Intellectual and Developmental Disabilities

Respite Support from Adolescence to Adulthood in Families of People with Neurodevelopmental Disorders

--Manuscript Draft--

Manuscript Number:	IDD-D-24-00028R1
Article Type:	Research
Keywords:	respite; caregivers; adults; neurodevelopmental disabilities; autism
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Abstract:	Respite is a priority for caregivers of individuals with neurodevelopmental disabilities across the lifespan. The present study aimed to characterize respite availability and frequency of use among 126 caregivers of individuals with neurodevelopmental disabilities (from ages 16 to 22) using an ongoing longitudinal sample. Results indicated that availability of respite support was greater and more consistent over time for those with lower verbal abilities compared to those with higher verbal abilities. On average, frequency of respite use from household members declined over time, with overall higher frequency of use for those with lower VIQ. Our findings indicate that respite for caregivers of individuals with neurodevelopmental disabilities remains important well into adulthood, particularly for those who care for higher needs individuals.

Respite Support from Adolescence to Adulthood in Families of People with Neurodevelopmental Disorders

Accessing reliable and appropriate respite has been identified as a top priority by families of autistic people across the lifespan (Bromley et al., 2004; Russa et al., 2015). Respite care is the “provision of care to [people] with complex care needs for a specific period of time with the intent of providing temporary relief to the main carers and their family” (Cooke et al., 2020, p. two) and can come from various sources, such as family members or professional respite workers. Access to high quality and consistent respite care can allow caregivers to hold employment and engage in social and leisure activities (Brandon, 2007; Harper et al., 2013), leading to improved well-being (Dyches et al., 2016). Although accessing respite can be a challenge that extends beyond childhood (Hall & Graff, 2010; Houser et al., 2014; Montes & Halterman, 2008), little research exists on the availability and use of respite care for caregivers during their children’s adolescence and adulthood. The current study uses longitudinal data on availability and frequency of respite support from adolescence to early adulthood among caregivers of autistic youths or those with other neurodevelopmental disabilities to begin to address this gap in knowledge.

Caregivers of autistic youths have sometimes described parenting as a “demanding but unpaid full-time job” which includes both providing direct care to their child as well as navigating complex service systems (Houser et al., 2014, p. 690). This is in addition to balancing responsibilities such as employment, responding to the financial costs of supporting an autistic child or adult, and other aspects of family life. According to caregivers, parenting demands often take priority over their own needs and desires (Davy et al., 2022). Thus, typical parenting challenges may be amplified and extended for caregivers of autistic people due to a myriad of factors including the unique needs of their child and the effort and time required to coordinate and attend specialty care appointments (e.g., behavioral services, speech therapy). For example, childcare needs often lead to increased stress and impact employment decisions among parents of autistic children, such as working reduced hours or quitting a job in order to reduce non-parental care and manage therapy schedules (Cooke et al., 2020; Houser et al., 2014; Montes and Halterman, 2008). Having access to respite has been found to improve caregiver well-being, marital quality, and quality of life (Dyches et al., 2016; Harper et al., 2013; Smith et al, 2010). Although respite is beneficial for families during childhood, many are faced with a "service cliff" as children age into adolescence and adulthood—losing access to services like respite before and during the transition out of high school (Laxman et al., 2019). Moreover, there is still little known about respite use later in life, as caregivers and their children navigate adolescence and young adulthood.

Caregivers can seek respite support from either formal or informal sources. For example, formal respite support may come from state and other publicly funded organizations (e.g., professional respite providers; Myers et al., 2007), which may play an important role in supporting caregivers of youths with autism or developmental disabilities (Montes & Halterman, 2008). In the absence of (or in place of) external or formal respite support, caregivers often turn towards informal sources of respite support, predominantly family members including spouses, siblings, grandparents, and extended family members (Cooke et al., 2020). Families may move to be closer to extended family in order to receive respite support (Divan et al., 2012; Cooke et al., 2020). Highlighting the common reliance on informal sources of respite, one study found that about 64% of families of autistic children had access to respite care which primarily included informal supports such as grandparents (28%), babysitters (27%), community agencies (21%), extended family (16%), and a combination of these (8%) (Harper et al., 2013). Similarly, caregivers of autistic children in a small qualitative study reported that informal respite from family members, older siblings, and neighbors were the most beneficial type of support (Hall & Graff, 2010). As such, not only is it important to consider whether families have access to respite support across the lifespan but who provides that support.

The need for and access to respite support differs between families, and perhaps within families across their child's development. For example, population density and proximity to services, which are likely related to urban or rural geographic location, may affect access to respite (Minhas et al., 2015). Given the financial burden of paying for respite, demographic family factors such as socioeconomic status (SES) may also play a role in respite use or access (Hall & Graff, 2010). Furthermore, it may be difficult for some families to ask for informal respite support due to shame, stigma, and isolation from their neighbors and family members (Houser et al., 2014), particularly families within certain communities or cultures (Cohen & Miguel, 2018; Minhas et al., 2015). In addition, differences between children such as severity of autism symptoms (Harper et al., 2013), level of independence in daily living skills (Marsack-Topolewski et al., 2021), level of language or cognitive functioning (Vas et al., 2021), gender (Harper et al., 2013), and degree of challenging behaviors (Nankervis et al., 2011) may also indirectly impact respite use and access; a respite provider may need a higher level of training to support those with more support needs. For example, results from a large survey study suggested that caregivers of autistic children who had a comorbid diagnosis of intellectual disability (ID) access more in-home formal respite compared to caregivers of autistic children without ID (Vas et al., 2021).

To date, nearly all research on respite support in autism and neurodevelopmental disabilities has been cross-sectional and focused on childhood. However, caregiving challenges persist and change across the lifespan for many families of youths and adults with autism and developmental disabilities. The majority of caregivers perform caregiving duties even during their children's adulthood (Forbes et al., 2022; Heller et al., 2007; Shattuck et al., 2020). A relatively small percentage of autistic adults identified in childhood may live independently; over half of some samples live with their parents during adulthood (Forbes et al., 2022; Roux et al., 2017). Studies show that many caregivers of autistic adolescents and adults report marked levels of stress affected by their caregiving responsibilities (Krauss et al., 2005; Rattaz et al., 2017; Smith et al., 2010), highlighting the relevance of respite support beyond childhood in this population.

Study Aims

Using a longitudinal sample of caregivers of autistic people and those with non-spectrum developmental delays identified in early childhood, this study followed caregivers of adolescents across approximately six years to answer the following research questions: (1) how much *respite support* from household members and from people outside the home do caregivers autistic individuals and individuals with other developmental disabilities have access to? (2) does *frequency of respite support use* from household members and people outside of the home change over time from adolescence to adulthood? and (3) do demographic and behavioral factors (i.e., gender, having an autism diagnosis, autism symptom severity, daily living skills, challenging behaviors, and verbal intelligence quotient [VIQ]) and sociodemographic factors (i.e., race, caregiver education, and urban/rural setting) predict trajectories of *frequency of respite support* use from household members and from people outside of the home?

Method

Participants

The current study uses data from an ongoing longitudinal study that has followed individuals with autism and other neurodevelopmental disorders and their families for over 30 years. The larger study included 253 participants. The majority of participants (*n* = 213) were referred to two tertiary autism programs (North Carolina and Illinois) at age two. An additional group with similar behavioral characteristics joined the study at approximately age 9 (Michigan; *n* = 40). Most participants received an autism spectrum disorder (ASD) diagnosis, with a quarter of the sample (22%) receiving diagnoses of other non-spectrum developmental delays (e.g., learning disability, intellectual disability, attention-deficit hyperactivity disorder). Data collection for all families occurred at the same intervals throughout the study. For purposes of the current analyses, data from adolescence and early adulthood was acquired at five timepoints (Age 16: M_{age}=16.2, Age 17: M_{age}=17.4, Age 19: M_{age}=18.8, Age 20: M_{age} =19.8, Age 22: M_{age} =21.7), when participants in the cohort were primarily attending school during the day (see Clarke et al., 2021).

The current study included a subset of 126 participants from the larger longitudinal study. Eligibility criteria for the current analyses required that caregivers completed the Modified Family Support Scale (Modified-FSS; Bromley et al., 2004) at least once ($M_{=}$ 3.5, range = one to five times). Although a subset of the sample never received a formal autism diagnosis throughout the course of the longitudinal study, these families are included in the current analyses because they have had similar challenges, and non-spectrum participants have similar adult outcomes and developmental trajectories over time compared to the autistic participants (Lord et al., 2020; McCauley et al., 2020). Adult children were predominantly male (80%), about a fifth of participants in this subsample identified as Black (16.7%) and about a fourth of caregivers reported education levels of less than a four-year college degree (27.0%). Compared to the initial larger sample, the subset of caregivers included in this analysis were more likely to have completed a four-year college degree ($p < .001$) and to identify as White ($p = .002$). Because the first data collection of the Modified-FSS occurred around the time that participants from Michigan joined the research study, they were less likely to be lost to attrition during the study and were more likely to be included in the current subsample ($p < .001$).

Procedures

A battery of assessments including diagnostic, cognitive testing, psychosocial instruments, and demographic questionnaires were collected through in-person visits, phone interviews, and via mail. In-person assessments occurred multiple times (ages 2, 3, 5, 9, 18, 21, and 26) and were conducted by graduate students, post-doctoral fellows, or research assistants supervised by licensed clinicians, all who were research reliable in administering the assessments and had no knowledge of participants' prior assessment results. Diagnostic information collected during the assessments was presented to a team of experienced clinicians and the research team to reach a consensus on diagnoses. Brief reports were provided at no cost to families about the results of testing. Questionnaires were sent to families approximately twice per year. All participants including caregivers and autistic individuals (when appropriate) provided written consent prior to each assessment. Institutional Review Boards at [*blinded for peer review*], approved the research, as appropriate.

Measures

Family Support

Four items included in a modified version of the Family Support Scale (Dunst, 1984; Bromley et al., 2004), were used to measure respite availability from household and non-household members (open-ended items) and frequency of respite use (Likert-type items). For respite availability, the identified primary caregiver responded to open-ended questions, described below. For *respite availability from household members*, participants provided an open-ended response to the question, “Do you feel comfortable leaving your child with ... household members if you need to be away from the house?”; responses were coded as “no,” “yes,” and “can stay home alone”, which were not mutually exclusive. Household members often included the second caregiver (often the father), siblings, and grandparents (if they lived with the family) of the autistic individual. For the second question regarding *respite availability outside of the home*, participants responded to the open-ended question “If none of your household members are available to care for your child when you need to be away from the house, who else can you contact for help?”; responses were coded as “yes support” along with the source of support (e.g., friends, relatives, co-workers, professional help, etc.) or no support. Coding of these two open-ended questions involved an iterative approach that included 1) becoming familiar with the data, 2) generating initial codes, 3) coding the data, and 4) updating the coding scheme as needed. All items were double coded and discrepancies between coders were resolved through discussions. To ensure all coders were consistent in applying codes, 20% of the data were coded by all coders and reliability was calculated (all above 80%).

Regarding *frequency of respite use*, parents responded to the two questions: “How often do you feel comfortable asking household members to care for your child?” and “How often do you feel comfortable asking this person [person outside the home] to care for your child?” Response options for these two questions were on a four-point Likert-type scale that ranged from one (*very rare or never)* to four (*every day*).

Verbal Cognitive Abilities

During each in-person assessment, standardized and developmentally appropriate cognitive assessments were administered to measure verbal and nonverbal cognitive abilities. Assessments included the Mullen Scales for Early Learning (MSEL; Mullen, 1995), Wechsler Intelligence Scale for Children (WISC-III; Wechsler, 1991), Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999), and/or Differential Abilities Scale (DAS; (Elliott et al., 1990, 2007). Intellectual quotients from the nearest previous timepoint (at around age nine) were used in the present study or from later years (if scores at age nine were unavailable). Ratio verbal and nonverbal intelligence quotients were calculated from age equivalent scores when raw scores did not place within standardized score ranges (see Anderson et al., 2014). Consistent with previous studies using this sample (McCauley et al., 2020; Anderson et al., 2014), verbal intelligence quotient (VIQ) was dichotomized and used to classify participants as more cognitively able (VIQ > 70; 41% of sample) or less cognitively able (VIQ ≤ 70; 59% of sample).

Autism Features

The Autism Diagnostic Observation Schedule-Second Edition (ADOS-2; Lord et al., 2012) is a semi-structured observation used to assess social communication and restricted and repetitive behaviors to inform a diagnosis of autism spectrum disorder. For diagnostic purposes, the ADOS-2 was administered at entry and each subsequent in-person visit by a clinician blinded to previous diagnostic classification. Calibrated Severity Scores (CSS) are derived from the ADOS-2. CSS scores measure autism symptom severity relative to an individual's age and language level (Gotham et al., 2012) and range from one to 10 in severity (higher scores indicate higher severity of autism symptoms).

Adaptive Skills

The Vineland Adaptive Behavior Scales-Second Edition (VABS-II; Sparrow et al., 2005) is a standardized parent interview of adaptive functioning. The VABS-II yields Daily Living Skills, Communication, and Socialization domain scores which are combined to generate an adaptive behavior composite standard score. Age equivalent scores of the Daily Living Skills (DLS) domain scores at age 18 (if not available, age 9 or closest age available) were used in the current study.

Challenging/Externalizing Behaviors

The Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2000, 2001) is a broad-band parent-report questionnaire of behavioral, emotional, and social behaviors for younger children (ages 1.5-5 years) and school-aged children (ages 6-18 years). The CBCL includes both internalizing and externalizing behaviors; for the purposes of the current study, only externalizing behaviors were of interest. The Externalizing subscale is composed of the Rule-breaking and Aggressive behaviors subscales. Items are rated on a three-point Likert scale (0=not true, 1 = somewhat true, 2= very true or often true). T-scores at approximately age 16 (if not available, age 18 or closest score available) of the Externalizing subscale were used in the current study.

Analytic Plan

Descriptive statistics were run to confirm that all necessary assumptions were met including normality of data and lack of extreme values. First, to characterize parents’ access to respite care support from household and non-household members, we calculated percentages of the sample who endorsed each possible response option regarding availability of respite (i.e., yes available, not available, or can stay home alone), and for non-household members, the source of support reported by parents at each timepoint. Percentages were also calculated within each the higher and lower verbal cognitive abilities groups separately. Then, to examine the trajectories of frequency of respite use, multilevel modeling using maximum likelihood was used to estimate changes in the frequency that parents asked individuals within and outside of their home for respite assistance for their autistic children as they transitioned from adolescence to adulthood (from ages of about 16 to 22). Our model structure included age/time (level one), individual (level two), and site (level three). We used null models (model with intercept only and no predictors) to test for clustering between-participants and between-recruitment sites. Unconditional growth models were then used to test the rate of change in the frequency that parents used respite within and outside of the home using participant age first as a fixed effect and then as a random effect. Models were compared using chi-square tests. Lastly, to test whether participant characteristics such as gender, having an ASD diagnosis, autism symptom severity (ADOS-CSS), challenging behaviors (CBCL Externalizing), adaptive daily living skills (VABS-II DLS), VIQ, and family sociodemographic factors like race, urbanicity and caregiver education predicted trajectories of respite availability, each factor was tested individually as a predictor of the intercept and as a cross-level interaction with age (i.e., predictor of slope).

Results

Availability of Respite Support from Household Members

The majority of the sample reported having respite support available from household members over time. Approximately 70-80% of caregivers of adults reported having respite support available from a household member at each time point (Figure 1a), with a greater proportion of caregivers of adults with lower verbal cognitive abilities endorsing available respite support (82-89%) compared to those of adults with higher verbal cognitive abilities (53-78%) (Figure 1b). Caregivers of participants with lower verbal cognitive abilities reported more consistent rates of respite support over time, while caregivers of those higher verbal cognitive abilities reported a decline over time. A small percentage (3-9%) of the sample reported that no household members were available to provide respite support across time (Figure 1a). About 15-20% of the sample identified that their adult child could stay home at each of the different timepoints (Figure 1a), a majority of whom were adults with higher verbal cognitive abilities (Figure 1b). The percentage of participants who could stay home alone was relatively consistent over this period of time.

[INSERT FIGURE 1a HERE]

[INSERT FIGURE 1b HERE]

Availability of Respite Support from Members Outside the Home

Approximately 60% of caregivers had respite support available from people outside of the home across all time points (Figure 2a). This proportion was notably lower than respite support from household members (described above). Caregivers of adults with lower verbal cognitive ability reported relatively high and consistent respite support available from people outside the home (75-81%) over time, with the exception of age 16 (Figure 2b). Yet for caregivers of adults with higher verbal cognitive abilities, availability of respite support outside of the home decreased over time (from 40% at age 16 to 24% at age 22; Figure 2b).

[INSERT FIGURE 2a HERE]

[INSERT FIGURE 2b HERE]

The four most common sources of respite support available outside of the home for the entire sample at each timepoint were friends of the caregiver (12-20%), relatives (4-16%), their siblings (i.e., aunt/uncles of autistic adult; 8-15%), and parents of the caregivers (i.e., grandparents of the autistic adult; 11-14%). The availability of respite support from siblings and relatives declined over time from approximately 15% to only 9% and 4%, respectively.

In contrast, a much smaller percentage of parents identified the availability of formal supports as their primary source of respite from outside the household. About 6-7% of participants reported the availability of formal support provided by professionals like Community Alternative Programs (CAP) across time. About 8% of families reported the availability of formal respite services at age 16, supports which consistently decreased to 1.43% at age 22. Group home support slightly increased from 0% at age 16 to 4.29% at age 22. The percentage of caregivers who reported available support from non-specialist hired personnel varied from 4% to 12% over time. At each timepoint, a relatively small percentage of the sample (about 6-12%) reported not having any respite support available from non-household members (Figure 2a).

Trajectories of Frequency of Respite Support Use

A significant amount of variation in frequency of respite support use within the home and outside of the home could be explained by between-participant differences (interclass correlation coefficients [ICCs]=0.42 and 0.47, respectively) but not between-site (i.e., North Carolina, Illinois, and Michigan) differences (ICCs= 0.05 and 0.00, respectively). Thus, a two-level model accounting for the nesting of time within person was used for subsequent models.

Respite Support Use from Household Members

Results indicated that on average at age 16, respite support was used from household members approximately once a week (B = 3.045, p<.001). In contrast with the availability of respite from household members reported above, the baseline model for frequency of use of respite from household members showed a significant declining trajectory from childhood to adulthood as a function of age, showing that caregivers less frequently used respite from people within their home as their autistic adolescents grew older (*B*= -0.086, *p*=.002). The addition of the random effect of age did not explain significance variance (*p* = .89), indicating that caregivers' respite support from inside the home changed similarly across participants. Nevertheless, the random effect of age was retained in subsequent models in order to test cross-level interactions with age (Heisig & Schaeffer, 2019). This shift in frequency of use of respite supports over time is not likely due to changes in residential status or independent living, as 65.6%, or almost two-thirds, of our sample lived at home at the end of the study.

Out of all of our predictors, only VIQ ability group emerged as a significant predictor of the intercept of frequency of respite support from household members (*B*=.433, *p*=.05), indicating that caregivers of those in the higher verbal cognitive abilities group used respite support from household members less often (*B* = 2.78), compared to caregivers of individuals in the lower verbal cognitive abilities group (*B*= 3.21, *p* <.001). Gender, having a diagnosis of ASD, autism symptoms (CSS scores), externalizing behaviors (CBCL), adaptive daily living skills (VABS-II DLS), caregiver education, race and urban/rural location did not predict caregiver's respite support use from household members (*p*>.05).

Respite Support Use from Members Outside the Home

On average, respite support outside the home was used approximately once per month (*B* = 2.445, *p* < .001) for the entire sample at the study outset. There was no significant effect of age for respite support outside of the home from adolescence to adulthood, indicating that, across the entire sample, there was no change in frequency of respite use from people outside of caregiver's home as their autistic adolescents aged (*B* = -.032, *p* = .22). Addition of the random effect of age was not significant, but was retained in subsequent models in order to test cross-level interactions with age (Heisig & Schaeffer, 2019)

Furthermore, there was a significant interaction between VIQ ability group and age in predicting frequency of respite support outside of the home ($B = -.12$, $p = .05$). That is, the change in frequency of respite support use from people outside of the home depended on VIQ status; caregivers of autistic adolescents in the higher verbal cognitive abilities group used respite support for their autistic adolescents less often as they got older, while those in the lower verbal cognitive abilities group remained relatively stable in their respite use over time. There was also a significant interaction between daily living skills and age ($B = -.001$, $p = .04$). Caregivers of autistic adolescents with higher daily living skills used respite support from people outside of the home less frequently as autistic individuals got older, while no such decline was evident in the those with lower daily living skills. Similarly, the interaction between externalizing behaviors and age was significant ($B = -.006$, $p = .01$). Caregivers of individuals with more severe externalizing behaviors used respite from people outside of the home less frequently compared to those with less severe externalizing behaviors as their children aged. Gender, having a diagnosis of ASD, CSS scores, caregiver education, race and urban/rural location did not predict caregiver’s respite support use outside of the home ($p > .05$).

Discussion

Adequate and reliable respite support systems are an important resource for families raising autistic youths with developmental disabilities. Although research has primarily focused on respite during childhood using cross-sectional study designs, for many families, there are continuing support needs that carry over into adolescence and adulthood in this population (Hare et al., 2004). This study provides longitudinal insight into the availability and frequency of use of both formal and informal respite support across these stages of development. While availability of respite was relatively consistent over time, patterns differed for those with higher and lower verbal cognitive abilities. Additionally, although frequency of respite use declined for many families in our samples from adolescence into adulthood, this pattern was not universal. Participant characteristics, including verbal IQ, daily living skills, and externalizing behaviors emerged as important factors impacting the trajectory of respite, especially from support sources outside of the home. In contrast, other adolescent factors such as gender, autism symptoms, and ASD diagnosis as well as sociodemographic factors including race, caregiver education, and urbanicity were unrelated to frequency of respite use.

Availability of Respite Support

Given that only about a fourth of parents reported that their adolescent or adult child could safely stay home alone, the majority of caregivers are likely to require respite for temporary relief or to engage in other activities unrelated to caregiving when their youth are adolescents and adults. Fortunately, most, but not all parents reported they have access to respite from someone in their household relatively consistently over time. For those with lower cognitive abilities, respite was also available from non-household members (e.g., friends, relatives, co-workers, professional help, etc.) for about 80% of participants. However, a much lower percentage of caregivers whose children were more cognitively able reported having support from someone outside of the home (20-30%). Perhaps there is a lower need for outside support in this group due to their ability to stay home alone. A different contributing issue may be hesitancy to ask for outside support due to the youths’ age and higher cognitive ability (Han et al., 2023).

Furthermore, although previous studies show that some parents experience guilt related to asking for support from friends, family members, and neighbors (Hare et al., 2004; Houser et al., 2014; Rizzo et al., 2024), our findings indicate that these sources were consistently identified as the most common types of respite support from non-household members. Interestingly, caregivers specifically identified their friends as the most common non-household source of respite.

Frequency of Respite Support Use Over Time

Verbal IQ, daily living skills, and externalizing behaviors seemed to drive differences in frequency of respite use, but unique patterns emerged for respite support from household and non-household members. Caregivers of individuals with lower cognitive abilities used respite from household members more frequently compared to caregivers of individuals who were more cognitively able across adolescence to young adulthood, with a decline in household respite support over time for all participants. In contrast, for respite support from people outside of the home, caregivers of youths with lower verbal cognitive abilities continued to seek respite support at a similar frequency over time (between once a week to once a month), while caregivers of youths with higher verbal cognitive abilities used respite from people outside of the home at significantly lower rates as their children aged (from once per week to rare/never). Similarly, respite use from members outside of the home decreased over time for those with higher daily living skills, while respite use remained the same over time for those with lower daily living skills. Of concern is that respite use from members outside of the home decreased over time for those with more externalizing behaviors. In comparison, for those with lower externalizing behaviors, respite use from members outside of the home increased over time. Prior research has indicated that individuals with challenging behaviors are likely to be excluded or turned away from respite services (Griffith & Hastings et al., 2014; Southby, 2017; Wodehouse & McGill, 2009), which may, in part, account for the decline in use of respite over time for those with more externalizing behaviors.

Results from this study suggest that caregivers often seek respite support from household members, as well as other people in their communities and social circles, well into their child's young adulthood. These findings also highlight that the need for respite support during this stage of development may be particularly pronounced for caregivers of those who are less cognitively able, have fewer externalizing behaviors, and lower daily living skills (Howlin & Moss, 2012). On the other hand, identifying appropriate respite care for a verbally fluent autistic adolescent who cannot stay home alone for several days, for example, while parents attend an event like a wedding or a family emergency, may also present unique problems. Notably, the observed declines in frequency of respite use for certain groups of caregivers may have several explanations. First, there may be decreased willingness or comfort in asking for informal respite potentially due to stigma surrounding the need for help, particularly into adulthood. Individuals may also be excluded from formal respite services, especially for those who have adults with difficult behaviors. There is a potential decline in the need for respite support as independence increases, more notably for those with higher daily living skills. There could also be a decline in frequency of respite use due to lack of availability over time. For example, siblings who may offer respite support while living at home, may be navigating their own adulthood transitions (e.g., attending college or full-time jobs).

Additional Behavioral and Sociodemographic Factors

Individual factors including youths' gender, having an ASD diagnosis, and severity of autism symptoms as well as sociodemographic factors like rural/urban geographic location, caregiver education, and race were not related to caregivers’ frequency of respite use over time from people that lived in their home such as youths’ siblings or outside of their home such as friends, babysitters, and/or professional support. Given that a majority of respite sources identified by our sample were informal, and likely unpaid, perhaps this mitigates the impact of family SES/resources. Additionally, this study adds to a growing body of literature in family research on autism indicating that factors outside of the autism diagnosis itself, like behavior problems and level of cognitive functioning, may have an even larger impact on family functioning at some timepoints and in some ways (Argumedes et al., 2017; Harper et al., 2013; Schiltz et al., 2018).

Implications for Clinical Practice and Future Research

Having a child with a neurodevelopmental disability can be isolating for caregivers (Laslo-Roth et a., 2022), yet friendships were identified as a key respite source in our study. There is need for improved system-wide support for caregivers through policy changes and funding for family-friendly activities, day programs, and living situations, especially as autistic children move into adolescence and adulthood (Halstead et al., 2017). Considering the observed decline in respite use reported by many families in our study, clinicians can ask whether respite is needed (i.e., level of independence of the client), available (i.e., is there anyone who can provide respite), and accessible (i.e., are there barriers to reaching out to ask for respite) as children transition to adolescence and adulthood, and connect caregivers to those supports if necessary. Caregivers of individuals with lower IQs and lower daily living skills reported higher respite use over time, in contrast to families with individuals who had more externalizing behaviors. While this distinction is important for clinicians and service providers to consider when working with families whose youth are transitioning into adulthood, it is possible that additional respite services are needed for all families caring for adults with neurodevelopmental disabilities during this time.

Although this study sheds light on the characteristics of autistic individuals that seem to impact respite support, future studies should build upon this work by examining specific reasons respite may change for families over time (e.g., less need vs lack of availability), potentially with the use of qualitative data. Finally, policymakers should allocate resources to support families with adults who have neurodevelopmental disabilities, based on their specific needs.

Strengths and Limitations

The current sample has several strengths including diversity in terms of ethnicity and geographic location (within the U.S.), and the characteristics of the of the sample, including a range from intellectual disability to high verbal IQs. Additionally, the longitudinal nature of the data allows for insight into respite for caregivers over time, especially as autistic people age. Results should be interpreted with consideration of the limitations of the current study. The sample was comprised of consecutive clients in early childhood in the early 1990's from the United States, which limits its generalizability. Formal sources of support differ across states in the U.S. and can be even more variable across countries with different support infrastructures in place for those with developmental disabilities. Additionally, we did not account for whether individuals who provided respite support moved in or out of the home over time.

Conclusion

This longitudinal study examined respite availability and frequency of respite use among caregivers of autistic adolescents and young adults with developmental disabilities across approximately six years. VIQ, adaptive skills, and externalizing behaviors emerged as the most salient factors impacting frequency of respite use during this developmental period, especially from non-household members. Surprisingly, other factors such as gender, autism symptoms, maternal education, race, and urbanicity were unrelated to respite use. Although respite is often thought of as support for caregivers of younger children, our findings indicate that this type of support remains important well into young adulthood for many caregivers, particularly for those who care for individuals with lower IQs and those who have higher care needs. Gaps in services, for example, for young adults with challenging behaviors and perhaps, in contrast, for those with fewer needs but whose families may still require help, were also revealed. As such, it is important to continue following individuals as they age into middle and older adulthood to determine and meet caregivers' respite support needs.

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Fig. 1a

Availability of respite support from household members from adolescence to young adulthood

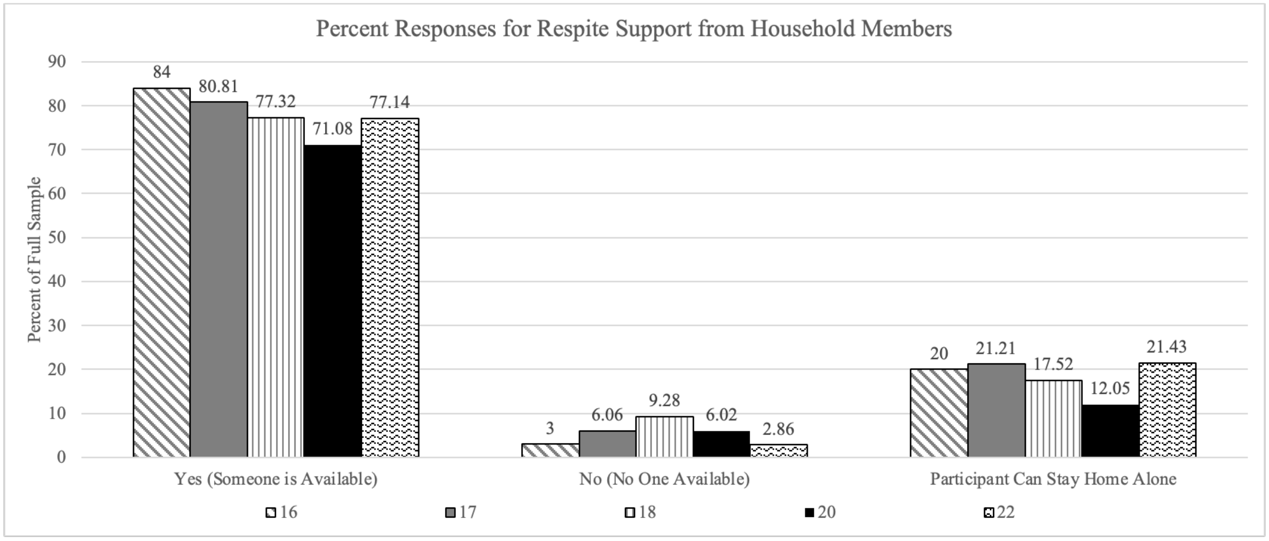

Fig. 1b

Availability of respite support from household members for more and less cognitively able adults

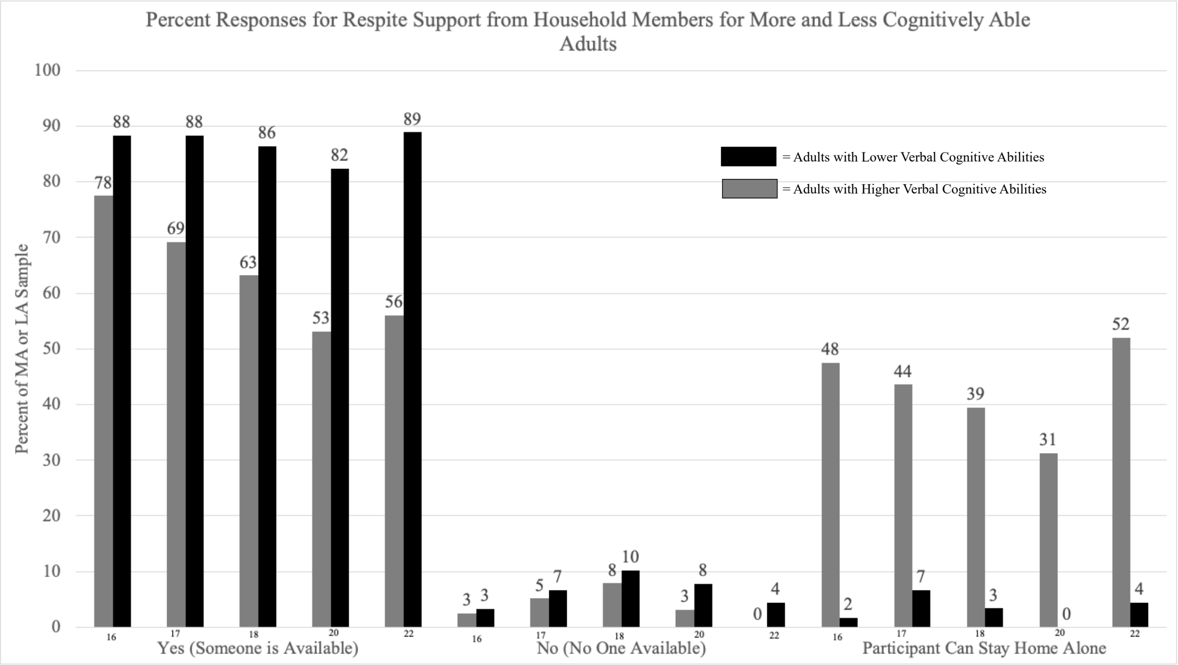

Fig. 2a

Availability of respite support from non-household members from adolescence to young adulthood

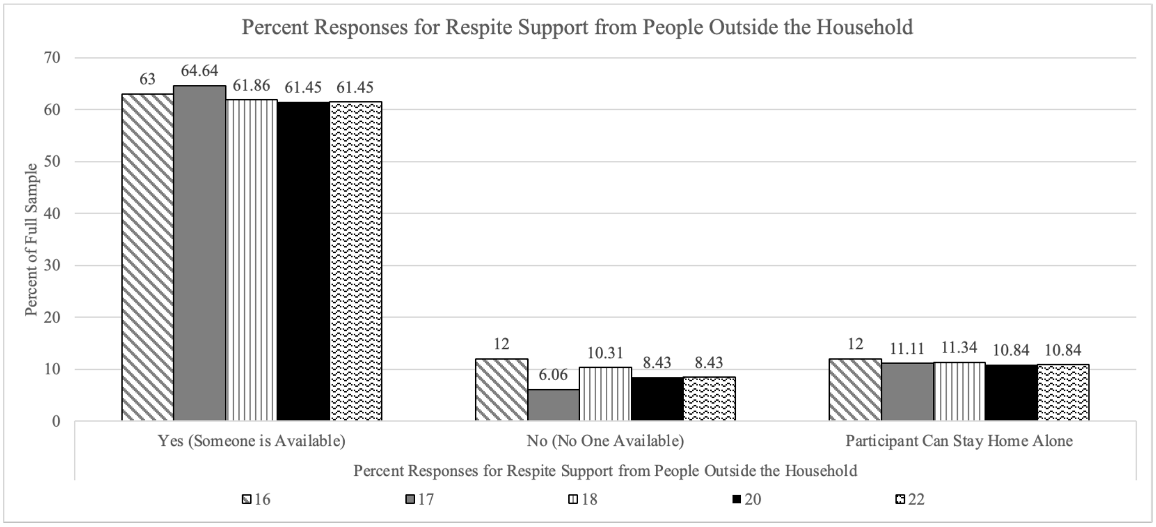

Fig. 2b

Availability of respite support from non-household members for more and less cognitively able adults