Intellectual and Developmental Disabilities

# Establishing an Advocacy Activities Scale for Parents of Individuals with Intellectual and Developmental Disabilities

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| **Abstract:** | Advocacy has long been heralded as a way to create change for individuals with intellectual and developmental disabilities (IDD) and their families. However, without an established measure, it is difficult to accurately characterize advocacy activities. Drawing from extant research, the Advocacy Activities Scale was developed to assess three domains of parent advocacy: advocacy for one's own children, advocacy for other families, and advocacy for systemic change. Factor analyses were conducted using data from two projects reflecting 382 parents of individuals with IDD from seven states and the District of Columbia. The scale confirmed the three moderately correlated domains of parent advocacy and demonstrated that the scale has high: reliability, validity, test-retest reliability, and moderate correlations with related measures. |

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## Abstract

Advocacy has long been heralded as a way to create change for individuals with intellectual and developmental disabilities (IDD) and their families. However, without an established measure, it is difficult to accurately characterize advocacy activities. Drawing from extant research, the Advocacy Activities Scale was developed to assess three domains of parent advocacy: advocacy for one's own children, advocacy for other families, and advocacy for systemic change. Factor analyses were conducted using data from two projects reflecting 382 parents of individuals with IDD from seven states and the District of Columbia. The scale confirmed the three moderately correlated domains of parent advocacy and demonstrated that the scale has high: reliability, validity, test-retest reliability, and moderate correlations with related measures.

*Keywords:* advocacy, caregivers, disability, factor analyses

# Establishing an Advocacy Activities Scale for Parents of Individuals with Intellectual and Developmental Disabilities

For many individuals with intellectual and developmental disabilities (IDD), their parents constitute their earliest advocates. In a study of 185 parents of autistic youth, parent advocacy activities were the single strongest predictor of the number of services received by the youth (Lee et al., 2022). Parents often advocate for their family members with IDD across their lifespans (i.e., individual advocacy, Burke, 2012). Aside from advocating for their own children, parents of individuals with IDD may advocate for other families of children with disabilities (i.e., peer advocacy, Burke et al., 2019) as well as for systemic change for all individuals with disabilities (i.e., systemic advocacy, Trainor, 2010). With respect to peer advocacy, parents of individuals with IDD often provide peer support to other families of individuals with IDD (Burke et al., 2019). Regarding systemic advocacy, in the United States, parent advocacy led to the passage of the Individual with Disabilities Education Act (IDEA; Yell et al., 2017). Internationally, parent advocacy has also facilitated the protection of the human rights of individuals with IDD (Cohen, 2013).

Reflecting on the different ways that parents can advocate, Balcazar and colleagues (1996) developed a taxonomy of advocacy activities. Specifically, they identified three developmental stages as a pathway for advocacy development: beginner, involved, and activist. Beginner advocates were new to disability organizations, conducted fewer advocacy activities, and were often passive in their advocacy roles. Parents may start as beginner advocates and, over time, engage in the involved and activist stages of advocacy. Involved advocates were active members of multiple disability organizations and engaged in regular advocacy activities. The most advanced group was the activists – advocates who were leaders in disability organizations and spearheaded legislative changes.

Despite the research and theory about types and pathways through advocacy, research *measuring* parent advocacy remains sparse. To date, only a few studies have empirically quantified parent advocacy. Nachshen and colleagues (2001) developed a Parent Advocacy Scale (PAS) focusing on five dimensions of advocacy: membership in organizations, role in organizations, advocacy actions, the focus of advocacy, and feelings toward advocacy. In their study, 26 parents of individuals with IDD completed semi-structured interviews encompassing the PAS. While the PAS offers an initial attempt to quantify advocacy, it does not draw from a theoretical framework and the activities do not map onto the domains of individual, peer, and systemic advocacy. Other studies have asked open-ended questions about advocacy. For example, in a survey study about advocacy, Krueger and colleagues (2019) asked one open-ended prompt: Describe a time when you advocated for your child. However, without sub-prompts exploring the specific domains of advocacy, it may be that parents do not fully share all of their advocacy efforts. Thus, the purpose of this study was to establish the psychometric properties and factor structure of an advocacy activities measure specifically designed towards multiple types of advocacy activities (i.e., individual, peer, and systemic advocacy) with a geographically diverse sample.

As suggested by Balcazar (1996), many families engage in individual advocacy. Indeed, most of the extant research about parent advocacy focuses on individual advocacy. For example, Lo (2005) asked parents of children with disabilities to answer 12 true/false questions about special education law. Correct responses were supposed to indicate the level of parent advocacy. However, their study did not measure advocacy activities—only knowledge. In contrast, to measure individual parent advocacy, Plunge and Kratochwill (1995) asked parents of children with disabilities to answer 17 questions about their participation in special education meetings in addition to 13 true/false statements about special education policy. However, their study was limited to advocacy activities in special education meetings, which are often only held annually. Advocacy can occur in many settings and, thus, it is important to develop measures that can be useful in multiple settings. Since advocacy is a lifelong endeavor (Burke et al., 2016), it is critical to have a measure of advocacy beyond the scope of an annual meeting.

As parents move through Balcazar's taxonomy of advocacy, they engage in systemic advocacy, which also requires careful measurement. Trainor (2010) identified parent advocates who were "agents for systemic change" as one of four distinct types of advocates based on focus groups and interviews with parents of individuals with disabilities. Among the few studies that have collected quantitative data about systemic advocacy, Wright and Taylor (2014) posited 17 questions to parents of individuals with disabilities. The questions related to the advocacy setting (e.g., schools, medical clinics, churches, rallies) and the effectiveness of their advocacy. However, the questions were limited to systemic advocacy at a physical location. Other forms of systemic advocacy (e.g., writing legislators and conducting social media campaigns) were not addressed in their study. Research is needed to understand the wide range of systemic advocacy activities that might be undertaken by parents.

Not specifically mentioned in the taxonomy of advocacy, peer advocacy is another aspect of advocacy in need of measurement. Advocacy programs, wherein an individual learns to advocate for other families of individuals with disabilities and/or navigate service delivery systems for other families, are becoming increasingly common (Goldman, 2020). Goldman and colleagues (2017) evaluated the effectiveness of the Volunteer Advocacy Project (VAP, a 36-

hour training about special education advocacy). Specifically, Goldman and colleagues developed a measure to ascertain the frequency with which VAP graduates advocated for other families of children with disabilities. In a study evaluating the efficacy of the Latino Parent Leadership Support Project (LPLSP, a special education advocacy program for Latinx families of children with autism), Burke and colleagues (2016) developed a measure to examine the peer advocacy provided by the LPLSP graduates to other families with children with disabilities. While helpful, these advocacy measures were developed within the context of advocacy programs (i.e., the VAP and the LPLSP). Further, both programs reflected special education advocacy—they did not focus on other forms of or contexts for advocacy. Thus, some items may not be appropriate for all circumstances of peer advocacy.

Without accurately quantifying parent advocacy, it is difficult to gauge the effect of advocacy on outcomes. Given research suggesting that parent advocacy activities have a strong association with the likelihood that individuals with disabilities receive needed services (Lee et al., 2022), it is critical to understand how much advocacy is needed to yield this change, and which activities (or types of activities) are most impactful. A measure of advocacy activities could also be useful for service planning; families who may not be able to advocate frequently or effectively may require more supports to achieve similar outcomes as families who advocate often. A measure of parent advocacy activities could be helpful in identifying families who need extra supports. Thus, a measure of parent advocacy activities has potential value for research as well as for practice.

To this end, the purpose of this study was to develop and test the Advocacy Activities Scale (AAS) measure with parents of children and young adults with IDD. Specifically, we had two research questions: (1) Does the AAS reflect the three types of advocacy activities?; and (2)

Does the AAS have high validity and reliability? To answer the first research question, we conducted exploratory and confirmatory factor analyses to evaluate the AAS to determine whether the covariance among the items aligned with the latent factors (i.e., individual, peer, and systemic). To answer the second research question, we conducted statistical analyses measuring internal consistency through Cronbach’s alpha, convergent validity using Pearson’s correlation, and test-retest reliability via intraclass correlation coefficients to determine the reliability and validity of the AAS. While Balcazar’s taxonomy (1996) did not address peer advocacy, our proposed AAS includes peer advocacy given its growing recognition as an important source of support to families (Goldman, 2020). Thus, our study goes beyond Balcazar’s (1996) taxonomy of advocacy by including peer advocacy. We hypothesized that each of the AAS items would load principally onto one of the three factors of individual advocacy, peer advocacy, or systemic advocacy without any cross-loadings. Because the AAS was developed for parents of children and young adults with IDD, the AAS may be used for school-based and, potentially, adult service delivery system advocacy.

# Method

## Participants

A total of 382 participants who were parents of individuals with IDD were included in this study. Most of the participants were female (81.94%; *n* = 323) and averaged 46.42 years of age (*SD* = 8.75), with a range from 17 to 71 years. The majority of respondents were White (70.42% or *n* = 269), with smaller proportions identified as African American (20.68% or *n* = 79), Hispanic (9.16% or *n* = 35), Native American (2.62% or *n* = 10), Asian (2.36% or *n* = 9), and other ethnicities (1.57% or *n* = 6). Regarding the offspring with IDD, they were predominantly male (70.94%; *n* = 271) and averaged 15.10 years of age (*SD* = 5.44, range = 2-27 years). See Tables 1 and 2.

## Recruitment

Data were collected as part of two multi-state projects to investigate the impact of advocacy programs among parents of individuals with IDD. The purpose of the first project was to test (via a randomized waitlist-control trial) an advocacy program about adult disability services for parents of transition-aged youth with autism; accordingly, the age criteria for the autistic youth was limited to the transition years and early adulthood. For this project, participants were recruited from three states in the U.S. (Illinois, Tennessee, and Wisconsin) through email circulations and postings to autism studies, research registries, disability agencies, school personnel, and autism support groups. Eligibility criteria for the study were: (a) parent or legal guardian of a youth with autism who was 16–26 years of age; (b) parent provided medical, psychological, and/or educational documentation of their youth’s autism diagnosis; (c) parent was able to attend a 12-week advocacy program; and (d) youth had lifetime scores indicating likely autism on the Social Communication Questionnaire (SCQ; Rutter et al., 2003)—a parent report screener for autism.

The second project was also a randomized controlled trial, with the purpose to test the effectiveness of a civic engagement program about special education among parents of children with disabilities. In this project, participants were recruited from five states in the U.S. (Illinois, Louisiana, Maine, New Mexico, and South Carolina) and Washington D.C. The Parent Training and Information Centers (PTIs) located in each of the sites assisted with recruitment. To be included in the study, participants needed to complete the pre-survey in English, have a schoolaged child with a disability (ranging in age from 0-27), and indicate a willingness to participate in a legislative advocacy program.

Altogether, due to the inclusionary criteria of the first project, a large portion (64.39%, *n* = 246) of the individuals with IDD was comprised of transition-aged youth (notably, transition-aged refers to individuals between the ages of 16-27). Specifically, 35.3% (*n* = 135) of the participants were 18 and older and were likely not receiving special education services and, instead, served by the adult service delivery system. Approval from the University Institutional Review Board was obtained for all study procedures and written consent was obtained from all participants.

## Procedures

To develop the AAS, we first reviewed the literature. Specifically, we examined extant research for all parent and/or disability advocacy measures related to individual advocacy, peer advocacy, and systemic advocacy (e.g., Trainor, 2010; Plunge & Kratochwill, 1995; Burke & Hodapp, 2016). After reviewing the extant measures, we came up with a total of 15 items for the AAS to reflect the three domains of parent advocacy (i.e., individual advocacy, peer advocacy, and systemic advocacy). The scale was piloted and tested with five parents of individuals with IDD for content validation, with minor wording changes made based on their feedback. The final instrument included 15 items and was answered on a 5-point Likert scale: (1) *not at all*; (2) *a little*; (3) *sometimes*; (4) *often*; and (5) *very often*.

## Analyses

The total sample (*n* = 382) was divided into two groups by using the odd-even split method: Group A (*n* = 191) and Group B (*n* = 191). Group A was used for the exploratory factor analysis (EFA) to establish the factor structure, and Group B was used for the confirmatory factor analysis (CFA) to confirm the AAS factor structures found in Group A. Baseline data collected via online surveys (prior to any treatment) were used for all analyses. The one exception was the test-retest reliability analysis; for this analysis, we utilized data from the control groups of both randomized-controlled trials as they had not received treatment and, consequently, we would expect their scores not to systematically change. All factor analyses were conducted using the *lavaan* package from *R* whereas reliability and validity statistical analyses were conducted using SPSS.

### ***Exploratory Factor Analysis***

EFA with maximum likelihood (ML) estimation and oblique rotation was performed to determine underlying common variance among items loaded on their respective factors. The use of ML has been advocated by several statistical researchers as best practice (e.g., Mabel & Olayemi, 2020; Sowell, 1992; Tabachnick and Fidell, 2007) because of its sensitivity to model misspecification and lower rates of type II error (Olsson et al., 2000). Additionally, oblique rotation was chosen to be most apt for the data given its assumption for factors to be correlated. To determine how many factors should be retained, we conducted parallel analysis, a method based on the generation of random variables for determining the optimal number of factors to retain (Horn, 1965). The process involves comparing eigenvalues extracted from experimental data with those from randomly generated data on a scree plot. Resulting factors with eigenvalues exceeding those extracted from the random data should be considered for retention. In this study, the following criteria were further specified: (a) all factors should have eigenvalues > 1; (b) all rotated factors should account for >5% of the variance in item scores; (c) sufficient factors to account for >60% of the variance in item scores should be included. Utilizing typical threshold guidelines for factor loadings (Howard, 2016), an item was placed in a factor if there was a minimal loading of 0.4 and it loaded highest on that factor. Pearson correlation coefficients were also computed between the factors to determine whether the factors are similar enough to pertain to a shared construct but not to the degree where they may be measuring the same constructs (i.e., coefficients with moderate correlation magnitudes were expected).

### *Confirmatory Factor Analysis*

Regarding the CFA, various fit indices were used to evaluate the model fit as recommended in the literature (Hu & Bentler, 1999). While the chi-square ($\chi^2$) statistics were reported, they were not considered as the sole indicator of model fit due to their tendency to reject models with trivial misspecifications on large sample sizes. Therefore, additional indices including the root mean square error of approximation (RMSEA), standardized root mean square residual (SRMR), Confirmatory Fit Index (CFI), and Tucker-Lewis Index (TLI) were also used to assess the fit. An RMSEA value of up to .05 indicates good fit, while values between .06 and .08 suggest adequate fit, and values exceeding .10 indicate poor fit. An SRMR value below .08 is indicative of good fit. Finally, CFI and TLI values greater than .90 are generally considered acceptable indicators of model fit.

### *Reliability and Validity*

To assess the reliability of scores for the AAS, internal consistency was measured using Cronbach’s alpha on the baseline data of the combined sample. To further examine the internal validity of the AAS, test-retest reliability was conducted between the baseline and post-test data of the control group participants (i.e., those who did not receive the treatment being tested in the larger studies). Additionally, given the importance of empowerment to parent advocacy as indicated by previous research (e.g., Burke et al., 2019), interscale correlations between the AAS and the family subscale of the Family Empowerment Scale (FES; Koren et al., 1992) which measured the expression of empowerment at the micro level, were analyzed to determine convergent validity. Previous studies have indicated high reliability of the FES subscale among parents of children with IDD ($\alpha$ = 0.89-0.92; Burke et al., 2022).

# Results

## Exploratory Factor Analysis

Following the guidance of the parallel analysis for the EFA using Group A (*n* = 191), two factors were indicated to be retained: “individual advocacy” and “advocacy for others”. See Figure 1. Notably, the “advocacy for others” factor reflected peer and systemic advocacy items. The factor analysis of the first EFA explained 57.9% of the variance with seven items relating to individual advocacy (variance explained = 31.58%) and eight items relating to advocacy for others (variance explained = 26.33%). Although the results of this EFA presented no items with low communalities (< 0.2) or loadings below the threshold of 0.4, it was found that item 7 loaded onto the factor relating to individual advocacy (versus for others) while items 8, 9, and 10 showed high cross-loading. As expected, the two factors were moderately correlated but were still distinct factors measuring different aspects of an overarching latent construct (*r* = .46). See Table 3.

To align with the theoretical framework (Balcazar et al., 1996), we additionally estimated a three-factor structure to evaluate whether each domain of advocacy would be reflected in the AAS. The second EFA explained 58.1% of the variance with seven items relating to individual advocacy (variance explained = 27.28%), three items relating to peer advocacy (variance explained = 12.89%), and five items relating to systemic advocacy (variance explained = 17.94%). No issues with cross loading or communalities were found but item 7 continued to load onto the factor reflecting individual advocacy. The three factors were all moderately correlated with higher correlations between Factor 1 and Factor 2 (*r* = .59) as well as Factor 2 and Factor 3 (*r* = .63) than Factor 1 and Factor 3 (*r* = .36). See Table 4.

## Confirmatory Factor Analysis

To assess the hypothetical structure of the scale obtained from the EFAs, CFAs with ML estimation were conducted on the second half of the sample (Group B, *n* =191). Two initial models were estimated, including a two-factor solution (Model A) and a three-factor solution (Model B), with item loadings hypothesized based on the structures identified in the EFA. Additionally, an alternative three-factor solution (Model C) with item 7 loading based on the structure in alignment with our conceptualized framework was specified and tested.

For Model A, the CFA indicated the two factors (individual advocacy and advocacy for others) identified in Group A were not a good fit for the data. Model fit indicators revealed poor to acceptable fit for the two-factor structure derived from Group A within Group B (using as values for acceptable fit, RMSEA < .08, CLI > .90, TFI > .90, and SRMR < .08; Hu & Bentler, 1999; see Table 5). See Table 6 for the standardized factor loadings of Model A.

For Model B, the CFA indicated the three factors (individual advocacy, peer advocacy, systemic advocacy) identified in Group A were a good fit for the data. All the model fit indicators revealed good to excellent fit for the three-factor structure derived from Group A within Group B (using as values for excellent fit, RMSEA < .05, CLI > .95, TFI > .95, and SRMR < .05; Hu & Bentler, 1999; see Table 6). Further, the results from the chi-square test indicate that the three-factor model was significantly better than the two-factor model ($\Delta\chi^2$ = 52.29, *p* < .001). The standardized factor loadings obtained for Model B are shown in Table 7.

For Model C, the CFA indicated the three-factor structure based on our conceptualized framework was not a good fit for the data. Model fit indicators revealed poor to acceptable fit (using as values for acceptable fit, RMSEA < .08, CLI > .90, TFI > .90, and SRMR < .08; Hu & Bentler, 1999; see Table 5). The results from the chi-square test also attest to the greater fit of Model B over Model C for the data ($\Delta\chi^2 = 61.29$, $p < .001$). The standardized factor loadings obtained for Model C are shown in Table 8.

## Reliability and Validity

The best fitting factor solution (Model B) was then used for subsequent validity and reliability analyses. For the internal consistency of the AAS, results demonstrated that reliability was high ($\alpha = .92$ for individual advocacy; $\alpha = .88$ for peer advocacy; $\alpha = .91$ for systemic advocacy; $\alpha = .94$ for the full AAS scale). Given that there was high internal consistency for the full AAS scale, the cumulative variable, ranging from 15 to 75, was subsequently used to check for test-retest reliability and convergent validity. The test-retest reliability results show that agreement over time was high (ICC = .90 for individual advocacy; ICC = .88 for peer advocacy; ICC = .80 for systemic advocacy; ICC = .91 for the full AAS scale). For the interscale correlation between AAS and FES, results indicated that there was a significant, positive relation between the family subscale of the FES and individual advocacy ($r = .32$; $p <.001$), peer advocacy ($r = .19$; $p <.001$), systemic advocacy ($r = .13$; $p <.001$), and the full AAS scale ($r = .27$; $p <.001$).

# Discussion

Consistent with the conceptual framework based on the taxonomy of advocacy developed by Balcazar and colleagues (1996), the AAS had strong reliability and converged on the three domains of parent advocacy. Specifically, factor analyses revealed that the AAS consists of three moderately correlated factors: individual advocacy, peer advocacy, and systemic advocacy. We have three main findings. First, the AAS reflects the taxonomy of parent advocacy (Balcazar et al., 1996). Further, if needed, individuals could only use subscales of the AAS if they are only interested in certain domains of parent advocacy. This finding is important as, to date, there are few measures of parent advocacy especially measures that reflect individual, peer and systemic advocacy.

It is important to note that one item did not map onto the taxonomy of advocacy activities as theorized. Item 7 (i.e., “talked with other parents about agencies and/or services to meet the other family’s child’s needs”) loaded better onto individual advocacy rather than peer advocacy. The unexpected loading onto individual advocacy may suggest issues with either the AAS and/or the nature of advocacy. Regarding the AAS, it could be that the participants did not carefully read that this item focused on advocacy for *other* families (instead of their own children). However, this error seems unlikely given that the word “other” was bolded and underlined. On the other hand, it could be that advocacy for other families helps families conduct better individual advocacy for their own children. Although not directly examined, some studies have found that by engaging in peer networking and learning from other families’ advocacy experiences, parents of children with disabilities report improved individual advocacy (Author, submitted; Rossetti et al., 2021). Thus, it could be that peer advocacy actually contributes to individual advocacy efforts.

Second, it seems that each subscale of advocacy uniquely reflects distinct advocacy domains: individual, peer, and systemic. Not only was the three-factor solution the best fitting model, but also the decreasing correlation sizes with the FES may reflect a developmental process of advocacy activities. Indeed, the size of the correlation between the advocacy domains gradually decreased as the AAS subscale became more focused on systemic rather than individual advocacy. In a study of individual and systemic advocacy among 127 parents of individuals with disabilities, Rossetti and colleagues (2021) found that when parents conducted systemic advocacy, they found it easier to do so with peers (i.e., other parents of individuals with disabilities). Consistent with this study, peer and systemic advocacy were more highly correlated than individual advocacy and peer advocacy and especially more so than the correlation between individual and systemic advocacy.

More research is needed to examine the AAS over time. As hypothesized by Balcazar and colleagues (1996), there may be a linear progression to advocacy with individuals first engaging in individual advocacy and, as time passes, conducting more peer and, eventually, systemic advocacy. However, some literature argues against a linear advocacy progression. Indeed, in a study of advocacy in early intervention, parents of 0–3-year-olds with IDD engaged in individual, peer, and systemic advocacy (Author, submitted). By longitudinally examining parents of individuals with IDD using the AAS, we can discern how and when parents may engage in different types of advocacy activities.

## Limitations

It is important to note some limitations of the current study. Although the data collected was from a large sample, there is limited demographic diversity. Most parents were White and female; their children were mainly adolescents and young adults with IDD, specifically autism. Further, all participants were interested in participating in an advocacy program. Thus, the findings may not be generalizable to the population of parents of individuals with IDD across the U.S. In addition, while all items consistently loaded onto their respective factors in both samples, the unexpected and incompatible loading for one of the items (Item 7) suggests that more research is needed. Specifically, further research may help ensure that the loading does not reflect a misinterpretation of the wording in the item.

## Directions for Future Research

Future research should explore how the AAS relates to similar constructs as well as its validity for predicting outcomes. Regarding the former, it is unclear why there was only a small-medium correlation between advocacy and empowerment. Research should discern how closely related the two constructs are given their smaller than expected relations. Aside from empowerment, researchers may also examine how the AAS is associated with related constructs such as knowledge of disability laws. In much of the research about advocacy programs, the constructs of knowledge, advocacy, and empowerment are often evaluated to determine the effectiveness of such programs (e.g., Taylor et al., 2023). Moreover, future research should examine the overlap between the AAS and other constructs. Relatedly, research is needed to ensure that the AAS is a valid measure to predict the outcomes of advocacy programs. While, at the most basic level, advocacy programs should increase advocacy skills, the ultimate outcome is often to improve outcomes for individuals with IDD whether via increased service access or new legislation. While we have cross-sectional evidence of these associations (Lee et al., 2022), future work should examine the direction of the effects of advocacy activities in relation to increased service access and other outcomes.

Additionally, it is important to examine the AAS with a racially diverse sample with a wide age range. Regarding the former, families of color may have different experiences and perceptions of advocacy due to structural and societal factors (Cohen, 2013; Pearson et al., in press). Given the increasing prevalence of racial diversity in the U.S. as well as the unique experiences with advocacy among racial minority families, it is imperative to ensure that the AAS is culturally responsive. To do so, researchers should intentionally examine the responsiveness of the measure among racial minority families. By prioritizing research on advocacy with diverse samples and examining the ways in which race and ethnicity intersect with advocacy activities, we can gain a better understanding of how to support all families in advocating for their offspring.

Regarding the latter, research is needed to discern whether the AAS would be relevant to parent advocacy of adult children with IDD – particularly beyond early adulthood. More than 35% of our sample was over 18 years of age and likely had exited high school. Thus, there is some evidence that the AAS may be relevant for advocacy in both school-based and adult service systems. Although the wide age range of this sample is a strength of the current research, the oldest youth with IDD were 27 years of age. Future research will be needed to understand whether the AAS accurately reflects parent advocacy activities beyond when their son/daughter is in early adulthood. There is a tremendous need for community and health-based services for adults with disabilities, especially as they grow older (Lund, 2011). It may be that some AAS items should be modified to reflect advocacy within the adult service delivery systems as individuals move into and through middle adulthood.

## Implications for Practice

Given the rise in advocacy programs (Burke, 2013), there are several implications for practice. Depending on the purpose of an advocacy program, the AAS may be an appropriate measure to determine the effectiveness of the program. For example, advocacy programs that teach parents to advocate for their own children with IDD (e.g., Taylor et al., 2023) may utilize the individual advocacy subscale of the AAS. Advocacy programs that focus on teaching parents to advocate for other families (e.g., Burke et al., 2016) may utilize the peer advocacy subscale of the AAS. Legislative advocacy programs (e.g., Rossetti et al., 2020) may utilize the systemic advocacy subscale of the AAS.

Family navigators may also benefit from using the AAS. Several family navigator programs have been developed wherein parents (Magaña et al., 2017) or professionals (Broder-Fingert et al., 2020) serve as “navigators” to help families of individuals with disabilities, primarily autism, access evaluations and services. It may be that navigators not only help families access services but also help families develop their own advocacy skills. In the latter sense, the AAS may be an appropriate outcome measure for navigator programs.

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**Table 1**

*Participants Demographics*

| Characteristic | % (*n*) |
|---|---|
| Gender | |
| Female | 81.94 (313) |
| Marital Status | |
| Married | 66.49 (254) |
| Race/Ethnicity* | |
| White | 70.42 (269) |
| African American | 20.68 (79) |
| Hispanic/Latino | 9.16 (35) |
| Native American | 2.62 (10) |
| Asian/Pacific Islander | 2.36 (9) |
| Other | 1.57 (6) |
| Educational Background | |
| Some high school | 2.62 (10) |
| High school graduate | 5.24 (20) |
| Some college | 20.94 (80) |
| College degree | 41.88 (160) |
| Graduate degree | 29.06 (111) |
| Household Income | |
| Less than $20,000 | 6.02 (23) |
| Between $20-40,000 | 11.52 (44) |
| Between $40-60,000 | 16.49 (63) |
| Between $60-80,000 | 16.23 (62) |
| Between $80-100,000 | 10.99 (42) |
| More than $100,000 | 33.77 (129) |

*Note*. *Percentages do not add up to 100% as participants could choose to check multiple responses

**Table 2**

*Individuals with IDD Demographics*

| Characteristic | % (*n*) |
|---|---|
| Age Group | |
| Early Childhood | 8.38 (32) |
| Middle Childhood | 25.13 (96) |
| Transition-Age & Above | 64.39 (246) |
| Gender | |
| Male | 70.94 (271) |
| Diagnoses* | |
| Autism Spectrum Disorder | 77.75 (297) |
| Attention Deficit (Hyperactivity) Disorder | 42.93 (164) |
| Intellectual Disability | 34.82 (133) |
| Speech or Language Impairment | 15.18 (58) |
| Learning Disability | 13.35 (51) |
| Developmental Delay | 13.35 (51) |
| Emotional/Behavioral Disorder | 10.99 (42) |
| Other Health Conditions | 8.38 (32) |
| Down Syndrome | 4.45 (17) |
| Hearing Impairment | 3.14 (12) |
| Visual Impairment | 2.62 (10) |
| Cerebral Palsy | 2.62 (10) |
| Traumatic Brain Injury | 2.36 (9) |
| Fragile X Syndrome | 0.26 (1) |
| Prader-Willi Syndrome | 0.79 (3) |

*Note*. *Percentages do not add up to 100% as participants could choose to check multiple responses

**Table 3**

*Loading, Communalities, and Inter-factor Correlations of the First EFA*

| Advocacy Activity | Factor 1 | Factor 2 | Communalities |
|---|---|---|---|
| 1. Searched the internet to find agencies and/or services to meet your child's needs | **.86** | -.17 | .63 |
| 2. Talked with other parents about agencies/services to meet your child's needs | **.83** | -.05 | .65 |
| 3. Called agencies to ask about services | **.83** | .03 | .71 |
| 4. Attended trainings about services and/or their rights | **.71** | .18 | .65 |
| 5. Documented their advocacy/communication with agencies and professionals | **.67** | .20 | .62 |
| 6. Asked questions to professionals about services | **.88** | -.05 | .74 |
| 7. Talked with other parents about agencies and/or services to meet their child's needs | **.72** | .14 | .62 |
| 8. Facilitated trainings or support groups for other families of individuals with disabilities | .30 | **.59** | .60 |
| 9. Reviewed the records of another family to help them advocate | .32 | **.58** | .61 |
| 10. Helped another family communication with agencies and professionals | .40 | **.49** | .58 |
| 11. Visited the office or held meetings with legislators about disability issues | -.01 | **.81** | .65 |
| 12. Written letters to legislators about disability issues | .01 | **.71** | .51 |
| 13. Tried to get media attention about disability issues | -.01 | **.76** | .58 |
| 14. Taken on leadership roles in national, state, or local agencies related to disabilities | -.02 | **.78** | .59 |
| 15. Presented at state or national conferences about disability issues | -.19 | **.74** | .46 |
| Inter-factor Correlations | | | |
| Factor 1 | - | | |
| Factor 2 | .46 | - | |

*Note.* Factor loadings > \|.40\| bolded. An oblique rotation was used.

**Table 4**

*Loading, Communalities, and Inter-factor Correlations of the Second EFA*

| Advocacy Activity | Factor 1 | Factor 2 | Factor 3 | Communalities |
|---|---|---|---|---|
| 1. Searched the internet to find agencies and/or services to meet your child's needs | **.83** | .01 | -.14 | .63 |
| 2. Talked with other parents about agencies/services to meet your child's needs | **.80** | .03 | -.04 | .65 |
| 3. Called agencies to ask about services | **.83** | -.01 | .08 | .72 |
| 4. Attended trainings about services and/or their rights | **.64** | .19 | .09 | .65 |
| 5. Documented their advocacy/communication with agencies and professionals | **.64** | .11 | .16 | .62 |
| 6. Asked questions to professionals about services | **.91** | -.08 | .04 | .77 |
| 7. Talked with other parents about agencies and/or services to meet their child's needs | **.61** | .26 | .01 | .63 |
| 8. Facilitated trainings or support groups for other families of individuals with disabilities | .13 | **.53** | .24 | .62 |
| 9. Reviewed the records of another family to help them advocate | .01 | **.86** | .04 | .80 |
| 10. Helped another family communication with agencies and professionals | .11 | **.81** | -.01 | .75 |
| 11. Visited the office or held meetings with legislators about disability issues | -.01 | .12 | **.75** | .69 |
| 12. Written letters to legislators about disability issues | .10 | -.11 | **.82** | .62 |
| 13. Tried to get media attention about disability issues | .06 | -.04 | **.81** | .66 |
| 14. Taken on leadership roles in national, state, or local agencies related to disabilities | -.05 | .26 | **.58** | .56 |
| 15. Presented at state or national conferences about disability issues | -.19 | .19 | **.58** | .42 |
| Inter-factor Correlations | | | | |
| Factor 1 | - | | | |
| Factor 2 | .59 | - | | |
| Factor 3 | .36 | .63 | - | |

*Note.* Factor loadings > |.40| bolded. An oblique rotation was used.

**Table 5**

*Summary of Model Fit for Two-Factor and Three-Factor Solutions of the AAS*

| Model | $\chi^2$ | *df* | RMSEA [90% CI] | CFI | TLI | SRMR |
|---|---|---|---|---|---|---|
| Two-Factor Solution (A) | 235.112 | 84 | .098<br>[.083, .113] | .940 | .925 | .097 |
| Three-Factor Solution (B) | 178.518 | 81 | .080<br>[.064, .096] | .961 | .950 | .065 |
| Three-Factor Solution (C) | 240.475 | 81 | .103<br>[.088, .118] | .937 | .918 | .079 |

*Note.* RMSEA = Root Mean Square Error of Approximation; CFI = Comparative Fit Index; TLI = Tucker Lewis Index; SRMR = Standardized Root Mean Square Residual.

**Table 6**

*Standardized Loading of the Two-Factor CFA (Model A)*

| Factor | Item | Loading |
|---|---|---|
| Individual Advocacy | 1. Searched the internet to find agencies and/or services to meet your child's needs | .78 |
| | 2. Talked with other parents about agencies/services to meet your child's needs | .87 |
| | 3. Called agencies to ask about services | .87 |
| | 4. Attended trainings about services and/or their rights | .83 |
| | 5. Documented their advocacy/communication with agencies and professionals | .71 |
| | 6. Asked questions to professionals about services | .83 |
| | 7. Talked with other parents about agencies and/or services to meet their child's needs | .86 |
| Other Advocacy | 8. Facilitated trainings or support groups for other families of individuals with disabilities | .78 |
| | 9. Reviewed the records of another family to help them advocate | .75 |
| | 10. Helped another family communication with agencies and professionals | .71 |
| | 11. Visited the office or held meetings with legislators about disability issues | .87 |
| | 12. Written letters to legislators about disability issues | .85 |
| | 13. Tried to get media attention about disability issues | .90 |
| | 14. Taken on leadership roles in national, state, or local agencies related to disabilities | .81 |
| | 15. Presented at state or national conferences about disability issues | .85 |

**Table 7**

*Standardized Loading of the Three-Factor CFA (Model B)*

| Factor | Item | Loading |
|---|---|---|
| Individual Advocacy | 1. Searched the internet to find agencies and/or services to meet your child's needs | .77 |
| | 2. Talked with other parents about agencies/services to meet your child's needs | .88 |
| | 3. Called agencies to ask about services | .87 |
| | 4. Attended trainings about services and/or their rights | .83 |
| | 5. Documented their advocacy/communication with agencies and professionals | .72 |
| | 6. Asked questions to professionals about services | .83 |
| | 7. Talked with other parents about agencies and/or services to meet their child's needs | .86 |
| Peer Advocacy | 8. Facilitated trainings or support groups for other families of individuals with disabilities | .84 |
| | 9. Reviewed the records of another family to help them advocate | .84 |
| | 10. Helped another family communication with agencies and professionals | .84 |
| Systemic Advocacy | 11. Visited the office or held meetings with legislators about disability issues | .90 |
| | 12. Written letters to legislators about disability issues | .87 |
| | 13. Tried to get media attention about disability issues | .91 |
| | 14. Taken on leadership roles in national, state, or local agencies related to disabilities | .80 |
| | 15. Presented at state or national conferences about disability issues | .87 |

**Table 8**

*Standardized Loading of the Three-Factor CFA (Model C)*

| Factor | Item | Loading |
|---|---|---|
| Individual Advocacy | 1. Searched the internet to find agencies and/or services to meet your child’s needs | .78 |
| | 2. Talked with other parents about agencies/services to meet your child’s needs | .87 |
| | 3. Called agencies to ask about services | .88 |
| | 4. Attended trainings about services and/or their rights | .82 |
| | 5. Documented their advocacy/communication with agencies and professionals | .72 |
| | 6. Asked questions to professionals about services | .83 |
| Peer Advocacy | 7. Talked with other parents about agencies and/or services to meet their child’s needs | .82 |
| | 8. Facilitated trainings or support groups for other families of individuals with disabilities | .75 |
| | 9. Reviewed the records of another family to help them advocate | .78 |
| | 10. Helped another family communication with agencies and professionals | .81 |
| Systemic Advocacy | 11. Visited the office or held meetings with legislators about disability issues | .90 |
| | 12. Written letters to legislators about disability issues | .88 |
| | 13. Tried to get media attention about disability issues | .90 |
| | 14. Taken on leadership roles in national, state, or local agencies related to disabilities | .79 |
| | 15. Presented at state or national conferences about disability issues | .87 |

**Figure 1**

*Horn's Parallel Analysis Plot Graph of the EFA*