0.03$) and 7 ($r = 0.57$, $p = 0.05$) but not 11 ($r = 0.56$, $p > 0.05$). 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 more likely to occur among families with a higher SES). This may explain the discrepant findings, since the AISDD does not contain financial accommodation items.

As expected, accommodations were greater among those with lower adaptive functioning and more challenging behaviors. These findings are supported by Feldman et al. (2019), who examined these links among caregivers who accommodated for their child’s restricted and repetitive behaviors (RRBs). 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. In another study, 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. 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).

Finally, AISDD scores were higher for those with co-occurring ASD + ID and those taking psychotropic medications. Together, these findings suggest that as severity of symptoms increase, so do accommodations—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 (Cho et al., 2000). Thus, this study provides a first examination of how specific DD diagnoses can impact caregiver accommodations.

Convergent Validity

The AISDD showed evidence of strong convergent validity with the PDH (a measure of daily hassles) and the CSQ (a measure of caregiver burden). High convergent validity between these measures is likely observed because of the way the AISDD was developed. Items were pruned from the initial item pool if they did not seem 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 (Kaat & Lecavalier, 2013). As a result, the item content of the AISDD overlaps 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 convergence across measures does not imply redundancy. First, much of the variance between the measures is unique (i.e., the highest correlation coefficient found, $r = 0.77$, reflects 59% shared variance). 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. Finally, advantages of the AISDD include that it is brief, was developed to be sensitive to change over time, and is suitable for a wide age range of individuals with DDs.

Limitations and Future Directions

Several limitations exist in the present study. First, the relatively small sample prevented us from conducting an independent confirmatory factor analysis or to examine measurement invariance. Second, 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. As income impacts day-to-day caretaking, the findings may not generalize to those with lower SES. In addition, 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 confirm the factor structure and examine measurement invariance in the AISDD. Importantly, including a typically developing sample could allow for a comparison of accommodations between groups. Further, future work should examine AISDD response patterns across families of a broad range of SES. 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 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 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.

Appendix 1: 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

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
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 me 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

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and data collection. LL contributed to conceptualizing the study and analysis, writing the manuscript, and provided funding.

Declarations

Conflict of interest The authors have no conflicts of interest to report.

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