

# Housing, Supports, and Service Needs of Adults with Developmental Disabilities

## State of Need in Central Virginia

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**AUGUST 2021 REPORT**

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**About CRAAG.** The Charlottesville Region Autism Action Group (CRAAG)'s mission is to raise awareness and enhance the quality of life for people with autism, developmental disabilities, and their families in Charlottesville City, Albemarle, Greene, Fluvanna, Louisa and Nelson counties. We are a volunteer action group for families, self-advocates, and professionals who are interested in all age groups and levels of need. The daily concerns of CRAAG's active volunteers inform our focus on the needs of students transitioning out of high school, adults throughout the lifespan, and their families. Our advocacy is person-centered, aimed at maximizing independent living with supports; meaningful employment; social connectivity; and community engagement. CRAAG's survey initiated a years-long initiative in our region to expand the number of housing options, supports and services available to meet the needs of adults with developmental disabilities. CRAAG began in 2010 in collaboration with CA Human Services (formerly Commonwealth Autism).

**About the UVA STAR Initiative:** The Supporting Transformative Autism Research (STAR) initiative, led by the University of Virginia's (UVA) School of Education and Human Development in partnership with colleagues from across the UVA, aims to improve the lives of individuals with autism and their families through ground-breaking interdisciplinary research and development of innovative models for care, support, and education.





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# Key Findings

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- This project presents data from a preliminary study exploring the housing and support needs of adults with developmental disabilities within the Central Virginia region. Our findings are highly consistent with the research literature on the needs and limited opportunities of adults with DD. We believe it is necessary to bring these findings to the attention of stakeholders and legislators to inform them on the current state of crisis in the developmental disabilities field.
- Data were collected from 79 family members of adults with developmental disabilities from across Virginia, but primarily in the central Virginia region, via an online survey in the spring of 2021. Respondents represent 4-8% of adults with a DD Waiver or on the DD Waiver waitlist in Region Ten.
- Adults have multiple support needs warranting comprehensive support, yet many families indicated having inadequate external supports. Adults were reported to rely primarily on their families for housing, funding for housing, and supports.
- 84% of families disagree that the available housing options for adults with DD in their area were adequate. Families lack confidence in the housing and support options availability to adults outside of the family home.
- Prevention against isolation is a high priority for families of adults, and is of particular concern for families of adults with autism.
- Over 25% of respondents were concerned about a lack of independence, limited transportation options, and distance from stores and amenities, which likely further exacerbate restricted opportunities to socialize and participate in their community.
- Families would benefit from education about the DD Waiver system and supports in connecting with the DD Waiver application process, as was indicated by many respondents not understanding their current funding status, what type of waiver they wanted for their relatives, or how to apply.
- In the future, families want their relatives with DD to have access to shared housing opportunities, independent housing and group homes. Despite this, the majority of families indicated wanting their family member to live with the family due to low confidence over the availability of current housing and support options for adults in their communities.
- Families are worried about the future based on their current experiences with services, supports, and housing options for adults with DD. The main worry expressed in free responses, concerns about inconsistencies in care, has many contributors. Staff turnover, which is very high in the developmental disabilities services field, may be even higher since the COVID-19 outbreak, and has frequently been shown to be a contributor to inconsistencies in care.
- An expansion of DD Waiver availability and increased staffing to ensure continuity of care for adults would alleviate the burden on many families.
- This project will continue to collect data on additional families of adults and self-advocates to further characterize the housing, supports, and services available across Virginia and identify additional areas for improvement.

# Executive Summary

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This project presents data from a preliminary study exploring the housing and support needs of adults with developmental disabilities within the Central Virginia region. While initially intended for the purposes of reorganizing our advocacy group, **our findings are highly consistent with those from larger datasets and the research literature on the needs and limited opportunities for adults with DD. We believe it is necessary to bring these findings to the attention of stakeholders and legislators to inform them on the current state of crisis in the developmental disabilities field.** To emphasize the representativeness of these findings, we draw parallels throughout this report between current results and those of other studies on this population.

Data were collected from 79 family members of adults with developmental disabilities from across the central Virginia region via an online survey. This survey asked respondents about adults' housing status, funding status through the DD Waiver system, support needs, and concerns that they have about their relative's current and future housing opportunities. The sample represented a high need group of adults; 81% of the sample had multiple diagnoses, 71% had autism, and 41% had intellectual disability. The following results were found:

**Most respondents indicated that they were aware of the Virginia Medicaid DD Waiver system, yet many adults did not have waiver funding, their families did not understand their waiver status, or their families did not know how to apply.** Specifically, 32 adults (41%) were on the waiver waitlist, 23 adults (29%) did not have a waiver and were not on the waitlist, and only 24 adults (30%) were receiving DD Waiver funding. These groups represent 4% of Region Ten's population receiving Waiver funding and 8% of adults on the DD Waiver waitlist.

**Adults have multiple support needs warranting comprehensive support.** Adults have between zero to 20 different needs from the list below, with the average number of support needs being 7 ( $\pm 5$ ). Adults with either a DD Waiver or who were on the DD Waiver waitlist had significantly more support needs than adults without a DD Waiver, with the top 6 most common needs relating to support with self-care routines, supervision, medication management, and safety. Adults without waivers had similar needs for socialization, skill building, and self-care skills.

**84% of families disagree or strongly disagree that the available housing options for adults with DD in their area are adequate. Families lack confidence in the housing and support options availability to adults outside of the family home.** Despite a strong desire for their family members to live independently, families most frequently indicated hoping that adults will be able to live in a shared living environment with a companion who is reimbursed for room and board. 37% of families hope that their family member will continue to live in the family home; qualitative data revealed that this was due to their low confidence in the available housing options and likely an expectation that they would receive better support and housing in the family home. 32% of respondents hoped that their relative would stay in their same current living environment.

Inadequate  
Housing  
Opportunities

Families would like their relative to be able to live independently, but **lack confidence in housing options** outside of the family home

70% of adults still  
live in the family  
home

# Executive Summary

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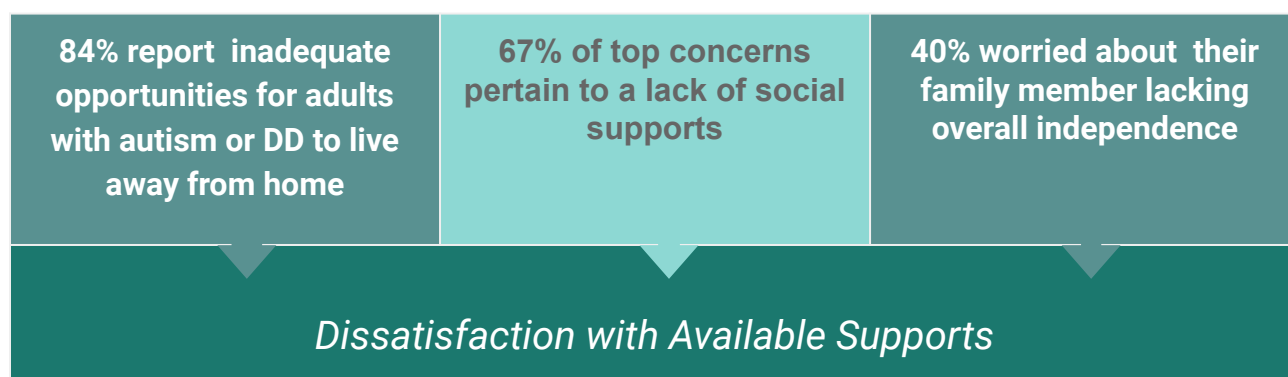
**Prevention against isolation is a high priority:** 65% of adults need opportunities to socialize and make friends. 4 out of the 6 top concerns of people with DD and their families pertain to being isolated in their homes and lacking social supports. Families were significantly more likely to endorse social support needs for adults with autism than adults without autism.

Over 25% of respondents were concerned about a lack of independence, limited transportation options, and distance from stores and amenities, **which likely further exacerbate restricted opportunities for adults to socialize and participate in their communities.** Families of adults without waivers were significantly more concerned about their relative being isolated in their homes and lacking transportation than families of those with waivers or on the waiver waitlist.

**In the future, families want their relatives with DD to have access to shared housing opportunities, independent housing and group homes.** Those with a waiver were most likely to want their relative with DD to live in a group home, supported living environment, residential housing with a caregiver, or residential housing with a family member.

**Families are really worried about the future.** Qualitative data analyses of families' responses to the question "what keeps you awake at night" showed that families have many worries; they are worried about adults experiencing inconsistencies in care, poor quality of life, few relationships, and are worried about what will happen to adults after parents are no longer able to support them. 59% of respondents indicated worry regarding continuity of care for their loved ones, specifically who will support their family member once their parents are no longer able. One major contributor to inconsistencies in care that has been identified in the developmental disabilities literature is staff turnover. National data found an approximate 44% turnover rate among direct support staff in 2019; local providers have anonymously shared experiencing even higher rates since the COVID-19 outbreak.

**An expansion of waiver availability and increased staffing to ensure continuity of care would alleviate the burden on families.** Worries were highest for families of adults on the DD Waiver waitlist, higher than families of adults with DD waiver funding or adults without DD Waiver funding.



# Method

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**Procedure.** Data were collected between February 10th and March 19th, 2021 through an online survey administered via Constant Contact's survey tool to family members of adults with DD across Virginia on their current funding options, housing status, and support needs, as well as their hopes for future housing and funding options. This survey was disseminated via the Charlottesville Region Autism Action Group (CRAAG) listserv, social media of partnering autism groups, church groups, parent resource centers, public schools, recreation programs, community service boards, service providers, and word of mouth. Survey questions were developed using key stakeholder input through CRAAG.

**Analytic Approach.** Data analyses were conducted by researchers from the University of Virginia's Supporting Transformative Autism Research Initiative. All statistical analysis was completed using Statistical Package for the Social Sciences 27.0 (IBM Corporation, 2021) software. Across variables, frequencies of response selections and average scores across the full sample were calculated to characterize the sample's support needs and current resources. Next, adults were compared based on their waiver access (i.e., having DD waiver funding, being on the DD Waiver waitlist, or not having a DD Waiver) to determine whether having a waiver or would result in significant differences in needs or supports. Finally, we analyzed whether there were significant differences in outcomes based on whether or not adults had an autism diagnosis. To interpret open-ended responses (i.e., Housing Worries and open responses to remaining survey questions), qualitative data analyses were conducted, for which we reviewed comments to identify common themes and develop a coding system. Individual responses were then grouped to identify percentages of respondents who indicated worries in individual areas, primary worries identified, and any patterns in worries across respondents. Qualitative data analyses were completed using Dedoose software (Dedoose, 2021).

**Report Layout.** Each section of this report represents a separate topic or theme represented within the survey. For clarity, each section is organized to first include a brief description of the question(s) used for data collection on that topic, followed by summary results for the total sample, results when comparing adults based on their waiver status (funded, on the waitlist, or unfunded), followed by results when comparing adults based on whether or not they have an autism diagnosis.

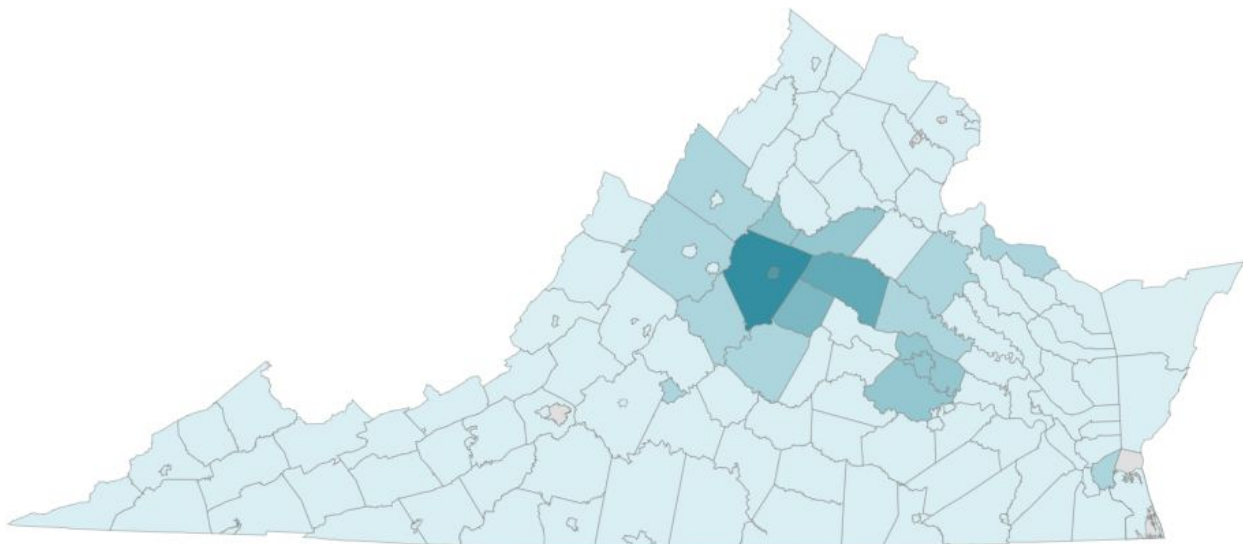
**Limitations, Strengths, and Future Directions.** As with most survey research, these findings are subject to the following limitations: a short data collection period, potential responder bias, and a lack of representation of young adults still enrolled in school. Most importantly, we lack representation from self-advocates - only one self-advocate initially completed this survey, whose data were not included in the current analyses so as to more clearly present the opinions of families of adults with DD and because our self-advocate sample size was insufficient to analyze. Strengths of the data include an overall strong response rate for survey research in a short time-frame, the inclusion of both quantitative and qualitative outcomes to inform a well-rounded representation of the perspectives of families on housing and support options, and representation from a wide geographic area in Central Virginia. **Most importantly, results from this survey are consistent with findings on adults with DD in the broader research literature, suggesting they are representative of the larger adult with DD population in Virginia.** In the future, we will expand upon and re-distribute this survey to gather data from self-advocates and more families from a wider area in Virginia.

# Method

**Respondents.** Respondents ( $n = 79$ ) were primarily parents (95%), or non-parent family members (5%) who provided information about the current support needs, housing options, and funding for their adult-aged child with a developmental disability (DD) or their adult relative with DD. Respondents represented the Virginia counties of Albemarle, Augusta, Buckingham, Caroline, Chesterfield, Fluvanna, Greene, Hanover, Henrico, Louisa, Lynchburg City, Nelson, Orange, Portsmouth City, Richmond City, Rockingham, and Westmoreland. These counties include much of Department of Behavioral Health and Development Services' (DBHDS) District 1 and some of DBHDS District 4 and 5.

**Adults with DD.** Adults were primarily in the transition-age range (16 - 24, 48%), followed by 25-34 years old (32%), or older than 35 (20%). Adults were predominantly male (71%) followed by female (28%) and non-binary (1%). They represented a complex needs group; 81% of the sample had more than one diagnosis. Adults were most frequently diagnosed with autism (71%), followed by developmental disability (DD) (47%), intellectual disability (41%), speech language disorder (34%), a sensory disorder (22%), seizure disorder (18%), or cerebral palsy (10%). With regards to mental and behavioral health, 19% of adults had a mental health condition including mood disorder and 8% had a behavioral disorder. Regarding genetic conditions, 8% of adults had Down syndrome and 1% had Fragile X syndrome. These rates of co-occurring conditions are comparable to the population of adults with DD surveyed by the National Core Indicators' 2017 - 2018, nationally-representative datasets of adults receiving DD services (National Core Indicators, 2018), specifically in prevalence of autism, Down syndrome, cerebral palsy, and mental health concerns. This survey sample included fewer adults with intellectual disability.

**Autism subgroup.** Of adults with autism ( $n = 56$ ), 54% were transition-aged and 84% were male, which is roughly consistent with the current 4:1 male:female ratio in the autism population (Lai et al., 2015). One adult identified as non-binary. 77% of adults with autism had at least one co-occurring condition: 32% had intellectual disability, 23% had a mental health condition such as a mood disorder, 25% had sensory processing disorder, 30% had a speech/language disorder, 5% had a behavior disorder, and 21% had other co-occurring conditions.



*Figure.* Larger numbers of respondents came from counties with darker shading.



# Results



# Current Living Environment

**Measure.** Respondents indicated where adults were living at the time of the survey using a multiple-choice format question.

**Results.** The overwhelming majority of adults were primarily reliant on family support, as indicated by 70% still living in the family home - rates were highest for adults on the waiver waitlist and without a waiver, though there were no significant differences across groups. Adults not living in the family home were most commonly living in a sponsored residential setting with a paid family member if they had DD Waiver funding (13%), a rental option (self or housing voucher funded) if on the DD Waiver waitlist (12%), or in a self-paid rental home if not receiving waiver funding (13%). These rates are consistent with national data (Larson et al., 2020).

Current Living Arrangement	Waiver	Waiver Waitlist	No Waiver	Overall
Family Home	67%	75%	65%	70%
Renter - Housing Voucher	4%	6%	9%	6%
Renter - Self Pay	--	6%	13%	6%
Sponsored Residential (with a paid family member in home)	13%	--	--	5%
Group Home	--	3%	4%	3%
Independent Living	--	3%	4%	3%
Shared Living	8%	--	--	3%
Other	--	3%	--	1%
Own a Condominium or House	--	--	4%	1%
Sponsored Residential (with a paid caregiver in home)	4%	3%	--	1%
Supported Living	4%	--	--	1%

**Adults with Autism.** As in the full sample and sample divided by Waiver status, adults with autism were most frequently living in the family home (70%), followed by a self-paid rental home (7%), and a sponsored residential placement with a paid family member (5%).

# Available Funding

**Measures.** Respondents were asked to indicate whether adults were receiving funding through a Medicaid-funded DD Waiver, were on the DD Waiver Waitlist, were applying for a DD Waiver, knew about DD Waivers, or were ineligible for a DD Waiver. For adults with waivers, respondents indicated what type of DD Waiver the adult had. Next, respondents indicated what resources were being used to pay for adults' housing (e.g., self-pay, earned income, special needs trust, Supplemental Security Income [SSI], etc).

**Results.** There was great variability across respondents in their DD Waiver status. Most respondents indicated that they were aware of the Virginia Medicaid DD Waiver system, yet many adults did not have waiver funding. Specifically, 32 adults (41%) were on the waiver waitlist, 23 adults (29%) did not have a waiver and were not on the waitlist, and only 24 adults (30%) were receiving DD Waiver funding. These groups represent 6% of the population within Region Ten with a DD Waiver and 9% of the population with Region Ten on the DD Waiver waitlist (Virginia Department of Planning and Budget, 2021). National estimates indicate that approximately 43% of adults with intellectual and developmental disabilities have a DD Waiver (Larsen et al., 2020).

Of those who did not have a waiver ( $n = 23$ ), 35% had not yet applied, 35% did not know about the DD Waiver program or did not know their status, 17% had been screened but found ineligible, 4% were in the application process, 4% indicated "other", and 1% indicated that the waiver was not applicable to them. In written comments, respondents who did not know about the DD Waiver program or their status elaborated that they were certain about how to check their status, if they were eligibility, what type of waiver they would be eligible for, and connect with appropriate agencies to apply for a DD Waiver. This suggests that families need more supports in connecting with or understanding the DD Waiver program.

With regards to funding sources for current housing, 56% of adults were reliant on more than one source of funding. Only 13% of adults were paying for housing using DD Waiver funding. The majority of adults (58%) were reliant on family financial support to pay for current housing options and 54% were at least partially using SSI to pay for housing. 24% of adults were paying for at least some of their housing using their own earned income and 11% were paying out of personal (non-earned) funds. 9% were using an ABLE account and 9% were using housing vouchers. No adults were using Special Needs Trusts to pay for housing.

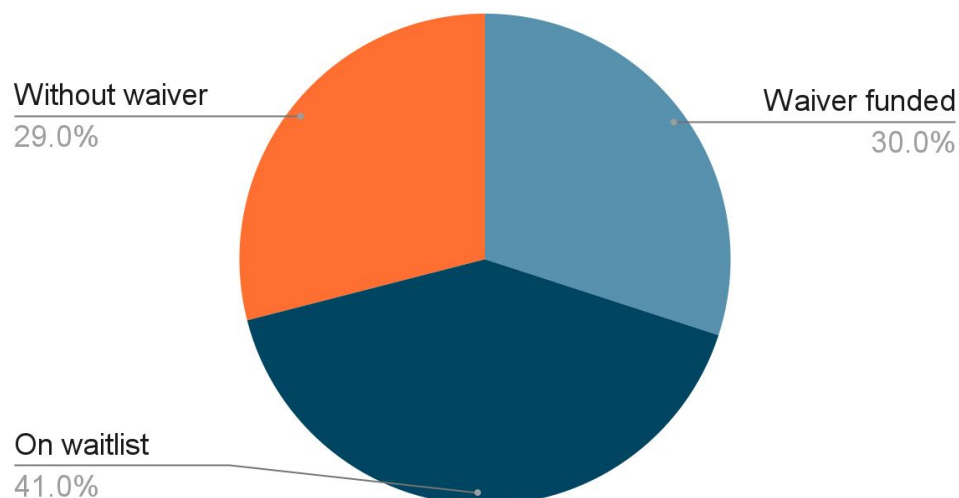


Figure. Waiver Status of adults in the full sample



# Available Funding

**Types of Waivers Received.** Of adults who had a waiver at the time of the survey ( $n = 24$ ), 38% had the Family and Individual Supports Waiver, 25% had the Community Living Waiver (25%), 8% had the CCC+ Waiver, and 21% had an unknown waiver type. Adults on the waiver waitlist ( $n = 32$ ) were approved for a Building Independence waiver (13%), Family and Individual Supports waiver (25%), CCC+ waiver (28%), or an unknown waiver type (34%). The large number of families who were unaware of what Waiver they had been approved for further supports that families may benefit from additional education and support around understanding different waiver options available.



**Adults with Autism.** Within the autism subsample, 32% did not have a waiver, 36% were on the waiver waitlist, and 32% had a waiver. Of those without a waiver ( $n = 18$ ), 45% did not know about the waiver program nor did they know if they had a waiver, 4% did not meet criteria for the waiver, and 6% were in the process of applying for a waiver or had not yet applied. There were no significant differences between adults with and without autism in the number of adults who had a waiver or in the types of waiver that they had.

**Waiver Satisfaction.** Respondents commented on having been denied waivers, having lost waivers, and on the length of waitlists. Respondents were not asked specifically to comment on their satisfaction with the waivers, since this was not within the scope of the survey; however, several respondents indicated dissatisfaction with the lack of services available to adults despite having waiver funding, commenting poor quality supports, inconsistent staffing, and low quality housing accessible through waiver funding (see Appendix).





# Support Needs

**Measure.** Respondents reported on the types of services that adults needed within their current living arrangement. Each response option was answered using a dichotomous yes/no rating scale. Examples of service needs included 24/7 supervision, assistive technology, and environmental modifications. Respondents were also allowed to provide free responses if adults' needs were not represented in the available options.

**Results.** Adults had multiple support needs that affect all aspects of daily living and indicated their need for comprehensive support. Adults were indicated to have from zero to 20 different needs from the list below, with the average number of support needs being 6.8 (standard deviation = 4.5). **Prevention against isolation was a high priority for families and individuals.** Out of 79 respondents, 65% were in need of opportunities to socialize and make friends. Indeed, loneliness has been identified as a prevalent issue among people with DD (Alexandra et al., 2018).

Need	Respondent
<i>Please select services needed in the current primary living arrangement</i>	
Community engagement - socializing - making friends	65%
Meal preparation and shopping	54%
Money management	52%
Skills building for living independently	47%
Transportation (non-medical)	47%
Medication management	42%
Safety and safety skills	42%
Assistance with daily living activities (ex: hygiene, bathing, dressing)	39%
Protection from exploitation	39%
Managing interpersonal relationships	37%
24/7 in-home supervision or up to 24/7 help with support needs	34%
Behavior management	32%
Companionship	30%
Respite for unpaid caregiver	24%
Up to 24/7 one-to-one in-home services focused on life skills	22%
Nursing or personal care	17%
Electronic equipment (ex: video doorbell, elopement, real time alerts, 2 way audio visual monitoring)	14%
Maintenance issues in home/apartment	14%
Assistive technology (ex: cognitive, hearing, mobility aids, etc.)	10%
Environmental modifications (ex: ramps, bathroom modifications, door widening)	9%
Other	6%

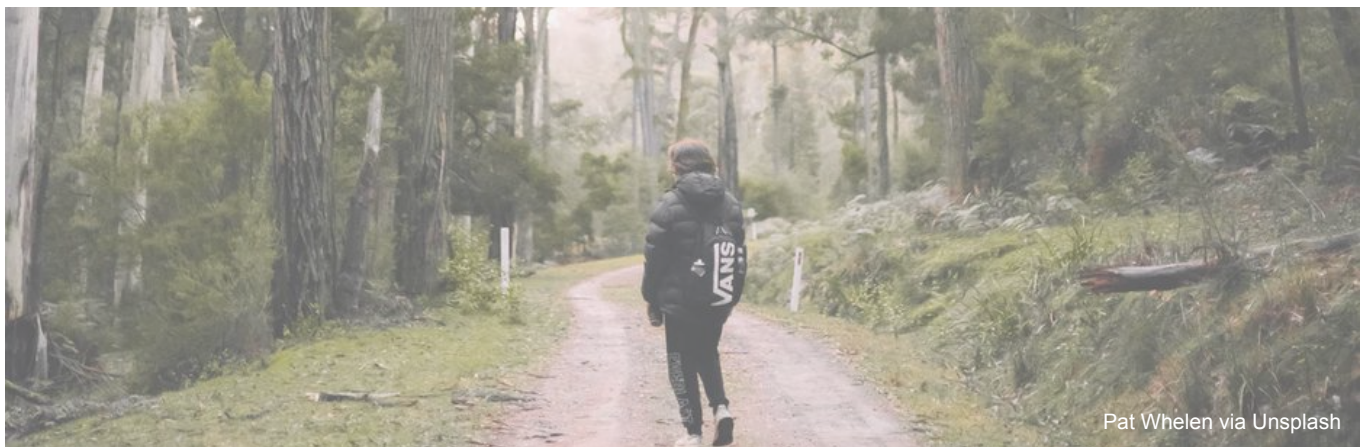
# Differences in Support Needs

When taking waiver status into consideration, it becomes apparent that families had some similarities in the needs they prioritized. **Adults with either a DD Waiver or who were on the DD Waiver waitlist had significantly more support needs** than adults without a DD Waiver, with the top 6 most common needs relating to support with self-care routines, supervision, medication management, and safety. Adults without waivers had similar needs for socialization, skill building, and self-care skills.

No Waiver	Waitlist	Waiver
70% Community Engagement & Socialization 52% Skill Building & Living Independently 52% Transportation (non-medical) 43% Protection from Exploitation 43% Money Management 43% Meal Prep & Shopping	75% Community Engagement & Socialization 53% Meal Prep & Shopping 50% Money Management 47% Staying Safe 44% Managing Medications 44% Companion Services	79% Assistance with Daily Living Activities 67% Meal Prep & Shopping 63% Money Management 58% 24/7 In-Home Supervision or Support 58% Medication Management 54% Protection from Exploitation

*"What or who will be providing supports to my child ten or twenty years from now when both parents are gone?"*

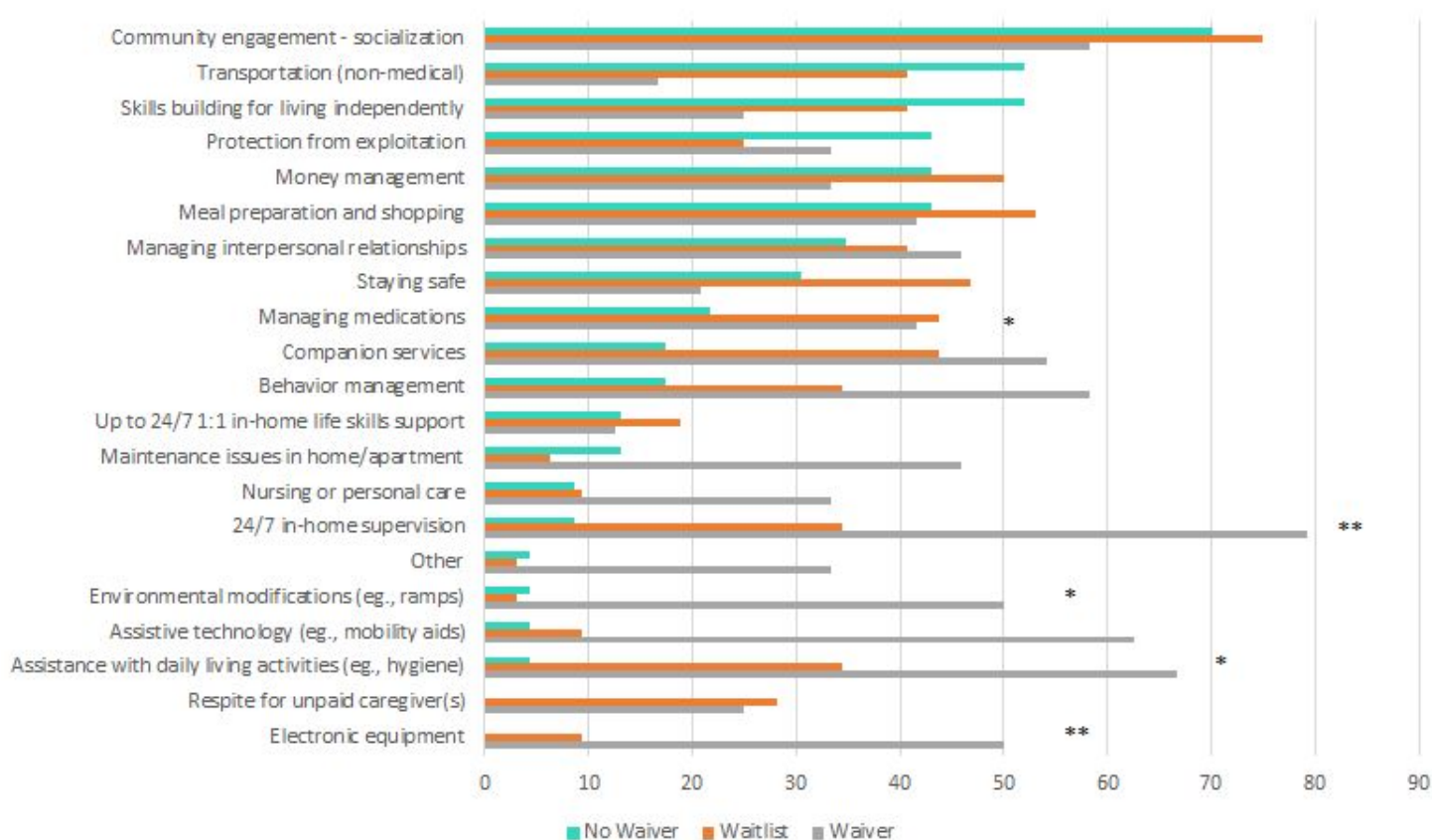
*"When I go... what happens? And if that happens sooner rather than later, we're really screwed."*



Pat Whelen via Unsplash

# Differences in Support Needs

**Waiver Status.** Adults with a DD Waiver were more likely to need certain **specialized supports** compared to those without a waiver or on the waiver waitlist. Significantly more adults with a waiver needed assistance with daily living activities, required 24/7 supervision, electronic equipment (e.g., video doorbell, elopement tracker, real-time alerts, 2-way audio visual monitoring), and environmental modifications. Adults with a waiver or on the waiver waitlist more frequently needed help with medication management than those without a waiver.



Key: Asterisks indicate significant differences in support needs at \*  $p < .05$ , \*\*  $p < .10$ , \*\*\*  $p < .001$ .

Figure. Concerns based on waiver status.

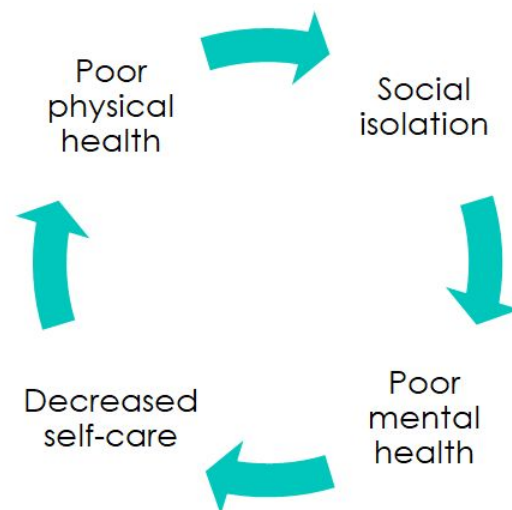
**People with Autism.** Adults on the autism spectrum were significantly more likely to need help managing interpersonal relationships, with 46% of adults with autism needing social skills support versus only 17% of adults without autism. Otherwise, there were no differences between adults with and without autism in the types of needs endorsed. Given that social communication difficulties are a key feature of autism not not broader developmental disabilities (American Psychiatric Association, 2013), this finding is consistent with the general autism and developmental disabilities literature.

*“With a very literal understanding of the world and trusting nature, as well as a need for friends and social interaction safety can be a 24 hour concern. So, as a young petite female **our daughter is very vulnerable to exploitation**, and safety is a primary concern at all times.”*

# Housing and Support Concerns

**Measure.** Respondents were asked to indicate if they had any concerns about adults' current housing arrangement (e.g., feeling isolated, lack of transportation into community, living in a nonpreferred area, etc.). Respondents also had the opportunity to include written responses if their concerns were not represented.

**Results.** In addition to a plethora of needs, respondents reported on several concerns regarding the availability of adequate housing and support options for adults. **Social isolation and support are immediate concerns.** Four out of the six top concerns of respondents pertain to adults having few opportunities to socialize, experiencing difficulties making friends, and feeling lonely. This is significant, as lacking or having inadequate social supports has been shown to be predictive of mental health problems in adults with intellectual and developmental disabilities (IDD) regardless of adults' place of residence, age, gender, and IQ (Scott & Havercamp, 2014). This same study found that adults who lack social supports are twice as likely to experience mental illness than adults with adequate social supports.



**A second frequently reported concern is adults' lack of overall independence**, and more specifically lacking transportation into the community and living at a distance from stores and amenities. Lacking independence and access to the community further restricts opportunities to socialize and build independent living skills, which in turn maintains adults' dependence on paid and familial caregivers. These findings indicate a need for greater opportunities and supports to build independent living skills.

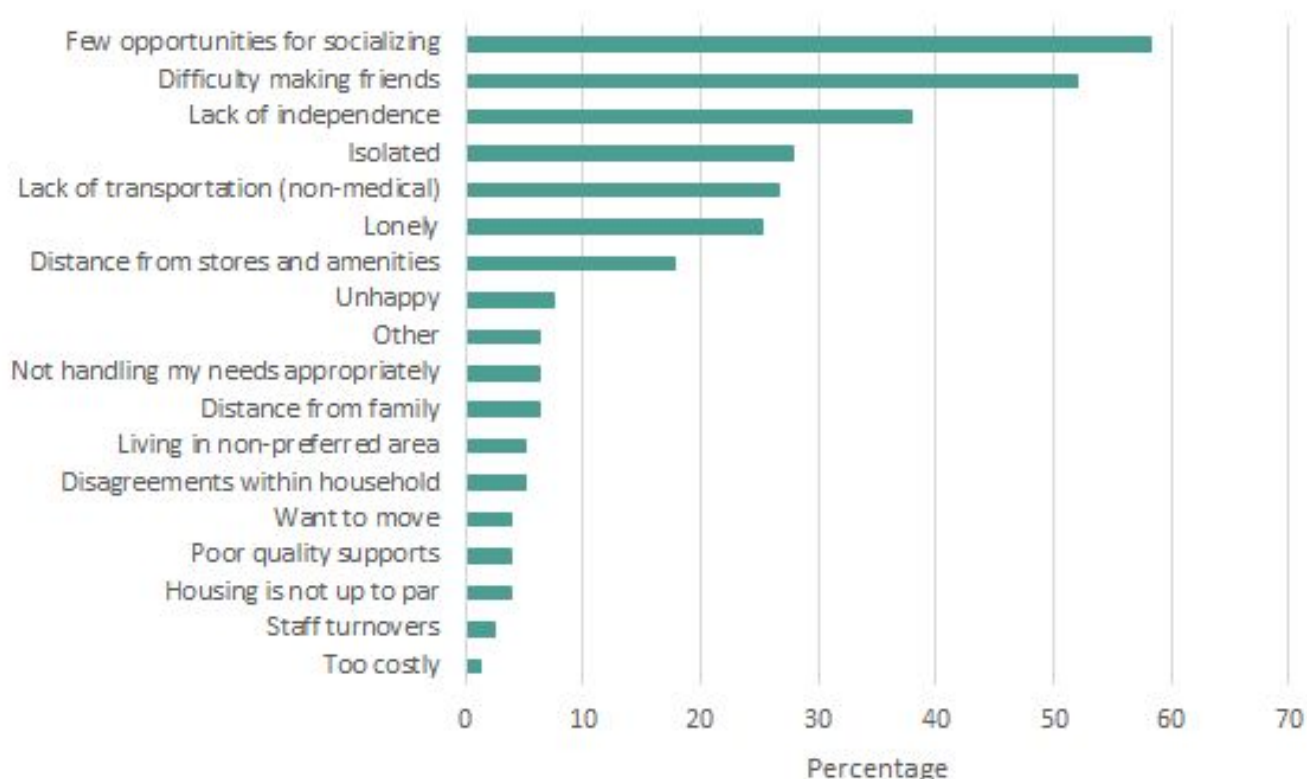


Figure. Frequencies with which individual concerns were endorsed across the full sample



# Housing and Support Concerns

**Concerns based on Waiver and Autism Status.** With regards to Waiver status, there were few differences in families' concerns for adults' housing and supports. The only differences found were with regards to adults being isolated and lacking access to non-medical transportation; families whose relative did not have a DD Waiver or were on the DD Waiver waitlist were significantly more concerned about these two quality of life indicators than families of adults with a DD Waiver. There were no differences in concerns across families based on whether their relative was on the autism spectrum.

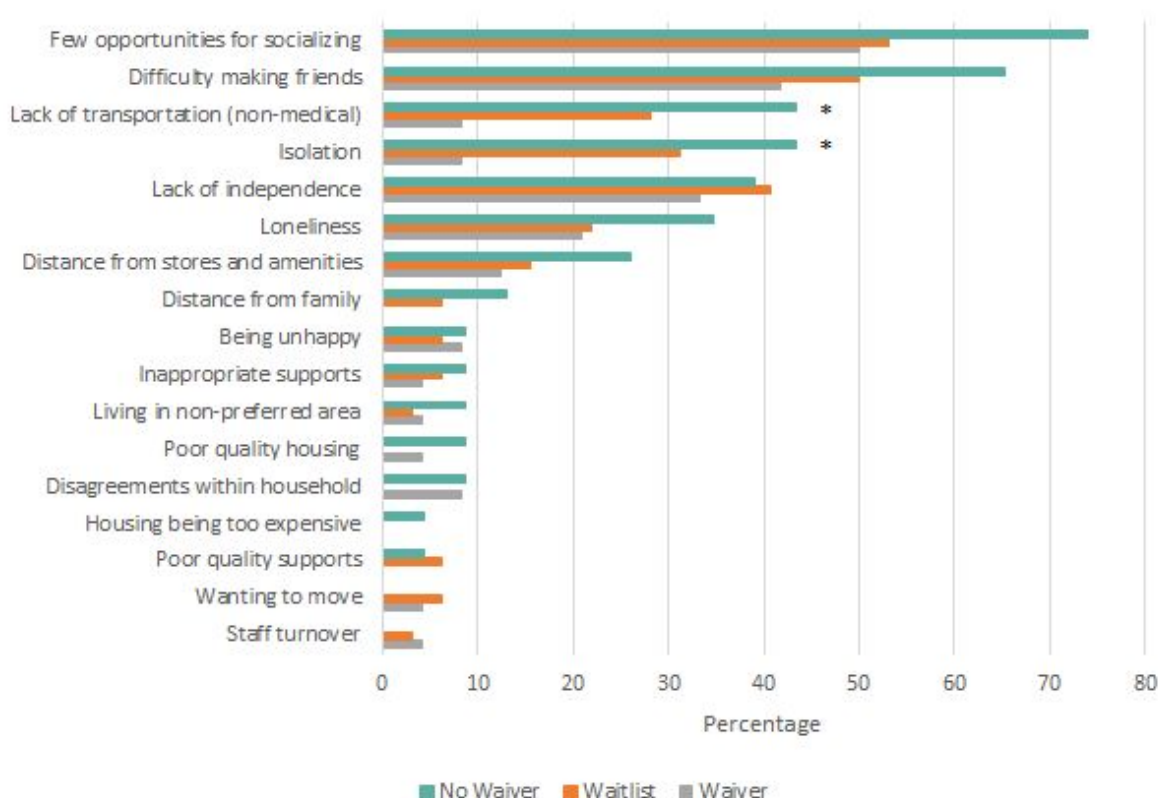


Figure. Differences in frequencies of concerns being endorsed by adults' DD Waiver status.

***“As an adult with aging parents, he needs to establish his own supported group living situation before his parents begin dying. Our ability to care for him will become more strained AND he needs to be settled elsewhere so that when family dies, he does not face all those changes simultaneously.”***



# Satisfaction with Housing Options

**Measure.** Respondents’ satisfaction with housing opportunities in their area for adults with DD was surveyed using one 5-point Likert scale question (ranging from Strongly disagree to Strongly Agree), “Our community has adequate opportunities for adults with autism or other DD to live away from the family home”. Respondents were also given the opportunity to elaborate on their response through a follow-up, free-response question.

**Results.** Across the board, **families are dissatisfied with the available housing options for adults with DD in their area**: 54% strongly disagreed with this statement, 30% disagreed, 11% were neutral, 4% agreed, and 0% strongly agreed. There were no significant differences in satisfaction between families based on their relative’s waiver status, nor were there differences based on whether their relative was on the autism spectrum.

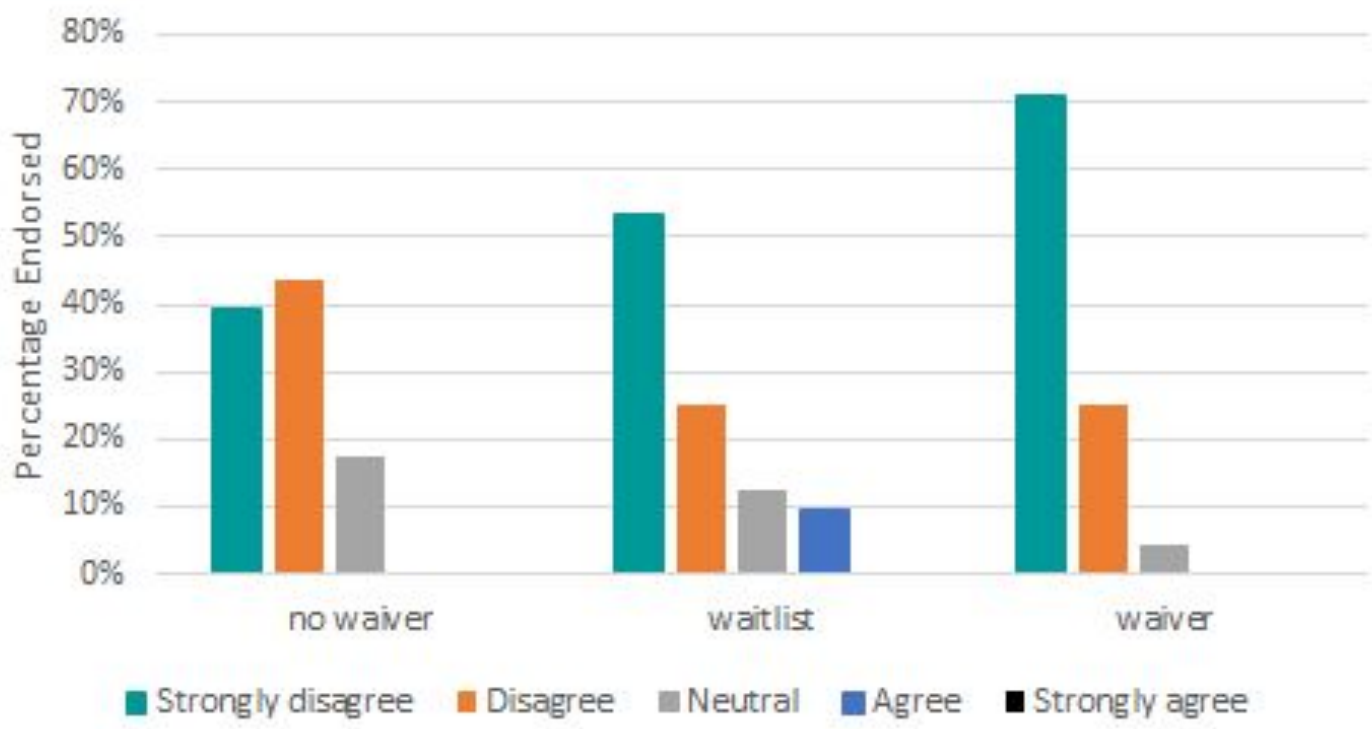


Figure. Housing satisfaction based on waiver status

Consistent with survey responses, respondents also expressed dissatisfaction with housing options in their area in their written responses. Below are example key quotes:

*There is an over-all general lack of available housing in our region. Contributing issues: independent resource centers, lack of housing on bus lines, lack of bus lines. Newer contributing issue: COVID and [executive orders] on rental policies.*

*From what I understand there [aren’t] enough waivers to support living away from [the family] home.*

# Hopes for the Future

**Measures.** Respondents were surveyed on the type(s) of housing they are interested in for their relative live in the next five years. Example responses included living with their family, in a shared living environment, or in sponsored residential housing. A follow-up, free response option was also included. Respondents whose relative was on the DD Waiver Waitlist were also surveyed on the type of waiver funding they hope their relative will have in the next five years.

**Desired Housing.** Respondents most frequently indicated hoping that adults will be able to live in a shared living environment with a companion who is reimbursed for room and board (37%). Many indicated that they hoped adults would continue living in the family home with a family member (37%). Qualitative responses clarify that this hope may be more so related to an expectation that adults will continue to live in the family home, as **many families lack confidence in the quality of housing and support options available for adults with DD outside of the family home (see Appendix)**. Similarly, 32% of respondents hoped that their relative would stay in their same current living environment. 27- 30% of respondents indicated hoping for a state-run housing option, such as a group home, inclusive housing of any type, supported living environment, or a sponsored residential setting. 11% were unsure of where they hoped their relative will live. There were no significant differences between respondents' desires for housing options based on adults' waiver status.

**Desired Funding.** With regards to adults on the waiver waitlist (n = 32), 28% of respondents hoped that their relative will have a Community Living Waiver, 25% hope for a Family and Individual Supports Waiver, and 13% hope for a Building Independence Waiver. 31% of respondents whose relative was on the DD Waiver waitlist did not know what type of DD Waiver option they hoped for, further suggesting that families may benefit from additional education about DD Waiver options.

**Autism subgroup.** As in the larger sample, families of adults with autism are primarily hopeful that their relative will live in a shared living environment with a companion (41%) followed by a group home with 24/7 in-home supervision (36%) or in the family home (30%). There were no significant differences in future housing interests based on an adult having an autism or other DD diagnosis. As with the larger sample, families of adults with autism were most interested in a Family and Individual Supports Waiver (40%), after which they are equally hopeful for a Building Independence Waiver (20%) or a Community Living Waiver (20%).



via Open Doors Therapy, Google Creative Commons

***“An inclusive housing situation, single sex most appropriate with peers, with a blend of funding supports to make it stable would be ideal. We would be willing to focus our future financial planning around supporting such a setting long-term in helping to cover support coverage.”***

# Families' Worries

**Method.** Survey respondents were asked the free-response question “What keeps you awake at night?” to explore their main worries and concerns regarding adults’ futures as it pertains to housing and supports. This question was important in giving a voice to families’ needs, hopes, and concerns for their relatives and their future, as well as the anxieties and frustrations that are often part of their daily lives. In order to analyze these free responses, each quote was coded for topics identified (e.g., loneliness, safety), using Dedoose, a qualitative data analysis software program. This allowed for themes to emerge. The infographic below represents main themes identified, with larger font sizes representing worries that were more frequently identified.



*Figure.* Word cloud representing major themes in families' worries.



# Families' Worries

The greatest worries across the board were related to **continuity of care** (59% of respondents) and what will happen to adults when their primary caregivers are no longer able to care for them. Worries about **parents' inability to care** (50%) and **parents dying** (35%) represent concerns families have about what will happen to their relatives after they are no longer there to support them. The high endorsement of worries in these areas indicate that there is a major need to supplement familial care with staffing and to help adults develop greater independence before their parents are no longer able to support them.

Similarly, respondents are worried about what adults' **quality of life** (35%) will look like in the future.

25% of respondents were concerned about **relationships**. These worries included stress over relationships such as burdening siblings and concerns about adults' abilities to make and maintain peer relationships. They also included concerns that adults might be exploited due to difficulties with or an inability to assess others' intentions during social interactions. Adults with DD have been shown to be at increased risk of abuse and neglect by others (Harrell et al., 2012; Hughes et al., 2012), often due to these specific challenges as well as difficulties with communication.

**"Many worries"** (23%) were mentioned quite frequently, pointing to the complexity of the issues faced by families, regardless of waiver status. This code was defined as having three or more distinct worries, which were also coded explicitly under existing codes (eg., coding Many Worries, Housing, Income, and Safety all for a single response).

***"[My child] is just afraid [to] be alone... Alone and safe could still be like a jail cell."***



Kindness+Play Cafe, Charlottesville, VA; Photo: Brittany Fan

***"What keeps me awake at night is my son's future and what it may look like when something happens to my husband or myself. He has siblings in town but we don't want them to feel totally responsible for him."***

***"It would be wonderful if he had some independent living arrangement with roommates and some support."***

## Top 5 Worries reported by families:

- 59% Continuity of Care
- 50% Parent Inability to Care
- 35% Parents Dying
- 35% Quality of Life
- 25% Relationships
- 23% Many Worries

# Families' Worries

**Waiver Status.** Several respondents expressed worries related to adults' DD Waiver services, though only one third of the individuals in question had waivers.

Families of adults on the DD Waiver waitlist and with a DD Waiver reported more concerns about continuity of care than those without a DD Waiver. Although adults have or are anticipated to have waiver supports, respondents still indicated extreme challenges finding respite staff and other providers to deliver waiver-covered services. This concern points toward a need for increased staffing to properly provide continuous care throughout individuals' lives. Expanding support by increasing the number of professionals in the direct support provider field staff and developing and disseminating efficient staffing practices may allow individuals and their families to feel more confident in hiring paid caregivers rather than relying on limited parental support.

Families of adults on the DD Waiver waitlist more frequently reported being worried about more areas of life than families of adults with or without a DD Waiver. This points to a need for waivers' availabilities to be extended to help relieve some of these needs as adults are waiting to receive funding to afford them quality service providers to promote quality of care and safety, two concerns that stand out when compared to the worries of those with a DD Waiver.

While families of adults without waiver support reported fewer worries, their worries were nonetheless for many of the same areas as those with a waiver or on the waiver waitlist. This indicates that supporting adults' continuity of care, quality of life, and relationships will prove beneficial to a wide range of individuals with varied living situations and developmental needs.

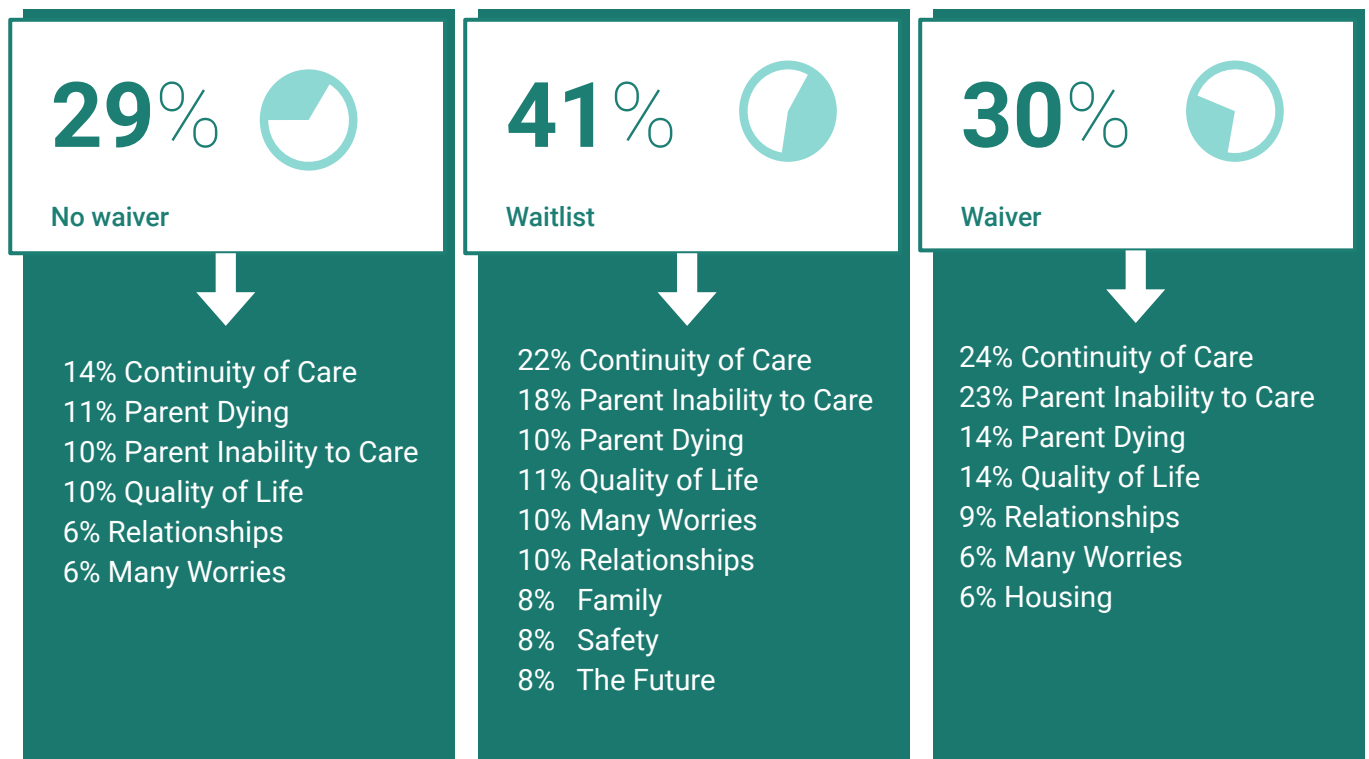


Figure. Worries listed in descending order by % selected, ending at first the first single-digit response

# Families' Worries

**Worries by ASD status.** 71% of the overall sample self-identified as having an Autism Spectrum Disorder (ASD) diagnosis. Compared worries by ASD diagnoses, those with ASD showed a wider range of needs than those without. Moreover, families of those with ASD report more concern regarding Relationships (20%) and Quality of Relationships (10%), likely due to the challenges in this area experienced by those on the spectrum.

While the top five worries of those on the spectrum were rather focused, an even split between concerns about Independence (9%), Family (9%), Safety (9%), and The Future (9%) may reflect the wide range of needs in any given ASD diagnosis.

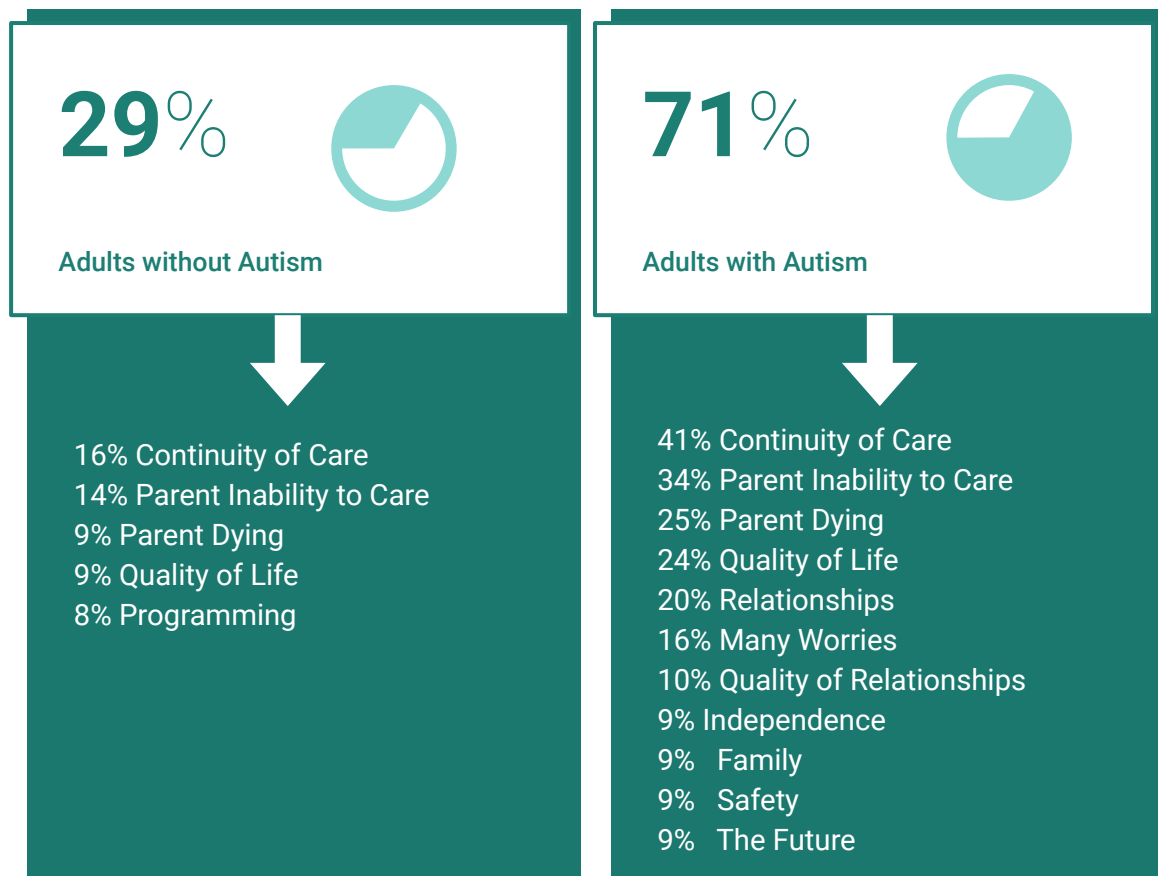


Figure. Worries listed in descending order by % selected, ending at first the first single-digit response

*"When I am gone [my child] will be so lost. He will be afraid, lonely, and confused. He will be living at the mercy of other people's whims and moods... Why will [staff] leave? Because they are paid so poorly to take care of our most vulnerable. There is no housing, no home appropriate for him."*

# Staffing Needs

Since the Housing, Supports, and Service Needs Survey did not include specific questions about staffing, yet quality of staffing emerged as a frequent concern throughout respondents' comments, we have included findings from a nationally representative sample of direct support providers who support adults with DD. In 2019, the Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS) administered The National Core Indicators Staff Stability Survey. This survey analyzed employment trends and characteristics of 3,604 Direct Support Provider agencies supporting adults with DD across 26 states. While participating states did not include Virginia, they represent over half of US states and include states surrounding Virginia (Washington D.C. Maryland, and North Carolina). The dataset is **considered representative of the national population of direct support providers**.

## Sample Breakdown:

- The majority (59%) of responding providers delivered direct support exclusively to adults with IDD
- **56%** provided residential supports to adults—such as community based group homes, supported living services, or intensive care facility - intellectual disability (ICF/ID) homes.
- **65%** provided in-home supports—such as personal care, habilitation, and respite.

***The average turnover rate among direct support providers supporting adults with DD in 2019 was 43.8%.***



The Creative Exchange via Unsplash

Contributors to this high turnover rate have been identified in the research literature include low pay (Ejaz et al., 2013), low sense of managerial and peer support (Ejaz et al., 2015), severity of aggression experienced in the workplace from consumers (Nevill et al., 2021), and lack of experience (Hensel et al., 2012). **The median hourly wage across direct support providers was \$12.00, which is much lower than average pay for direct support providers working with other populations**, such as geriatric adults and inpatient psychiatric populations (Martin 2015).

Anecdotally, the COVID-19 pandemic appears to have led to an even greater turnover rate among direct support providers. Indeed, **in 2021, local adult DD providers in Virginia are reporting seeing a turnover rate of 72% and higher**. One potential explanation for this is other employment fields attracting the workforce away from DD services by offering competitive pay after experience significant workforce loss during the pandemic. In Tennessee, workers performing in-home support services are paid less if the person they are caring for has an intellectual disability than they would for people with other types of support need. For example, while hiring organizations are compensated at a rate of \$4.03/quarter hour by Tennessee Medicaid, Tennessee's Department of Intellectual and Developmental Disabilities compensates the same services at \$3.91/quarter hour, contributing to shortages in staff. In July of 2021, a group of lawyers filed suit against the state of Tennessee, alleging that these types of **pay disparities constitute discrimination against people with intellectual disability** (Wadhvani 2021).



# Staffing Needs

Additional data from the NCI demonstrated that there is a high population of direct support professionals with limited experience - a contributor to inconsistent quality of care and staffing for adults with DD.

## DSPs who left employment between Jan. 1, 2019 and Dec. 31, 2019:

- 33% had been employed for < 6 months
- 18% had been employed 6 - 12 months
- 20% had been employed 3+ years

## DSPs employed as of Dec. 31, 2019:

- 31% had been employed less than 1 year
- 18% had been employed between 1 and 2 years
- 12% had been employed between 2 and 3 years
- 37% had been employed 3 or more years



photo via TheARC.org

Quotes from respondents to the current survey echo findings from the NCI Staff Stability Survey. Quality, consistent direct support providers are essential for providing adequate support to adults, particularly after families are no longer able to provide for them. Families were concerned that if they are unable to access consistent quality support through direct support professionals now, how will their family member be able to after they are gone?

***“...the supports our daughter gets will not be enough, or will fall apart.”***

*“Even the supports we are supposed to have are not actually available. **What we need most are competent, reliable caregivers.** That is not going to happen until they are paid what they are worth and if they meet those criteria they are worth a fortune. Our daughter makes more money working in a pet store than [our son’s] attendants are allowed to earn and that’s just **WRONG.**”*

# Appendix

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## Qualitative Responses: *“What keeps you awake at night?”*

### Missing Needs

#### Programming

"The idea that my husband and I will die or be unavailable and the supports our daughter gets will not be enough, or will fall apart."

"Considering the profound state of flux affecting the nation, society, and culture, I worry about the continued existence of the programs on which we all rely."

"What or who will be providing supports to [my] child ten or twenty years from now when both parents are gone?"

"That there will be no safe and emotionally supportive living placement for our son when we are no longer able to care for him. We see nothing on the horizon to ease our fears and give us any sense of certainty. Our son is lucky to have the Community Living Waiver. He also has a place at VIA for day support/work and education. We would like to find a safe and happy living situation. I think it is important for that arrangement to be stable. I think that it would be very difficult for him if he had to move from place to place. Change is difficult. He needs help and reminders about many things to remain healthy and safe. He does not need help with many daily living skills - he needs reminders. We need to find an agency to be responsible for the staffing and upkeep of as permanent a home as possible. I would like to be able to assist with his transition and be around for awhile to help out."

"See above. Additionally, my son has been at the leading edge of every autism innovation and program in our locality. There has never been anything ready made before he aged up/out and forced the issue. I REALLY need adult supported living to be there BEFORE it's an emergency, ideally many years before (and in the next 3-5 years, tops), so that he can get used to it while we are all still around and able to be part of his new life, visit, etc. There is no way for me to adequately describe the amount of stress and worry"

#### Self (caregiver/parent)

"What happens if we (parents) are gone? Who would care for our son? Lack of opportunity and freedom for our son. We (as parents) are not able to be away from home at the same time because of the level of care he requires. This at times puts our occupations in jeopardy."

#### Housing

"She would like her own room but we can't afford to make that happen"

#### Funding

"Lack of long term living situation in sponsored residential"

# Appendix

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## Transportation

"Paying rent, navigating apartment maintenance (e.g. what to do if the sink is clogged), food shopping, executive function to cook, time management, travel (bus, car) anxiety, isolation"

"I worry about how my daughter will live independently and be safe and healthy on her own. Also, if she will be able to be employed and transportation issues for her. She depends on me for all her needs"

## Living wage

"Worry that he won't be able to afford to live in a nice place. The cost of living is very high in the area. Will he make a living wage?"

## Insurance

"In the short-term coverage if there was a hospitalization, which likely could be managed with friends. In terms of her two siblings with children between 8-12, it is if there was a major health care change in us in the next 10 years how to avoid impacting their lives while children are in still in the house. Further along in aging how to look at funding for long-term health care needs, keeping government benefits AND where could our youngest daughter live with support services as in a nice assisted living community near a sibling. I do not see how one can provide funds for this options AND still meet Medicaid rules. Again, a sorority type living where girls are able to come and go during the day and be at home with a cold and engage in varying activities. With housing in a safe environment. Most of girls I know will never be able to stay safely alone at night so if we can't figure that out it would be just a fruitless effort."

## Recreation Opportunities

"Near Term - The fear that our son will not be in a position to develop meaningful relationships outside of our family, have meaningful work and opportunities for recreation. Long Term - The fear that when we are both gone that our son will end up in an environment that does not value him as a unique individual."

## Gaps in Care

**Continuity of Care** \*continuity of care was the highest populated code. Excerpts were filed by their second relevant code.

"What will happen to my sibling when I can no longer help her OR if something happens to me and or die!!!!"

## Parent inability to care

"What will become of our son when we can no longer care for him."

"Worrying about who will care for him when I no longer can."

"What happens if my wife and I are no longer available"

"Who will take our place when we can no longer care for him is the constant concern"

"Who will take care of my son if something happens to my husband and I."

# Appendix

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## Parents Aging

"Who / How will our son be taken care of when my ex-wife or I cannot"

"My son is 36 and will live a long life. His 3 parents and his current caregiver are all in their 60s and 70s. He is fairly high-functioning, but does not notice and/or report safety issues, so cannot live independently. He cannot manage his money other than small amounts. He needs supervision that is consistent enough to notice when he's been out of soap for a week or the microwave caught fire because he put his bathing suit in it to dry. Thanks for asking!!! It feels lonely out here."

"What will happen to my child when I am unable to care for him because of my age or health."

"Wanting to get my daughter into a more independent living situation. As I get older, I fear I will no longer be able to take care of her."

## Parents Dying

"Who will be able to provide the necessary supports for our son after we die or are otherwise no longer able to provide for his needs."

"What will happen to our daughter when we are gone."

"I wonder who will watch over my daughter when I'm gone."

"Worrying about what will happen after my wife and I are gone."

"Worrying we won't always be around"

"When I go... what happens? And if that happens sooner rather than later, we're really screwed."

"What will happen to [her] if something happens to me. I would like her to be able to stay in our home but she could not live alone."

"That when my husband and I are gone there will be no support for my autistic son"

"Same as most parents of children with any disability: who is going to make sure he is ok when I am gone. He worries about this too."

"Wondering what will happen after I'm dead."

"What happens when his parents pass away."

"Not knowing what will happen to my son if my wife or I die."



# Appendix

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## Parent Involvement/Coordination

"Our son is high functioning; so, it feels like we get lost in the middle as far as what help we should get him"

"Worrying what will happen to my son if something happens to me or my husband. Who would make sure he's okay, that he has someone to care about him and to help if needed."

"Who is going to take the place of a parent who manages financial, medical and home maintenance issues."

"He is wholly dependent on me and I cannot live forever. When I am gone he will be so lost. He will be afraid, lonely, and confused. He will be living at the mercy of other people's whims and moods. There will be good people and not so good people. There will be people he cares for and people he is afraid of. But all these people will leave and he will suffer loss after loss after loss. Why will these people leave? Because they are paid so poorly to take care of our most vulnerable. I say "different, not less than" but society reveals its indifference by paying so poorly. It is clear that our beautiful forever-children are considered "less than." My very reasonable and yet primal fear is compounded by the fact that there is nowhere for my minimally verbal sweet autistic man-child to go after I am gone. There is no housing, no home appropriate for him. I was able to build a school for him because he had a legal right. How do I build a home when he has no legal right to one?"

"Worrying about how to arrange an independent living situation for my son which would allow him to be content with his life"

"It's concerning to imagine my son no longer having me to care for him and my not having adequately arranged for his future."

## Well-Being at Risk

### Challenging Behaviors

"Wondering if my son's behavior will be a problem long-term"

### Discrimination

"Exploitation, discrimination, and anxiety"

### Physical Health

"Seizures. Will [my son] be safe and loved after I pass away? How will his care be paid for?"

### Understanding cause and effect

"Worried about him losing his housing. He has no income. Can not get a job due to prior conviction. Does not think about how actions can cause problems. Does not have good role models. Wants to live at home with me which is not going to happen."

# Appendix

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## **Mental Health**

"Safety and happiness of my children."

## **Will they be loved?**

"Worried that son won't have enough friends. Worried he will be taken advantage of. Worried that no one will love and know [him] like I do."

## **Exploitation**

"I really just do my best to try to address the problems and otherwise don't let myself dwell on them, but I do know that when we can't take care of our son, there will be no one but his sister and we cannot expect her to take care of him, nor do we feel this would be good for either of them. Plus, she might not be able to. So what then? Exploited? Lonely? Endangered? Unable to realize his very real talents? A beautiful potential completely lost?"

"What happens when we are gone. With a very literal understanding of the world and trusting nature, as well as a need for friends and social interaction safety can be a 24 hour concern. So, as a young petite female our daughter is very vulnerable to exploitation, and safety is a primary concern at all times.

Managing anxiety triggers, and meds needed, and yet letting her have the independence she wants is challenging."

## **Lack family support**

"Worrying about what will happen to my son when my husband and I can no longer care for him. We have no family support and limited financial means."

## **Safety**

"Need more time but we all want the vulnerable people to be protected."

## **Isolation**

### **Friends**

"The future for my son. Will have have friends. What if something happens to my wife and me."

"Hoping she can stay independent without burdening her siblings after we are gone. Wishing she had friends"

### **Making friends**

"What happens to our son after we die. There are no close relatives to step in. We would like to help him be as independent as possible, make friends, and enjoy his life."

## **Limited options for ASD/DD individuals**

"Limited options in the area for individual's with DD and Autism"

# Appendix

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## Social Isolation

"Being in the same house as my teenager but rarely seeing him. He's always on his computer or in his room."  
"Being alone"  
"My child losing his current educational/residential placement and not having somewhere else to be. My child missing family due to his group home limiting access because of Covid. Group home not in his home community"

## Social Wellbeing/Challenges

"Wanting to meet new people."

## Family

"if family will live nearby when I am gone"

## Siblings

"1) what will she be able to go after she graduates from [high school] next year? (She needs a 1:1) 2) what will happen to her when I'm gone? (the burden will fall on her sister -- which isn't what I'd want for her)"  
"The future - what will happen to my son when I'm dead. I do not want this responsibility passed on to his sister."  
"What keeps me awake at night is my son's future and what it may look like when something happens to my husband or myself. He has siblings in town but we don't want them to feel totally responsible for him. It would be wonderful if he had some independent living arrangement with roommates and some support."

## Fearing what the future holds

### The Future

"Thinking about the future."  
"Worrying about his health, safety and future."  
"Who will provide care for my son when I am no longer here"  
"who will care for him in the future"  
"The need to understand options for our future"  
"Knowing how our son will be cared for when we are no longer able to do so"  
"Worrying about what will happen to my almost 30 year old autistic son when my husband and I pass away."

## Many worries

"Too many things to answer here!"

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# Additional Reading

For additional reading on housing and support options for adults with DD, visit:

- [Assessment of Virginia's Disability Services System: Residential Services | Day and Employment Services 2021 Report](#)
- [National Core Indicators' 2019 Staff Stability Report](#)
- [2019-2020 National Adult Family Survey Report](#)

# Resources

Below are resources about housing and support options for adults with DD:

- [The Autism Housing Network](#)
- [CRAAG's Transition checklist](#)
- [Roadmap for Autism Services from Diagnosis to Adulthood](#)

Interested in getting involved? [Click here](#) to learn more about CRAAG's 24/7 Supports, and Maximizing Independence, and Preparing for Life After High School Workgroups. [Click here](#) to sign up for the CRAAG newsletter.

# Acknowledgements

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