



The Housing Needs of People with Autism

Six Case Examples

2023

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The Charlottesville Region Autism Action Group

The Charlottesville Region Autism Action Group (CRAAG) aims to raise awareness and enhance the quality of life for people on the autism spectrum, people with broader developmental disabilities, and their families in Virginia. CRAAG began in 2010 in collaboration with Commonwealth Autism. It is a volunteer group for families, self-advocates, and professionals interested in all age groups and levels of need. The daily concerns of CRAAG's active volunteers inform its areas of focus. Advocacy is aimed at maximizing independent living, meaningful employment, social connections, and community engagement. So far, CRAAG has begun a multi-year initiative in Central Virginia to expand the number of safe and appropriate housing options as well as resources and services available for adults with developmental disabilities.

CRAAG parents, who all serve as primary caregivers and advocates for their adult-aged children, provided all content of the current report and reviewed and approved final drafts.

The UVA Supporting Transformative Autism Research Initiative

The Supporting Transformative Autism Research (STAR) initiative, led by faculty in the University of Virginia's School of Education and Human Development, aims to improve the lives of people on the autism spectrum and their families through conducting ground-breaking, interdisciplinary research and developing innovative models for care, support, and education. Comprised of a team of researchers, clinicians, family navigators, students, and staff, STAR engages in autism research, outreach, education across Virginia as well as internationally.

The UVA STAR Initiative helped prepare this report by designing the questionnaire, collecting data, and compiling content into this report.



Statement of Need

Why Do The Unique Needs of Autism Require Attention?

While there is a broad range of need across the entire developmental disability (DD) community, autistic adults experience unique challenges that require creative housing solutions in order to maximize their opportunities for high quality of life – namely, independence, safety, and community engagement^{1,2}. Compared to people with other types of DD, autistic adults experience more mental health disorders³, challenging behavior (e.g., aggression, self-injury)⁴ and are at higher risk of certain physical health problems (e.g., sleep disorders, gastrointestinal disorders, epilepsy). Autistic adults are also more likely to be abused, exploited, and neglected than people with other forms of DD⁵⁻⁷, though this risk is high across all DD types. In their early 20s, autistic adults have been shown to have far lower employment rates (58%) than peers with other forms of DD¹¹. Designing supports for autistic adults can be uniquely challenging, because within the same person, there may be great variability in functioning across skills – for example, the same person may have much weaker social and communication skills compared to stronger self-care skills⁸⁻¹⁰. These factors translate into having complex support needs that are challenging to address within standard housing placements currently available to Virginians with autism. As a result, autistic adults experience low satisfaction with their living arrangements¹², which inevitably translates into poorer overall quality of life.

What are the Current Supportive Housing Options for People with Autism?

Supportive housing options for adults aged 18 and older will ideally ensure that daily needs are safely met, while maximizing quality of life and independence in the least restrictive environment possible and being embedded within the community¹³. Some adults with higher support needs may need more structured settings with 24/7 professional supports to ensure safety, while others may require partial, minimal, or zero professional supports. Due to this variability, the Centers for Medicare and Medicaid Services (CMS) give states latitude to develop and provide such creative settings through a “Heightened Scrutiny” process. It also enables states to conduct site reviews for settings that are more restrictive to residents to ensure that care guidelines are being followed¹⁴.

How are Housing and Support Options Funded in Virginia?

Virginia currently has 17,539 Developmental Disability (DD) Home and Community Based Services (HCBS) waiver slots available to fund appropriate housing and support options for people with DD, including autism. There are *three types of DD HCBS waivers* in Virginia:

1. The **Community Living (CL) waiver** is designed for children and adults with high medical, behavioral, or support needs and provides services 24 hours per day, 7 days per week.
2. The **Family and Independent Supports (FIS) waiver** is for children or adults with moderate support needs who require assistance from a few to most hours of the day.
3. The **Building Independence (BI) waiver** is available for adults who can live, work, and function independently in most areas and need some drop-in support that is typically supplemented by non-waiver rent subsidies¹⁵.

Statement of Need

Differing residential arrangements are available through these 3 waivers, with arrangements intended to meet varying levels of need:

Residential Service	BI	FIS	CL	Setting	Structure
Independent Living Supports	X			Any residential setting	Services focus on skill building and support to secure and maintain a self-sustaining, independent living situation in the community.
Shared Living	X	X	X	The person/ family's home or community settings	Services are designed to ensure the health, safety, and welfare of the person and expand daily living skills.
Supported Living		X	X	Any residential setting	'Round the clock' staffing is available from paid staff who can respond to needs in a timely manner.
In-Home Support Services		X	X	The adult's and/or family's home	Services are designed to ensure the health, safety, and welfare of the individual and enhance daily living skills.
Companion Care		X	X	The adult's home and in the community	Provides non-medical care, socialization, or support to adults ages 18 and older.
Personal Assistance		X	X	Varies	Includes monitoring health status, assisting with maintaining a clean and safe home, and providing direct support with personal care needs at home, in the community, and at work.
Respite Services		X	X	Varies	Provides temporary, short-term care for someone when their unpaid, primary caregiver is unavailable.
Group Home			X	A DBHDS licensed home	Paid staff are available 24 hours per day to provide skill building and other direct supports as necessary to enable each person to reside successfully in the community.
Sponsored Residential			X	A DBHDS licensed family home	Family members are the paid caregivers ("sponsors") who support the adult as needed so that they can successfully reside in the home and community.

For additional information on residential service options, please visit [My Life My Community's Navigating DD Waivers Guide](#).

What are Autism Families' Concerns with Current Waiver Services?

Theoretically, Virginia's waiver services can be tailored to the unique support needs of any individual with DD. However, there are a number of barriers to providing suitable residential options for many individuals, especially those with autism, primarily: (1) the demand for waivers far exceeds available slots, (2) there is a significant lack of service providers in many parts of the state, (3) the Family and Independent Support waiver is not ideally designed to support housing solutions for many people with autism, especially those with significant behavioral challenges and/or requiring 24/7 supervision, and (4) there are insufficient providers available to manage challenging behavior, resulting in increased risk of people with autism going into crisis and requiring emergency hospitalization.

Statement of Need

An elaboration on each of these barriers can be found below:

- 1. Waiver availability:** As of November 2022, there were **14,433 people on the waitlist** for a DD HCBS waiver, and 3,199 of those were Priority One, indicating that they would likely need waivers in the next year or less. Reasons for emergent need include the loss of their primary caregiver; showing increased behavioral, medical, or physical care needs that risk the safety of self or others; being discharged from an institutional setting into the community; or aging out of the pediatric care system¹⁶. Of those with a DD HCBS waiver, 49% were still living with their parents or other family members¹³. This situation raises concerns because adults cannot typically rely on aging family members for support over time, especially when faced with complex needs.
- 2. Limited availability of quality service providers:** The number of quality direct support providers is limited, a deficit that has become increasingly apparent since the COVID-19 pandemic. Limitations in pay, training, and advancement opportunities for direct support professionals, compounded by the challenge of the role, lead to limited entry into the profession as well as a high turnover rate¹⁷. Even those with a HCSB waiver experience great difficulties finding quality service providers to hire through waiver funds.
- 3. The challenge of implementing true “person-centered” solutions for adults with autism under current housing options:** One of the unique challenges of autism compared to other examples of DD, is that many people experience major within-person variability in daily living and executive functioning skills, which are core to independent functioning^{8,9}. This results in challenges for many adults, families, and service providers in identifying and accessing appropriate, person-centered housing and support options that address the unique needs of people with autism. The autism community requires **creative solutions** that involve the direct engagement of autistic adults, their families, and appropriate advocates to identify and connect with true person-centered housing options that appropriately meet the autism community’s variable needs.
- 4. Virginia’s noncompliance with the Department of Justice settlement agreement concerning unmet behavioral health care needs, especially for individuals in crisis:** There is an insufficient number of residential providers equipped to deliver appropriate behavioral supports for adults who engage in challenging behavior, which increases adults’ risk of escalation and crisis. Once in crisis, adults are at high risk of hospitalization in emergency rooms or psychiatric hospitals, as existing mobile crisis supports have limited capacities to support the autism community. Worse yet, adults may face incarceration after aggressing towards others. Jails, emergency rooms and psychiatric hospitalizations typically do not have the resources to effectively support patients with autism and broader DD, thereby perpetuating a cycle of poor quality of care and ongoing behavioral health concerns.

Purpose and Sources

The **purpose of this report** is to illustrate the challenges of implementing person-centered planning for adults with autism through describing the unique and highly varied needs of six adults with autism who have recently sought out appropriate housing options in Virginia.

Methodology

Six parents who serve as the primary caregivers and advocates for their adult-aged child with autism completed a survey about their adult-aged child's support needs, housing preferences, and hopes for the future. The following pages provide an overview of each adult's functional status, with each adult described using a pseudonym to protect their anonymity.

The sample of adults represents five males and one female who have support needs ranging from low to very high. Five out of the six adults have both autism and intellectual disability, ranging from borderline to severe. The questions answered were:

1. What are your child's social skills like?
2. What type of social environment do you think your child wants to experience both inside (e.g., roommates, alone) and outside of their home?
3. What types of supports are needed to make these social goals possible?
4. Does your child have any physical health conditions (e.g., epilepsy, sleep disorder, gastrointestinal disorder, diabetes, etc) that impact daily functioning?
5. Beyond autism, does your child have any mental health (e.g., depression, anxiety) or developmental disability diagnoses (e.g., language disorder, motor disorder) that impact daily functioning?
6. How does your child communicate (e.g., non-verbally, single words, using fluent speech)?
7. What types of supports does your child need to complete self-care skills (e.g., hygiene, household chores, healthcare management, self-advocacy, transportation)?
8. Is your child employed in a full or part-time paying job in the community?
9. What types of support do or would they need to secure a paying job?
10. What types of challenging behaviors does your child display? How often do they occur, and what types of impacts have these behaviors had on your lives?
11. How long can your child be left alone at home alone without supervision?
12. What safety concerns (e.g., internet safety, exploitation, abuse, neglect) do you have for your child at home and in the community?

Summary of Findings

The 6 case examples shared on the following pages illustrate the broad range of needs experienced by people on the autism spectrum. Developing appropriate housing solutions for the autism population is especially difficult due to autistic people's wide range of skill levels, strength, support needs and behavioral challenges inherent to autism. As a result, standardized, "one size fits all" housing and waiver options often do not adequately meet their support needs. Solutions cannot be applied based on individual characteristics, like cognitive level, but must take the full person into account.

Spectrum of Housing Needs. Appropriate housing options for adults with autism differ due to unique abilities, support needs, and personalities. Almost all adults need at least some degree of assistance from a caregiver or family member. Some of the described adults possess numerous independently living skills yet have been unable to find housing options that accommodate the limited supports they do need. As a result, they will continue to rely indefinitely on the support of their aging parents. However, these adults long for independence from their caregivers and to be surrounded by a community of neurotypical peers. Other adults require a highly structured, supportive environment to ensure safety and well-being, including 24/7 eyes-on supervision to prevent harm to themselves or others.

"My greatest fear is that someone will take advantage of his loving heart and do him harm."

Safety Concerns. Multiple parents reported feeling that their children could not be left alone for long periods of time, yet extreme challenges in finding qualified respite providers to deliver appropriate support and supervision. Safety is a major concern across all adults on the spectrum - ranging from physical safety associated with risk of injury to self or others due to challenging behavior; risk of sexual abuse or exploitation; and the risk of exploitation due to challenges with understanding "stranger danger" and safe online communication.

Lifelong Support Needs. Multiple adults described will need caregiver support for the rest of their lives. Parents expressed concern over who would provide these supports given the current challenges they experience finding appropriate respite supports. Some parents expressed that having caregivers of similar ages to their children could help them make social connections with their peers and reduce social isolation.

"She would want roommates and feel like she [has access to] a lot of community interaction as any neurotypical person might."

Social Needs. Some adults have a longing to make friends and be surrounded by neurotypical or neurodiverse peers in their communities. Others would prefer to live alone due to the challenges they experience with social interactions or past negative experiences with roommates; however, financial constraints often make living alone unfeasible.

Brandon

Brandon has a Family and Independent Supports waiver. He lives at home with his aging mother and during the day, attends a day support program in the community. He would like to live somewhere that feels familiar. According to his mother, a house with 3 other adults with autism and two "parental" adults, all of whom have their own rooms, would work well for him. They would share communal spaces, and visitors or helpers would also come in and out. The home would have some outdoor space and each person living in the home would have the option of joining the larger community from day to day. The most ideal arrangement would be a cluster of houses on a single plot of land, as just one home wouldn't suffice for the variable needs of the autism community.

Physically, Brandon has gastrointestinal issues, which upset him and disrupt his daily functioning. Related to his autism, Brandon has a language and motor disorder. He also experiences anxiety and depression. He is an unusually large man (over 7 feet tall and just under 500 pounds) meaning that the world doesn't fit him. This, in a way, acts as a second disability. Showers and bathtubs are not built to his scale, nor are counter tops or toilet seats. Hospital beds are too short, as are emergency stretchers. Carnival rides cannot accommodate him. Golf clubs are too short, as are broom sticks and shovels. In addition, due to his height and weight, others openly stare at him, openly ask about his height, and are amazed by the size of his feet.

Brandon requires complete support with healthcare management and advocacy. His mother currently assists him with hygiene tasks (showers, shaving), does his laundry, chooses his clothes, and prepares his food. With time and trained instructors, he could be taught these skills, though he currently does not have such supports.

“The home would have some outdoor space and each person... would have the option of joining the larger community.”



Socially, Brandon often enjoys being in the company of others, but from a safe distance. He avoids direct social interaction with strangers but loves to be around those he knows. He will say "Good Morning" every day and will wait for a response of "good morning" from you, but otherwise he does not usually respond to initiations from those outside of his safe social circle.

Brandon communicates using written words, gestures, a few spoken words prompted by his environment, facial expressions, and through his own physical prompting. He will read and follow a social narrative about complex subjects such as viruses or read about the moon and the stars. He can follow a sequence of diagrams to build something like a Lego structure. He cannot, however, follow the complex directions that would have him able to hold down a job.

More about Brandon

Brandon is currently unemployed and has not received training in job skills. He would require appropriate education, environmental support, and visual supports. The space would also need to be able to fit his body.

Challenging behaviors – self-injury, property destruction, and aggression – occupy a large portion of his family's life. Brandon's most worrisome behavior is his self-injury to his head. Brandon pounds on objects with both his head and wrists -- it can be hard to tell whether he is happy or feeling other emotions. He also will stand in a doorway and jump up to jam his head into the upper lintel. His family home has four shattered windowpanes and two picture windows with ominous cracks. They have large holes in the plaster and in the drywall ceiling. Their car has a series of dents strung above the windows, all along the passenger side. His mother has replaced the windshield twice in the last year.



According to his day placement, Brandon hits others with a single pop on the head once or twice a month, which is very startling to staff. He will hit his mother repeatedly, requiring her to be faster than him. He engages in loud vocalizations that are very disruptive. They seem to occur when things are not going his way.

Brandon needs a caregiver to always be in the building with him, though he can be out of sight.

Brandon is a huge man with all the vulnerability of a one-year-old. He is in danger of casual cruelty, neglect, and intentional harm. He cannot report on any events that have occurred in the past, even in the last five minutes if his location has changed. When he does try to report on an event, his words or gestures seem unreliable or nonsensical to others and are usually ignored. His family has seen him be hurt by others and unable to communicate what happened, even when prompted or it is written out for him. Experiences that are upsetting to him are topics he does not want to revisit, which makes reliable reporting even more of a challenge.

“The dignity and safety of each person must be a high priority and that means that individual communication supports must also always be in place.”

Steven

Steven has a **Community Living waiver**. He lived at home with his parents until about two years ago. **Over the past two years, Steven has lived in 2 group homes and 3 Sponsored Residential placements, attempting to find the appropriate fit that can support his unique needs and the severity of his challenging behavior.**

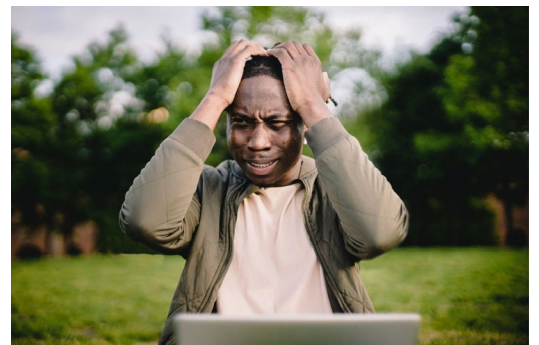
Steven can become agitated when frustrated, which can, but infrequently does, lead to self-injury, aggression, and property destruction. Sometimes the trigger of his aggressive behavior is recognized, but most often it is not. His escalation routine involves frenzied pacing, throwing his glasses or other items, biting his forearm, hitting himself on the head, and flailing his arms. He has attacked caregivers - these incidents are very infrequent but can happen without much warning.

Steven requires 24/7 supervision and cannot be left unsupervised for more than 30 minutes. He has not expressed a preference for any particular social environment. He does enjoy his current day program, which provides a wide variety of activities and the appropriate level of supervision.

Steven has no concept of personal safety, stranger danger, and needs to be closely supervised in public, especially near busy streets and in parking lots. Steven is extremely vulnerable to exploitation and abuse, as he will comply with instructions from anyone. He has little to no ability to protect himself in dangerous situations. When younger, Steven was at continual risk of running away, but that risk has reduced in recent years.

Steven has language disorders, including apraxia of speech (a motor speech disorder that makes it hard to speak). He is of good health, with no identified medical or mental health disorders. He is functionally nonverbal and has very limited expressive language skills. His default answer to almost all questions is “yes”, regardless of if he means it. When he says “no”, he really means “no”. If he is not understood, he can spell out what he wants, but spells very fast and with poor articulation, which cannot always be followed. He can be asked to write down what he wants. Steven can read and understand simple verbal and written directions.

“His escalation routine involves frenzied pacing, throwing his glasses or other items, biting his forearm, hitting himself on the head, and flailing his arms. He has attacked caregivers - these incidents are very infrequent but can happen without much warning.”



More about Steven

Steven **loves to help around the house** and helps with chores with close supervision and extensive prompting. He enjoys performing household cleaning tasks (sweeping, dusting, emptying wastebaskets, etc.). Under supervision, Steven can operate kitchen appliances like the microwave, toaster oven, and hot plate. He can load and unload the washer and dryer, hang clothes up to dry, and fold laundry using a folding board. He eats and clears his dishes independently. Steven is very compliant and will typically follow instructions.

Despite his motivation to work, **competitive employment has not been a feasible option for Steven due to occasional aggressive behaviors and the extensive supervision that would be required.** While he demonstrates the clear ability to learn skills through guidance, prompting, and repetition, his family and support team have been unable to find such opportunities for him.

Steven has limited social skills and opportunities to engage with peers. He tolerates others quite well and will interact with others if directed (i.e., play board games, etc.). He will not seek out social contact. He needs a good day program and community engagement opportunities to facilitate social engagement.

Regarding his self-care, Steven can perform some basic personal hygiene tasks, but requires close supervision and extensive prompting to complete tasks thoroughly and properly (e.g., teeth brushing) or clean up after himself (e.g., toileting). He learns these types of tasks through lots of repeated practice. Steven has learned basic steps in taking a shower by applying soap to different parts of his body and washing it off while counting to 5. Steven cannot shave himself. He cannot complete dental care properly without prompting, which has recently led to developing gingivitis.



Paul

Paul is on the DD waiver waitlist. He is a 23-year-old young man with autism and intellectual disability who recently moved into his own apartment with a neurotypical roommate. **Socially, Paul is quite verbal; however, his social interactions are often stilted and appear awkward to neurotypical peers.** His judgement regarding social safety is quite limited, and he does not demonstrate stranger danger. Appropriate eye contact is clearly a learned behavior for Paul; that is, he makes eye contact when directed or if he really wants something - your attention, your pizza, etc. His parents describe his state is more classically autistic. Paul will never be fully independent due to his disabilities.

Despite his challenges, **Paul recently fulfilled his dream of moving out of his parents' home and to live in the community. Paul's parents spent well over a year planning for his move and continue to manage all aspects of his support plan.** They located a suitable apartment; recruited, vetted and trained a support team that included several college students who would serve as aides and roommates; coordinated with various local and state agencies; and created a schedule. Paul now lives in a nearby apartment with two roommates who double as life skill coaches.



Without supervision, Paul cannot be left alone at home. He will never develop the ability to protect himself from people who wish him harm either physically, sexually, or materially. His family's greatest fear is that someone will take advantage of his loving heart and do him harm.

A good summary statement of Paul's support needs is that he does not require line-of-sight care in the home but will require direct support when in the community. He can complete basic personal hygiene tasks, assist with laundry and house chores, and use public transport with supervision and direction. Paul requires a capable adult to prepare his medication, although he can self-administer with minor nudging.

“Paul's parents spent well over a year planning for his move. They located a suitable apartment; recruited, vetted and trained a support team that included several college students to serve as aides and roommates; coordinated with various local and state agencies; and created a schedule.”

More about Paul

Paul understands relatively complex instructions, which enables him to be employed part-time, working 16 hours a week at a garden center. For the foreseeable future, he will need a 1:1 job coach. Paul also participates in several community activities including Special Olympics, adaptive team sports, and a special athlete weightlifting program. His support team includes several undergraduate and graduate students who intentionally work to provide Paul with opportunities to connect with the broader university community. **Paul's parent continue to work to ensure that community living remains a sustainable, affordable, and life-long option for their son.**

Regarding his mental health, **Paul has an anxiety disorder for which he takes medication.** Like other aspects of Paul's health, it is challenging to know whether his anxiety is part of or caused by his disabilities.



Paul can become anxious, **and at times angry, leading to challenging behaviors including screaming, hitting himself on the head, and spitting.** These behaviors are less frequent than when he was younger, but they still occur and are quite difficult. On a more daily basis, Paul engages in a wide range of verbal scripting. This interferes with his ability to engage effectively with others and disrupts family life (e.g., conversations, flow of activities, and interactions).

Paul has a seizure disorder and asthma. His medication regimen places him at risk for weight gain and related disorders such as diabetes, hypertension and renal dysfunction. To date, his family has avoided any medical interventions for his weight gain with rigorous physical activity and dietary planning.

Winston

Winston currently resides with his family in a country home and is on a waiver waitlist. His preferred living environment is one that mirrors the highly structured setting he experiences at school. **Finding suitable coaches and direct support providers for Winston has been a challenge due to his high energy levels, leading to several unsuccessful hires.** Despite showing little interest in community engagement, activities such as outdoor exercise, and interactions with animals and nature have positively impacted him.

Winston does not have a job and would require full-time supervision and support if he were to work. Considering the limited options available, his family is proactively working to establish a therapy farm for people on the autism spectrum with more significant support needs. This venture aims to provide him and his peers with both employment and potential housing opportunities that are safe and appropriate.

Social interactions and communication are areas of difficulty for Winston. **He rarely shows enjoyment in interacting with others and struggles with socially appropriate behaviors** like maintaining eye contact and using body language effectively. His communication is typically limited to single-word requests or gestures, leading his family to be unsure of his exact needs and what triggers his challenging behaviors.

“Getting him out of the house and exercising has a positive effect, as does engagement with animals and nature.”



Winston exhibits significant obsessive-compulsive behaviors. These manifest in aggressive property destruction, pica, and self-injurious behaviors like picking at scabs or hangnails until they bleed. He also displays elopement and occasional unpredictable aggression. **The severity of his challenging behaviors require Winston to have 24/7 supervision.** Fortunately, **Winston does not have any medical diagnoses.**

His family has been working on helping Winston increase his self-care skills his entire life, and they are still developing. He requires **regular prompts from his family to complete all self-care tasks.**

“We have concerns whenever he is not being directly supervised within arm’s reach.”

Jessica

Jessica has a Family and Independent Supports waiver and currently lives with her aging parents in their family home. She wants to live in the community with roommates, just as any neurotypical person might. To live independently, Jessica would need help with time management, shopping, and meal preparation, remembering to take medication, and transportation. Jessica currently needs daily support to complete these tasks.

Jessica is fluent verbally, although to facilitate her understanding, she may need instructions repeated, simplified, written down, or modeled to fully comprehend.

Jessica is very sociable and converses well, despite facing some auditory processing challenges. She enjoys exploring new situations, particularly when she has a companion. However, her very literal understanding makes it difficult for her to grasp sarcasm or teasing. **Jessica yearns for more in-person friendships while maintaining a strong presence on social media. Although she wants increased independence, she requires significant skill-building beforehand.**

“She wants to have roommates and feel like she is living with a lot of community interaction- just like any ‘neurotypical’ person might.”

“Internet safety is a concern...she has been a victim of sexual abuse online.”



Although Jessica can be left alone unsupervised all day, her family is concerned about her physical and internet safety. She has been a victim of sexual abuse online and is very gullible. While she loves to run, she does not understand the need to follow safety guidelines while running as a small, young female, and needs reminders to keep her home secure when alone.

Sudden changes or unexpected events can cause huge anxiety that sometimes escalates to a meltdown and refusal to participate in anything. If pushed further, she may break property, or very occasionally, aggress towards others. Consequently, she requires additional family and peer support to anticipate and prepare for changes.

Jessica currently holds a part-time job at a store. **To either sustain her part-time position or secure a full-time job, she requires transportation, support in self-advocacy for her needs at work, and assistance from a job coach or caregiver to help employers understand her abilities and how to best support her in the workplace.**

Jessica has a managed seizure disorder, auditory processing difficulties, and anxiety. Her anxiety and seizure disorder are managed through medications.

Jamie

Jamie is on the waiver waitlist, which means he's part of the Department of Justice settlement population in Virginia. He lives independently with his dog in a community-based apartment, which is made possible through the support of his parents. He requires regular check-ins and support from his parents as they have been unable to find reliable paid supports beyond a vocational coach. Over a nine-year period since high school, he has had three different living situations: two apartments with roommates who were not his friends and an apartment where he lived by himself. Jamie enjoys living alone and has discovered that this suits him best; living with roommates did not lead to developing any friendships, and ultimately only made him feel lonelier.

Jamie needs reminders and support to complete personal hygiene tasks, maintain a good diet, stay on top of refilling the medicines in his pill box, and maintain his dental care. He is a safe driver, but anxiety around parking, traffic and nighttime driving limits how often he goes out into the community. His parents are deeply involved in his everyday life and frequently talk to him on the phone to provide advice, plan to address his support needs, and help alleviate misunderstandings and worries. They help him understand and learn skills by breaking tasks down into smaller steps. He requires reminders and repeated prompts to complete tasks across all aspects of his life. **His family wonders who will answer these calls when they are no longer able to support him in this way.**

Jamie receives Medicaid, Medicare, Supplemental Security Disability Income, and support from a state housing program, which is specifically provided to the Department of Justice settlement population. The program pays up to 70% of a person's rent, which is a huge benefit for a low-income person. After a mental health hospitalization, he receive funding through Medicaid to pay for a companion who helped rebuild his life. **Losing any one of these programs would be life altering, another major concern for his aging parents.**

Socially, Jamie is fully verbal and able to have conversations with others. It takes most people a little while to recognize that he has autism. He does well with customers, co-workers, managers, and his family members, especially when he is interested in the topic of the conversation. Most of his free time is spent online dialoguing with peers and playing video games. His only in-person social activities are occasional family get-togethers. He has given up on making friends. **Jamie's family wants to see him more engaged in the community, with more friends.**

"It was lonelier to be alone with others close by. So, he decided to try living alone. He is surprised at how much he enjoys living alone. It has worked well for now three years."

More about Jamie

Like many people with autism, **Jamie has regular gastrointestinal issues and a sleep disorder.** He has a picky diet, which contributes to his gastrointestinal issues. **In addition to autism, Jamie has mood disorders.** He is anxious, irritable, and on edge much of the time. He takes medications for these disorders, regularly meets with a psychiatrist and therapist, and has had several mental health hospitalizations. **Jamie gets stuck on thoughts, aversions, concerns, and past problems.** Once he comes to a decision or opinion, it is almost impossible for him to consider an alternative view, even when safety is at stake. **His psychiatric care is critical to his well-being and is a big concern for his family.**

Jamie has been successful in getting an associate degree. He required a lot of academic and parental support to complete his college classes. His post high school education has not led to a better paying full-time job because full-time work exhausts him.

With the support of a vocational coach, Jamie has successfully attained and held the same part-time job at a local store for the last five years. His coach meets with him several times a month and with the store manager at least monthly and as needed. The consistent and active engagement by the coach is crucial to Jamie's ability to sustain this job. Before this coach joined his support team, holding a job was very difficult and he was fired a few times. **His family believes the state vocational agency should offer ongoing job support for employed individuals with autism and other DD to help avoid gaps and breakdown in employment.**



Despite being well-read and knowing a wealth of information thanks to his avid newspaper reading, he tends to overwhelm others by consistently sharing various facts. He often initiates conflicts with friends and family to assert his ideas. His previous attempts at romantic relationships have not been successful, leading him to develop aversions to certain activities. **These behaviors significantly hinder his family's efforts to encourage his engagement in the community.**

Jamie is vulnerable to manipulation by peers, both previously at school and in the workplace. He has felt pressured into giving peers money, providing rides, sharing games, and even breaking rules. He is afraid of being used and abused. Bullying he experienced during his school years continues to impact his daily life.

Fortunately, Jamie has not had any criminal justice system interaction, but the possibility of it, even at this age, is a major concern due to his history of being manipulated and victimized.

Conclusion

Brandon, Steven, Paul, Winston, Jessica, and Jamie represent a diverse range of experiences common among autistic adults. These experiences include challenges in finding safe and suitable housing options, limited opportunities for secure social interactions, diminished social support networks, a high prevalence of physical and mental health conditions that necessitate additional support, and an ongoing requirement for coaching in self-care, advocacy, and employment skills.

The perspectives shared by families within the Charlottesville Region Autism Action Group, as detailed in this report, are representative of a larger community of autism families who have **major concerns and fear around what will happen to their loved ones when they are no longer able to care for them**. These families are united in their desire to see increased efforts to revise and improve person-centered planning options for people with autism. There is significant need for innovative housing and residential service options to suit the breadth of the autism spectrum, ranging from individuals with low to high support needs. These settings must be safe and appropriate, equipped with qualified and caring support teams, and provide equitable access to the community. Families hope to see a future for their loved ones that will enable them to live in a home and social setting where they can reach their full potential. The significant shortfalls in service provider capacity in Virginia, as well as variety of housing options, require attention.

We recommend that efforts be made by DD organizations and funding agencies to:

1. **Expand HCBS waiver service provider capacity** to address current shortfalls and prepare for future increases in waiver slots.
2. Require housing for people with DD to be an **integral component of affordable housing planning**.
3. Engage with key stakeholders (self-advocates, parents, guardians) to **develop and provide sustainable funding for creative person-centered and cost-effective solutions**, such as “Our Stomping Ground” in Northern Virginia, and other effective models.
4. Create **service provider and property developer incentives** to fill housing and residential services capacity gaps.
5. Prioritize solutions to **maximize community integration based on individual preference** rather than forcing prescribed solutions that may not be in the best interests of the individual. Sensitivity to the needs of high need individuals unable to express preference for themselves must be carefully assessed by working closely with families and caregivers who understand their needs based on a lifetime of experience in supporting them. The state should welcome engagement from support teams and creativity when developing solutions. Solutions need to be truly person-centered, particularly for those who demonstrate high support needs as a function of challenging behavior or limited verbal communication skills.

For additional information and discussion of the content of this report, please contact craag1@gmail.com.

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