VANDERBILT KENNEDY CENTER

Summary of Needs and Recommendations:

for Support Staff of Adults with Intellectual and Developmental Disabilities

A project of the Vanderbilt Kennedy Center Treatment and Research Institute for Autism Spectrum Disorders (TRIAD)

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Section I

Introduction

In September 2023, the Department of Intellectual and Developmental Disabilities, now the Department of Disability and Aging (DDA), began a new project with TRIAD, Vanderbilt Kennedy Center's Autism Institute. The goal of the project is to strengthen DDA's capacity to support autistic people and others with neurodivergent-support needs related to behavior, communication, and/or sensory reception who are supported by residential and day programs in Tennessee. The joint committee elected to focus on methods to improve the physical and emotional safety of persons supported through improved technical assistance and training for service providers, specifically Direct Support Professionals (DSP).

The project includes the following objectives:

1. Conduct a community-informed evaluation of Tennessee's system of services and supports for autistic people and others with neurodivergent support needs across the lifespan. The evaluation should include gaps, challenges, and opportunities for innovation. Contributors may include but are not limited to people with disabilities, family members, caregivers, service providers, advocates, and policy makers.
2. Facilitate discussions with other state agencies to strengthen interagency coordination related to serving autistic people and others with neurodivergent support needs.
3. Evaluate Enabling Technology tools that can help autistic people and others with neurodivergent support needs increase their safety, independence, self-determination, and overall quality of life.
4. Develop recommendations for a multidisciplinary capacity building framework for strengthening the specialized skills and competencies of providers that serve autistic people and others with neurodivergent support needs.

In the following report, those receiving services will be referred to as persons supported and to those providing services will be referred to by their role (e.g., DSP, house manager, leadership, administration) or broadly as state service provider or agency.

TRIAD Project Activity

To address the project's first objective, conduct a community-informed evaluation, TRIAD conducted eight focus groups with 33 people across Tennessee. In each region of the state, TRIAD held a focus group inclusive of Direct Support Professionals (DSP) and agency administrators. Two additional focus groups were conducted with caregivers, both caregivers of adult children who are currently supported by state day/residence programs and caregivers of adult children who are unable (i.e., appropriate placements unavailable, not enough staff to support, preference for their loved one to be at home within their own community) to be supported by providers at this time. Additional information regarding the composition of each group is provided in Table 1.

The primary purpose of the focus groups was to ask about the perceived barriers and facilitators to maintaining the physical and emotional safety of persons supported. The facilitator's guide is provided in Appendix A. With the assistance of DDA, we recruited a group from East, West, and Middle Tennessee based on their availability and willingness to participate.

Improving Training for Support Staff of Adults with Intellectual and Developmental Disabilities

Number of

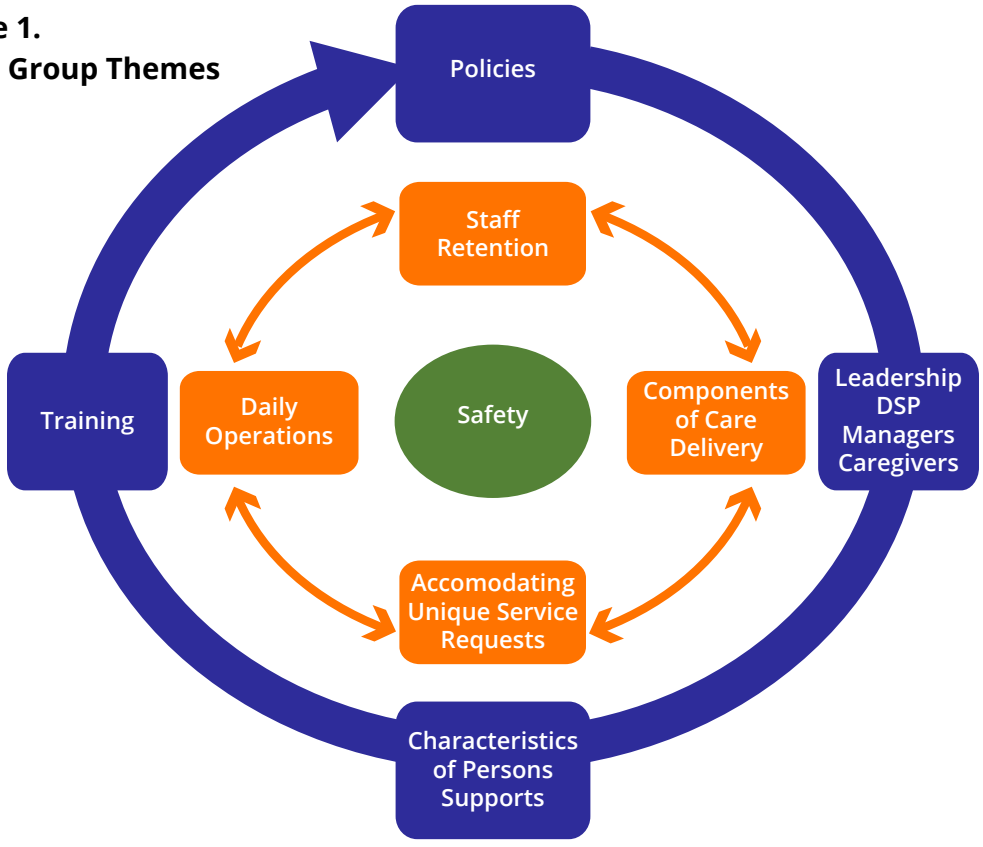
Focus Groups	DSP	Admin/Leadership	Caregivers
Group 1 and 2 (East TN)	5	7	
Group 3 and 4 (Middle TN)	2	3	
Group 5 and 6 (West TN)	3	5	
Group 7			4
Group 8			4

Section II

Summary of Needs and Recommendations for Support Staff of Adults with Intellectual and Developmental Disabilities

Qualitative results from the focus groups and survey are below. Figure 1 represents common themes that emerged from the focus groups. The first inner circle represents immediate, internal influences on safety including staff retention (e.g., turnover, burnout), components of care delivery (e.g., quality of care), accommodating unique service requests (e.g., accepting persons supported at lower levels), and daily operations (e.g., documentation, internal communication). The outer circle represents broader, systemic influences on safety itself including policies (e.g., external state and program policies), training (e.g., organization-level training provided), characteristics of persons supported (e.g., complexity of diagnosis or behavior), and staff variables (e.g., level of experience, socioeconomic factors).

Figure 1.
Focus Group Themes



SYSTEMATIC, EXTERNAL FACTORS INFLUENCING SAFETY

1. Training

Participants discussed the specific training provided for new DSP staff members including Relias online modules (i.e., online training platform), crisis management training (e.g., CPI), and on-the-job training (e.g., shadowing). Training was also discussed broadly in relation to the organizations' capacity to manage persons supported with dangerous behavior; some individuals expressed concern that their entire organization lacked training in managing complex behaviors, which affects their ability to accept these types of referrals. In addition, most DSPs expressed concerns related to the threat of accusations and legal consequences for using physical interventions associated with crisis management which make the job highly stressful.

❑ ***Relias Modules***

Most staff members found the Relias, online training modules, to be minimally helpful in supporting their implementation of routine job duties. While they understood the necessity of these modules for learning about basic job duties, they reported that the most valuable training came from in-person experiences with the person supported.

❑ ***Crisis Management***

Services providers reported the use of several different safety training formats including, CPI (Crisis Prevention Institute), PCM (Professional Crisis Management), and Ukeru. These training programs are intended to teach staff members what to do in moments of dangerous behavior or crisis. Many DSPs reported feeling nervous and scared around using crisis-management procedures. Some, like Ukeru, are reported to be hands-off and trauma-informed, however, this leaves some staff members with limited options of what to do if a person supported becomes physically aggressive, causing them to feel unsafe. However, staff members also reported fears related to the use of physical management procedures and the potential for investigations and job suspension should these strategies be used incorrectly. One caregiver suggested crisis-management programs would be more effective if individualized to the person supported.

❑ ***On-the-job Training***

Most DSPs and house managers felt that the most effective training occurred when new staff members worked directly with a person supported while simultaneously receiving support from a supervisor or an experienced DSP. However, opportunities for such overlap are limited. The time a DSP spent shadowing another member of a person's supported staff before being left to care for a person supported was reported to range from 12 hours to 10 days. Focus group members acknowledged it

requires significantly more time than typically allocated to learn how to best support someone with such complex behavior. One caregiver reported that it took an average of six months for a new DSP to achieve the capacity, knowledge, and experience to work with their adult child because of their complex behavior. However, focus group members also noted lack of funding to support in-vivo training and staff shortages as barriers to participating in more extended training opportunities.

> *"But as far as training goes, … shorten the* [online, Relias module] *training. Give a person more hands-on time. Hands-on in the home, dealing with the individual, and, or letting them know what to expect before they walk into the house. Because if not, then you're going to find somebody looking for another job."*
>
> HOUSE MANAGER, MIDDLE TN

❑ ***Additional Training Considerations***

Administrators reported that lack of training affects other aspects of their agencies, too. Some reported that the lack of training to support persons with dangerous and complex behavior made it challenging to know when to accept referrals for persons with these needs. Some agencies were able to deny referrals that they believed they could not safely support, while others felt the pressure to take more persons supported despite inadequate training or resources.

> *"So, without the appropriate training, we're kind of in a rut and can't move forward with accepting new referrals. And, I know there's plenty of people out there who need support, and we can't accept them because we are just kind of at a loss in terms of what kind of training do we help to provide staff, how do we help to support them to be able to support these people?"*
>
> LEADERSHIP MEMBER, EAST TN

❑ ***Summary***

DSPs face significant challenges in ensuring both their own safety and that of the individuals they support. The threat of accusations and legal consequences for using physical interventions makes the job highly stressful; these concerns were raised across almost every DSP interviewed. Current training often falls short in preparing DSPs for the safety challenges that can often be associated with serving persons who engage in dangerous behaviors. There is a consensus among DSPs that the existing training opportunities lack practical relevance and are insufficient for teaching new staff how to handle dangerous and complex behaviors, which likely impact the frequency of dangerous events and staff turnover. Administrators were less concerned about the relevance of the current training model and were more concerned about staff turnover in that turnover occurs so rapidly that they cannot sufficiently train new DSPs.

Focus group members voiced concerns related to the inability of many DSPs to connect with the persons supported on a personal, relationship level. Additional training topics including how to support sensory needs, understand nonverbal communication, and support individuals with co-morbid diagnoses were also recommended. Finally, DSPs expressed a need for more effective de-escalation training, ideally involving in-vivo practice rather than just theoretical knowledge. In addition, many individuals with dangerous and complex behavior have experienced trauma. Participants felt that the current training resources do not adequately address working people who have experienced trauma.

2. Policies

Leadership members and caregivers spoke frequently about policy issues that indirectly affect safety, including reimbursement rates, specific waivers restrictions, and cost caps.

For example, service providers express a desire to pay DSPs more money to work with more complex persons supported, however, they are unable to because of the reimbursement rates associated with the Community First CHOICES (ECF CHOICES), waivers. Service providers also expressed a desire to provide more training support for new DSPs but cannot afford it.

> *"I think it would be nice if we could do that across the board* [provide more time for DSP to shadow] *because we can't always. So, having more time for the person to be in the home, shad owing the person who has supported that individual for a period of time, and they can really share some insight and they can model what good behavior looks like, how you de-escalate. All those things would be better served if we could spend three weeks a month shadowing, but then that equates to a double cost for staffing that we're not getting reimbursed for."*
>
> REGIONAL AGENCY DIRECTOR, WEST TN

Or, relatedly, agencies may feel that for safety reasons a person supported could benefit from having a 2:1 staffing ratio, but the reimbursement rates only support having one staff. Additionally, many focus group members spoke about the inadequate number of providers and agencies equipped to provide the needed services for complex cases, those eligible for a Group 7 or 8 designation.

> *"I have two Group 8s I'm looking at, right now, that I'm going to have to take at Group 6 because we don't have the qualifications to be able to support them, under the Group 8 current contract.*
>
> REGIONAL AGENCY DIRECTOR, MIDDLE TN

Many individuals, both service providers and caregivers, mentioned the differences between the 1915(c) waivers and the ECF waivers, which affect the level of support available. Caregivers and focus group members highlighted many features of the 1915(c) waivers that were preferred (e.g., additional staff funded to work with one person supported).

❑ ***Summary***

Funding limitations, such as inadequate reimbursement rates for higher levels of care, impact the quality of services agencies can provide. Providers struggle to cover the costs of intensive support (i.e., training resources, sufficient staff). This is exacerbated by system constraints, such as those noted across waiver programs. Although the conversations were directed towards promoting safety through improved training, across all groups—administrators to caregivers—state level policy issues were consistently highlighted, suggesting that the discussion of safety cannot be separated from the policies under which each agency operates within.

3. Characteristics of Persons Supported

All the focus group members highlighted the complex nature of the persons they support. Many persons supported have high medical and behavioral needs, which can affect the safety of everyone in that environment. In addition to the complications that arise from various diagnoses, group members spoke of accepting referrals coming straight some intensive mental health hospitals and jail. Many of these complications arise from the person supported' s inability to communicate, have agency over their lives, and cope with the challenges of everyday life. The staff members supporting the persons supported do their best to support and manage the behaviors, but rarely are the persons supported given access to therapy and treatments that teach new skills.

The complexity and severity of behavior may not only affect the safety between the personal supported and their staff; focus group members consistently shared concerns related to safety issues that y brought up issues that stem from the complications of having roommates.

> *"So, he has housemates living with him, families are upset, housemates are upset, staff are upset. So that's the biggest one currently that we have, I think is a safety concern. And we've had some major issues in the past where it's a huge safety concern. There was one individual that we had to rotate shifts, administrative staff, because we didn't have anybody to work with this gentleman."*
>
> LEADERSHIP, EAST TN

The complexity of the persons supported highlights the need for increased training around dangerous and complex behavior, and comorbid considerations.

4. Characteristics of Staff: Leadership/DSP/Mangers/Caregivers
Focus group members also discussed characteristics of staff members that may affect safety including their previous experiences, their own mental health issues, the physical size of the staff member (i.e., focus group members often reported petite and female employees having a more difficult time safely managing behaviors), and their motivation and commitment to the job.

> *"I think you can't go without saying that it is an entry-level position. It's poorly paid. People are dealing with other things, homelessness, food insecurities, and I mean when you can't get your own basic safety needs met for yourself and you're trying to support somebody else, it's challenging. And we try to help them the best we can to meet those needs."*

LEADERSHIP, EAST TN

ORGANIZATIONAL, INTERNAL FACTORS INFLUENCING SAFETY

1. Staff Retention
The primary issue discussed across DSPs, house managers, caregivers, administrators, and leadership members, as it relates to safety, was the agencies' ability to retain staff. This was cited as the number one factor influencing safety. Respondents discussed the complexity of the persons they support and the necessity to be able to have the time to train new staff members on the person supported.

> *"I think even across the board in this field, the people who are in this field across the board, everybody, the compensation has always been so poor, but a higher level of quality of work is asked for and it's required. And people, like I said before, who have the compassion to do it, who are still here doing it, it is kind of like a part of their life, but you don't get compensated even half of what you're worth. Not that it's measured through that way, and there are other ways that you may, but it's the whole field. A lot of people are not coming here and the people even to work, and then the people who have been here, who have felt unappreciated, who have worked, are leaving. It's a turnover, and I shudder to think that when all the people who are here who do have the compassion leave, what kind of state it's going to be in. Because all the knowledge, all the experience, it's just going out the door because of feeling the feeling of just some of the people that we support feel unappreciated, overworked, not feel valued."*

DIRECTOR, WEST TN

The common reasons it was difficult to retain direct care staff were a) inadequate pay, b) the challenging nature of the job (i.e., managing dangerous behavior), and c) inherent risks associated with supporting persons with complex behavioral needs.

> *"So, majority of the people that work, here, have two jobs. They cannot afford to work, here, alone. They can't afford to work in this field, alone. If they're in the field, they're working at two different agencies that provide the same services, because they can't afford to just work one. .....But that, always, always, been in the back of my mind is you've got people that are supporting individuals that are tired....So those are things that, systemic, we need to be looking at, and keeping in the forefront of our mind if we want to have success in supporting all people, but, especially, people with high behaviors."*

LEADERSHIP, MIDDLE TN

To elaborate on c), multiple DSPs discussed the fear of "doing something wrong" in the moment when dealing with dangerous behavior, keeping themselves safe, keeping the person supported safe. They discussed being afraid of being put on probation while an investigation occurs, and they do not get paid during that time.

> *"Yeah, the laws scare you....you want the safety of the individual, but you also have your own personal safety. But then again, the state care more about the individual, and you're just staff. Because they want ... "Oh, how did you hold him? Oh, you were holding him?" Said, "Abuse." Now you have abuse in your record, for not actually abusing anybody, but because you tried to use step 1, 2, 3. And then maybe in the three, it was faster than it was supposed to be. And he fall, right? ... So sometimes, this puts us in a difficult position. That's why, sometimes, people leave the job. Because we're like, "Oh, God. This is so scary." Oh, you don't want to go to jail."*

DSP, MIDDLE TN

❑ ***Summary***

High staff turnover is exacerbated by low wages, leading to burnout and a lack of continuity in care. The stress of managing dangerous behaviors with insufficient support can drive staff to leave the field. The high turnover rate among DSPs means that many staff do not have the opportunity to gain the experience necessary to effectively support persons supported with complex behaviors.

2. Daily Operations

Focus group members discussed activities related to daily operations that may affect safety including proper documentation, internal communication, following proper protocols, and responding to safety and crisis situations.

> *"Communication is often a barrier. Staff are often not told the likes/dislikes, frustrations, challenges, triggers, etc. of an individual. Generally speaking, this can be difficult due to high turnover rates and coverage for staff to attend in-person training."*
>
> LEADERSHIP, SURVEY RESPONDENT

Focus group members discussed ways in which daily operations could be improved including clarity around reporting dangerous behavior standards and increased daily communication from house managers and leadership, especially when onboarding new DSPs and during shift changes.

3. Components of Care Delivery

When discussing components of care delivery, interviewers focused on strategies and tactics for preventing dangerous behavior, de-escalation from dangerous behavior, and managing crisis situations. However, the job duties of the DSP, house managers, and leadership certainly extend beyond just managing dangerous behaviors, including, but not limited to, assisting with medication management, daily hygiene routines, job training and support, support in the community, and attending regular medical appointments, to just name a few.

Most focus group members discussed the safety training they initially received (e.g., PMI, CPI, Ukeru) and what they learned from getting to know the person supported. DSPs also reported learning how to support the persons supported through trial and error versus relying on the training provided to them. When asked what the most effective strategies are for preventing dangerous behavior, many DSPs cited their relationships with the persons supported. If they had a better, more trusting, relationship with the person supported, that person typically did better. When they knew the person supported well, they knew the events that typically triggered dangerous behavior and how to de-escalate the situation faster. High turnover rates complicated the method of care delivery because time spent with the person supported appears to be the most effective way to learn how to support that person. In addition, almost all DSPs spoke about how the training provided is rarely individualized to meet the diverse needs of all persons supported.

> *"I think that's why it's so easy for them* [leadership] *to try and tell us what we should and need to do because they're not in a situation. I guess the one thing that's going to help this person is not going to help the next person. So just like the training we're doing now, that's not going to help for every single behavior we have. We should have multiple types of things that is different for each house."*
>
> DSP, WEST TN

> *"They're* [outside Behavior Analysts] *expert in certain behaviors, but they're not experts in certain behaviors that we deal with. We know these people's behaviors. They need to take the time out of the day to listen to the people whose dealing with this. Not just give us a baseline thing that you're taught. You need to learn what we're saying triggers the behaviors and all that, and then give us some feedback."*
>
> DSP, EAST TN

4. Accommodating Unique Service Requests

All agencies who participated in the focus groups discussed the various ways in which they accommodated complicated referral requests. For example, if a person is designated for Group 8 enrollment, the agency must provide the oversight of a Board-Certified Behavior Analyst (BCBA) and a registered behavior technician (RBT). If an agency does not have these staff members, and many do not, they would be unable to enroll this individual or they would enroll them at a lower level with less support and resources. As another example, one agency spoke of the challenges in working with an individual who constantly spit at other residents and at staff. Due to the person's supported cost cap, they could not acquire the necessary support to address his needs and associated safety concerns. As illustrated here, a collective concern among focus group participants is that current policy restrictions may directly impact the availability of training, opportunities for staff support, and challenges with staff retention.

A SUMMARY OF FACILITATORS AND SUGGESTIONS FOR IMPROVEMENT

Recommendations for Improvement

1. Enhanced Training Programs

a. Hands-On Training: Implement in-person, hands-on training sessions focusing on de-escalation techniques and physical safety. This should be coupled with real-life scenarios to help DSPs practice and understand the complexities of managing severe behaviors.
b. Trauma-Informed Training: Integrate trauma-informed care into all training modules. This should include understanding how trauma impacts behavior and practical strategies for addressing trauma-related needs.

2. Focused Support and Resources

a. Increased Supervision and Feedback: Ensure DSPs receive ongoing supervision and feedback, including regular case reviews and practical sessions with experienced professionals.
b. Specialized Training for Severe Cases: Develop specialized training modules for handling severe behaviors, including crisis management, sensory issues, and nonverbal communication.

3. Structural Changes

a. Funding and Pay Differentials: Advocate for increased funding and pay differentials for DSPs who work with individuals with intense behavior issues. This can help attract and retain skilled staff.
b. Flexible and Adequate Staffing: Ensure that staffing levels are sufficient to meet the needs of individuals, including having enough staff for one-on-one support when necessary.

4. Feedback Mechanisms

a. Regular Evaluations: Establish mechanisms for regular evaluation of training effectiveness and DSP performance, incorporating feedback from individuals supported, families, and DSPs themselves.

Section III

Survey and Interview Responses

SURVEY RESPONSES REGARDING POTENTIAL BARRIERS TO SAFETY

TRIAD sent out a survey out to DSPs and administrative and leadership members of the service providers who participated in focus groups, but also broadly to other organizations in Tennessee. 184 DSPs and 133 administrative and leadership team members responded to the survey. Additional survey results are available in Appendix B.

DSPs survey cited:

- lack of communication around client needs,
- lack of training provided around de-escalation of dangerous behaviors,
- too high client-to-staff ratios, and
- lack of training provided around prevention of dangerous behaviors as the biggest barriers to safety within their agency.

Similarly, administrators and leadership also cited:

- lack of training provided around de-escalation and prevention of dangerous behaviors,
- lack of communication between DSPS and between DSPs and administrators/ supervisors, and
- lack of motivation and morale among staff.

INTERVIEWS FROM PERSONS SUPPORTED

We sought to recruit feedback from the persons supported. We asked organizations to use an interview form to recruit feedback from the persons supported and to do so in way that worked for the staff and the person supported. We received many filled out forms and highlighted some of their responses below. Staff members who knew the clients well often asked the questions and recorded their responses.

Persons Supported 1 (OP) from SRVS (aged 19, been with SRVS for 1 year)	
Interviewer: House manager	
1	***What do you like about the staff that work with you? What do they do that you like?*** He states that his PS helps him out when he has a problem. He stated when he is mad, his PS process with him and calms him down before he gets too upset. He states his APC does the same thing. He likes one of staff because he engages in playing his game with him. One of the staff he likes that she does nice things for them and she does Freedom Friday with them. He states his PS drives him crazy but he loves me (lol). He states his APC gets on his nerves but he loves her (LOL)
2	***What do you wish the staff would do more? What do you wish the staff would do less?*** He states he just wants his staff to continue working with him and helping him out. He wants staff to stop redirecting him so much

Persons Supported 2 (SS) from SRVS (no demographic info provided)	
1	***What do you like about the staff that work with you? What do they do that you like?*** He states he love his APC. He states she does everything for them. She always assisting my housemate and me.
2	***What do you wish the staff would do more? What do you wish the staff would do less?*** N/A (no answer provided)

Persons Supported 3 (CK) from Emory Valley (aged 35)	
1	***What do you like about the staff that work with you? What do they do that you like?*** • "They're nice" • "They help us out" • "They make sure I get my meds"
2	***What do you wish the staff would do more? What do you wish the staff would do less?*** • "Teach me to be more independent" • "Would like for them to do less for me and allow me to be independent"

Persons Supported 4 from Emory Valley (aged 61)	
1	***What do you like about the staff that work with you? What do they do that you like?*** • "They're good to me" • "Wait on me" • "Help me with my oxygen"
2	***What do you wish the staff would do more? What do you wish the staff would do less?*** • "Take us out to eat more" • "Smoking so much"

Persons Supported 5 from Emory Valley (aged 30)	
1	***What do you like about the staff that work with you? What do they do that you like?*** "They're nice, polite, work hard, and protect me."
2	***What do you wish the staff would do more? What do you wish the staff would do less?*** Communicate better, be more mindful at times, wish they would nag less

Persons Supported 6 (AB) from Emory Valley (aged 34)	
1	***What do you like about the staff that work with you? What do they do that you like?*** "They're funny; they help me cook, take me out places"
2	***What do you wish the staff would do more? What do you wish the staff would do less?*** • "Take me on vacation" • Stop rushing her when getting up and allowing me to do what I want. She does not like the night staff.

Persons Supported 7 (KD) from Emory Valley (aged 45)	
1	***What do you like about the staff that work with you? What do they do that you like?*** "They care about me, make me laugh, take me on adventures"
2	***What do you wish the staff would do more? What do you wish the staff would do less?*** • "Let me cry and not tell me to stop" (Let her have her moment) • "Stop doing everything for me, stop being on the phone while working"

❑ ***Summary of Interviews with Persons Supported***

The feedback from the persons supported highlights the value of relationships between a person supported and their staff. The persons supported were able to easily report what they enjoyed about their staff (they're nice to them, make them laugh, help them out) and what they didn't like (if staff were overbearing, nagging, pushing them too much). Relationships take time and trust to build, highlighting even further the necessity of retaining quality staff.

Staff are coming into the client's home and should conform to the persons supported preferences as much as possible (not smoke too much, be on phone less). In addition, from these interviews and other comments from DSPs from the focus groups, it is clear that the quality staff know they are there to support and help the client, not act at their parent, babysitter, or manager. It is also apparent, that building trusting relationships between staff and persons supported is key. That can only happen when staff are given sufficient time to learn about the person and spend time with them.

CAREGIVER RESPONSES ABOUT THE SAFETY OF THE PERSONS SUPPORTED

A summary of barriers and concerns

1. Safety and Training Concerns

a. Staff Safety: Direct Support Professionals (DSPs) face significant challenges in ensuring both their own safety and that of the individuals they support. The threat of accusations and legal consequences for using physical interventions makes the job highly stressful. Current training often falls short in preparing DSPs for the physical safety challenges that come with severe behaviors. Real-life examples highlight the need for better preparation and strategies.
b. Training Quality: There is a consensus that training often lacks practical applicability, and new staff may not receive adequate preparation to handle complex behaviors. This can lead to unsafe situations and high turnover rates among staff. In addition, effective DSPs, often go above and beyond, but there's a noticeable lack of such tailored, empathetic approaches in many DSPs.

There's a concern that many DSPs lack basic common sense and an ability to connect with the persons supported on a human, relationship level. There's a need for more comprehensive training on sensory issues and nonverbal communication, especially for those who are nonspeaking. In addition, DSPs noted that they are often not taught about various diagnoses and thus are ill equipped to effectively support people with comorbid diagnoses.

There's a call for more effective de-escalation training, ideally involving hands-on practice rather than just theoretical knowledge. In addition, many individuals with severe behaviors have trauma backgrounds, which are not adequately addressed in current training models, which was noted by several individuals.

2. Systemic Issues

a. Funding and Resources: Funding limitations, such as inadequate reimbursement rates for higher levels of care, impact the quality of services. Providers struggle to cover the costs of intensive support and often cannot afford necessary resources or sufficient staff. There is a significant gap in funding, which impacts the ability to provide adequate support and training. This is exacerbated by system constraints, such as those seen with different waiver programs.

b. Waivers and Services: Many individuals, both service providers and caregivers, mentioned the differences between the 1915(c) waivers and ECF Choices, which affect the level of support available.

3. Caregiver and Staff Challenges

a. Turnover and Pay: High staff turnover is exacerbated by low wages, leading to burnout and a lack of continuity in care. The stress of managing severe behaviors with insufficient support can drive staff to leave the field. The high turnover rate among DSPs means that many staff do not have the opportunity to gain the experience necessary to effectively support clients with complex behaviors.
b. Behavioral Management: There is a need for effective behavioral management strategies and appropriate physical interventions. Staff often feel ill-equipped to handle severe behaviors safely due to inadequate training and support. This was reported by all individuals we spoke to including caregivers, DSPs, and leadership members.

4. Family and Caregiver Perspectives

a. Home vs. Group Settings: Many families prefer home settings over group homes due to the stability and familiarity they provide. However, policies often prioritize group settings and fail to accommodate individual needs effectively.
b. Integration and Flexibility: Families and caregivers express frustration over rigid systems that do not account for individual preferences and needs, leading to missed opportunities for meaningful community integration.

5. Quality of Life and Service Delivery

a. Engagement and Activities: Ensuring individuals are engaged in meaningful activities is crucial for their well-being. There are instances where staff fail to initiate activities, leading to boredom and increased behavioral issues.
b. Provider Constraints: Providers face difficulties in maintaining quality care due to financial constraints and inadequate support from funding agencies. This impacts their ability to manage intense behaviors and maintain safe environments.

Overall, addressing these issues requires a multi-faceted approach, including better funding models, improved training programs, and more flexible service options to accommodate individual needs. Ensuring that DSPs are well-compensated and supported will also be crucial in improving the overall quality of care and support for individuals with severe behaviors.

When caregivers were asked, what is the single most important issue in keeping their children safe:

"I think adequate compensation for staff. And in our son's house and I think a lot of places the agency's actually spending more because they don't have enough staff because people have to work time and a half. And the other part of that is our house manager often works 60 hours a week. She's 65 years old, she's wonderful. We're scared to death that one day she's going to say, "I want to have a life." And so it's not just they're driving the cost way up because people are perpetually working over time, but you tend to drive people out, because they don't want to work 60 hours a week."

"There are some agencies that really pride themselves on serving folks with intense behavior issues. We need more of those. And I don't know if that could be an additional, that would be a way to use those shared savings to give some agencies pilot projects to focus their intense work on supporting people with intense behaviors. But we talked with one out of West Tennessee called BSTN, and we were literally in the middle of an ISP meeting for Evan with them agreeing to come to Middle Tennessee to support him. And when they found out he was on the statewide waiver and not the comprehensive aggregate cap waiver, so funding versus of like $350,000 at that point versus like $160,000, they're like in the middle of the meeting, oh, well, we can't come to Middle Tennessee and support him for that amount of money. Sorry.....So if we could have agencies that this is what they want to do, I don't know if they would be any more successful in finding DSPs, but if there were financial incentives to do it and they felt supported in doing this work, maybe we could have more consistent staff and our kids could be safer."

Regarding how to retain quality staff
"...Or an extra maybe a six month bonus for staying, a one year bonus for staying? I don't know if they could do ratings from the families and give them bonuses based on how the families feel like. I feel like they are not really treated with a lot of respect and in different incidents they've been the scapegoat. There was an example where they had notified the house manager and whoever that Peyton had injuries, but when I realized he had injuries and brought it to their attention, they tried to act like they hadn't been told and I know they had been. So I think just being repeatedly thrown under the bus, it also just is not a good thing for morale. I think we need to treat them like they're more important by paying them more, by recognizing their efforts because honestly, the DSPs are what is going to make or break our children being able to stay in these homes."

"I guess when you were talking and telling us what you were interested in knowing, to me it's, unless we can find people that don't leave like the revolving door and take the time to get to know and understand and build a rapport with our loved ones, it's very difficult to have consistent behavior management when you have a revolving door of people that something better comes along, they're going to leave. I think the rapport and the mutual respect is just imperative. And that's what I've not been able to find except in one person who's his behavior analyst, who's literally been with him since 2012. So that was a blessing, but that is unique. I know that just with all the conditions right now, that would prevent DSPs from flocking to the field. That's where we all are, I think."

"We have been involved with the START team, which is the crisis prevention and intervention team, and they can't get any traction with the DSPs. Evan currently has no house manager. He has not had a house manager since July. And the DSPs currently, he has no permanent staff with him at all. It's whoever's willing to work that week with him. They say they simply cannot staff a home in Franklin because nobody wants to drive from Antioch to Cool Springs. And so we've actually been given a notice of discharge. The agency says they're not going to continue to support Evan, and the process has begun to look for another agency."

"And many of our loved ones cannot communicate what it is they want or need. The other side of it is our loved ones, they need to trust. They need to develop a trust for the person. They need to be respected, that they feel safe, that they feel understood to the best of someone's ability. That their preferences and needs and wants and desires are at least being taken into consideration. And to me, if you had a DSP that was just more invested in the position, I think that would be a win-win, hopefully the fact that our loved ones felt that this person really cared about them truly and was taking every step that they could to get to know them, some of these behaviors, they might be minimized, I don't know."

Section IV

Recommendations for a Multidisciplinary Capacity Building Framework

Addressing the issues identified by focus group members and survey respondents requires a multi-faceted approach, including better funding models, improved training programs, and more flexible service options to accommodate individual needs. In addition, ensuring that DSPs are well-compensated and supported is crucial to improving the overall quality of care and support for individuals with dangerous behaviors.

To address the gaps in training, we propose a multi-tiered approach to building providers' capacity to support individuals engaging in dangerous behavior. The proposed service line model includes opportunities for knowledge-building web-based curriculum modules, developing skills with interactive training and supervision activities for DSPs, engaging administrators in capacity building opportunities, and strengthening broad support within a statewide network.

Multi-tiered Capacity Building Model

Tier 1 - Building Knowledge: Develop an online training curriculum that addresses specific needs highlighted in both the survey and focus groups.
This curriculum would include topics such as:

- Building rapport and relationships
- Understanding nonverbal communication
- Preventing dangerous behaviors
- De-escalating dangerous behaviors
- Addressing trauma-related needs
- Identifying diagnosis specific considerations
- Improved communications to promote safety

Tier 2 - Building Community: Develop Communities of Practice

- Connect agencies across the state to share information and resources related to the curriculum modules and allow for further discussion and application exercises.
- The goal of communities of practice is to create interactive, collaborative spaces for shared professionals.
- The communities of practice would include an additional webinar series that expands upon the topics learned in the new curriculum.

Tier 3 - Building Capacity: Develop a Technical Assistance and Coaching Service Line for DSPs, house managers, and other support staff.

- Many agencies spoke of the need for training and support for dangerous behaviors but reported a lack of experience and access to those with expertise, such as a Board-Certified Behavior Analyst (BCBA). To circumvent the time, effort, and cost it would require for every agency to hire multiple BCBAs, it is recommended that a network of skilled behavioral providers (e.g., BCBA's and Registered Behavior technicians) be developed to provide technical assistance and training.
- Technical assistance, by this expert team, would be customized to each agencies' service requests and focused on building capacity of that agency to address the needs of persons supported with complex behavior needs through root cause analyses
- DSPs, house managers, or other staff members would be trained, coached, and supported through the implementation of the evidence-based, trauma-informed strategies learned in the online curriculum
- The focus would be on building the staff member's capacity, not on the network providing direct support to the persons supported

This would allow for the development of an extensive collaborative network of support across the state so that state agency providers and their teams are able to support the full set of needs each persons supported demonstrating complex behavior needs brings to their agencies.

Section V

Appendices

APPENDIX A: FOCUS GROUP PROTOCOLS

Focus Group Protocol: Professionals (Admin, supervisors, direct service professionals)
Moderator Guidelines
Introduction
Participant login/ Moderator Introduction
Introduce Purpose of Focus Group • "We want to learn about how service providers are training and providing ongoing supervision for direct support professionals who are supporting adults with intellectual and developmental disabilities. We would like to learn about the barriers and challenges in keeping clients and staff safe. • We're looking into things like how staff are trained to handle problems and keep everyone safe, what problems they face in keeping a safe place, and what could be better about the training and care they get. • There are no wrong answers but rather differing points of view. Please feel free to share your point of view even if it differs from what others have said. Keep in mind that we're just as interested in negative comments as positive comments, and at times the negative comments are the most helpful."
Focus Group Norms • Speak freely and openly; the goal is to hear as many perspectives as possible. • Speak one at a time. • Confidentiality statement • Do not disclose personal health information (PHI) due to audio being shared with external transcription services.

Focus Group Protocol: Professionals (Admin, supervisors, direct service professionals)

Moderator Guidelines

Topic Areas and Questions

Review the Problem/Background: Need for quality service provision for adults being supported by day programs and residential programs, specifically in direct care staff's ability to prevent, manage, and respond to dangerous behaviors.

General introduction

1. What is your role in the program? (administrator, supervisor, direct service professional)
   - Primary responsibilities? Setting? How many clients do you oversee/support?
   - Other things you step in and do/help with?

General questions related to addressing dangerous behaviors in residential and day programs.

2. How big of a problem is physical safety–for both clients and staff–in residential and day programs?
   - What are your primary concerns?
3. Describe the common dangerous behaviors (i.e., aggression, self-injury, pica, elopement) that occur in your residential program and/or day program?
   - How common is the occurrence of these dangerous behaviors day to day? What are some example experiences and how was the situation resolved? From your perspective as (administrator, supervisor, direct service professional), how do dangerous behaviors in residential programs and day programs compare?

Perceptions of the current state of affairs of training/ability to safely and effectively address dangerous behaviors.

4. Describe the current training provided to you/direct support professionals *to keep clients and staff safe*.
   - In what ways is this adequate?
   - Inadequate?
5. Describe the training provided on both learning how to *prevent <u>and</u> de-escalate dangerous behaviors*?
   - In what ways is this adequate?
   - Inadequate?

Focus Group Protocol: Professionals (Admin, supervisors, direct service professionals)
Moderator Guidelines
6. What would make the current training model (content or delivery method) and ongoing supervision provided more beneficial to you to keep clients and staff safe? • What is missing? • What needs to be modified? • What needs to be removed? ***Barriers to achieving safety and effectively addressing dangerous behaviors.*** 7. Beyond training, what are other barriers to maintaining physical safety? (ask for examples) • Barriers to *responding to* dangerous behaviors? (ask for examples) 8. How can we resolve these barriers/challenges? ***Personal Stories*** 9. We would like to hear a little about your own experience with residential and day programs. • From your perspective as (administrator, supervisor, direct service professional) what has worked well? What would you have change? • What can be done to better support you as a (administrator, supervisor, direct service professional) in keeping a safe space for clients and staff? ***Wrap-up*** 10. Of all the things we discussed, what do you consider the most important issue? Why? • Thank you all so much for being here. Before we end, is there anything else anyone wanted to say but hasn't had the chance yet?
Staff person ends the recording and/or the Zoom meeting.

Focus Group Protocol: Caregivers
Moderator Guidelines
Introduction
Participant login/ Moderator Introduction
Introduce Purpose of Focus Group • "We want to learn how to improve care for adults with developmental and intellectual disabilities being supported by residential and day programs. Specifically, we want to learn how to increase their physical safety when being served by these programs. • We're looking into things like how staff are trained to handle problems, what problems they face in keeping a safe place, and what could be better about the training and care they get. We would like to learn about the current training models and also, beyond training, what else is a barrier to safety. • There are no wrong answers but rather differing points of view. Please feel free to share your point of view even if it differs from what others have said. Keep in mind that we're just as interested in negative comments as positive comments, and at times the negative comments are the most helpful."
Focus Group Norms • Speak freely and openly; the goal is to hear as many perspectives as possible. • Speak one at a time. • Confidentiality statement • Do not disclose personal health information (PHI) due to audio being shared with external transcription services.
Topic Areas and Questions

Review the Problem/Background: Need for quality service provision for adults being supported by day programs and residential programs, specifically in direct care staff's ability to prevent, manage, and respond to dangerous behaviors.
 	
General introduction
1. Tell me a little bit about your son/daughter.
2. Is s/he in a residential or a day program?
3. What are your overall general impressions of residential/day programs?
  • What are the benefits?
  • What are the challenges?

Focus Group Protocol: Caregivers
Moderator Guidelines
Topic Areas and Questions (continued)

General questions related to addressing dangerous behaviors in residential and day programs.

4. How big of a problem is physical safety for your son or daughter?
5. What are some of the dangerous behaviors that occur in the program? (i.e., aggression, self-injury, pica, elopement)
   - To your knowledge, how common is the occurrence of these behaviors day to day?

Perceptions of the current state of affairs of training/ability to safely and effectively address dangerous behaviors.

6. How are direct support professionals trained to keep your son or daughter safe?
   - How adequate is this training? (please describe)
7. How are direct support professionals trained on preventing (i.e., knowing your son or daughter well enough to know and avoid triggers and know and provide things they love) and de-escalating dangerous behaviors (i.e., ability to calm them once they are escalated)?
   - How adequate is this training? (please describe)
8. What would make the current training model (content or delivery method) and ongoing supervision provided more beneficial to keep your son or daughter safe?
   - What is missing?
   - What needs to be modified?
   - What needs to be removed?

Barriers to achieving safety and effectively addressing dangerous behaviors.

9. Beyond training, if a problem for you and your son or daughter, what are other barriers to *maintaining* physical safety? Barriers to *addressing* dangerous behaviors?
10. How can we resolve these barriers/challenges?

Personal Stories

11. How were you oriented to the program?
12. Would you be willing to share any specific, personal stories around this topic of physical safety in the program?
    - What effect did this have on your son/daughter?
    - What effect did this have on you?

Focus Group Protocol: Caregivers
Moderator Guidelines
Personal Stories 13. How were you oriented to the program? 14. Would you be willing to share any specific, personal stories around this topic of physical safety in the program? • What effect did this have on your son/daughter? • What effect did this have on you? ***Wrap-up*** 15. Of all the things we discussed, what do you consider the most important issue/concern to you as a caregiver? Why? • Thank you all so much for being here. Before we end, is there anything else anyone wanted to say but hasn't had the chance yet?
Staff person ends the recording and/or the Zoom meeting.

APPENDIX B: ADDITIONAL QUOTES FROM FOCUS GROUP MEMBERS

Regarding the Relias training modules
"So the Relias is almost like a theoretical process, where you have to do the theory, and then working for the individual is practical. So everything you are supposed to do practically is already on the Relias. You see the point? So you're already following, you've already studied, and then you're in the field working. So from time to time, you're expected to go back to the notes, to go back to theory, refresh your mind, and then go back to the field. So the job is the field, while the theory is, "Hey, look at what … this is about. This is the job. As a DSP, look at what DSP is."

DSP, MIDDLE TN

Staff Retention
See some thoughts below from respondents on this topic:

"Carly made me take another point that's very well-stated is that we have a high percentage of our staff are working a second job because one job won't provide for their family. So the stress level, the burnout, it becomes more likely when we can't pay people a livable wage. So, that's a factor, I think, we just have to always consider. (Leadership)"

LEADERSHIP, WEST TN

"There's a lot of training that needs to go into that to be prepared for what that's going to look like to be able to support someone, especially if they're coming from a pretty intensive mental health hospital. And I mean, we've taken someone from jail in the past. He left and one day. I don't know where he is. So we weren't in a prepared position for that. So we have learned that maybe that's not something that we need to do, and I think we're a little bit more selective on who we take, and make sure that we have staff that would be able to support those people. So the goal is that it's not that we don't want to take them. It's that we need more assistance with preparing our staff to be able to support them. (Leadership)"

LEADERSHIP, SENIOR VICE PRESIDENT OF OPERATIONS, EAST TN

"I think adequate compensation for staff. And in our son's house and I think a lot of places the agency's actually spending more because they don't have enough staff because people have to work time and a half. And the other part of that is our house manager often works 60 hours a week. She's 65 years old, she's wonderful. We're scared to death that one day she's going to say, 'I want to have a life.' And so it's not just they're driving the cost way up because people are perpetually working over time, but you tend to drive people out, because they don't want to work 60 hours a week. The only other thing I wanted to throw in is if you haven't talked to them, you ought to talk to the Tennessee Disability Coalition. They probably deal with more families with children with severe behavior issues than anybody else in the state."

CAREGIVER

"…Federal offense, if something go wrong. And then you hear the stories of staff, and then it's like, I'll go work at a warehouse, because it's easier."

DSP/STAFF

"I know that we touched on this earlier, but also there is an instance in which this individual made a claim that wasn't true and this person had to go on leave, and with that they also don't get paid during that time. And it's my understanding that this employee was unable to pay their rent and things like that, which is also a big concern. I think if I was in that position and that was a scenario, I'd be like, 'That's too much for me. I'm out.' Even just the risk of it, because even when you're doing the orientation, as soon as they say, 'Okay, well if you mess up, you're going on leave.' And even though I'm a therapist, I was like, 'Man, I don't want that to happen to me.' That's almost enough to make you want to reconsider."

LEADERSHIP

Training

"I mean, the training is okay. It gives you an idea of what you're about to get into. But once you get into it, it's different. It's like, you have to overcome the fear, you have to overcome the what ifs. What if I put this guy in CPI? I might break something. He might break something on me. I mean, there's a lot of … And that is the main fear, because coming into the field or whatnot, or training, you feel like, if something happens, who's going to help me? Who's going to support me? I did everything they told me to do. I did what the training said. Now, what if something happens, and this and that. So I could possibly get … Because they always say in some of the trainings that this is a federal offense, and all this and that, and whatever else. And it's like, that's scary."

DSP, MIDDLE TN

Regarding the complexity of clients and ability to support clients with complex behaviors
"I think going off about what you're saying too though, is that we lack some type of training to help us to support people that have some of those types of behaviors. One of the big ones is self-injurious behaviors….And then on the other side of that is that we have people that will go to the emergency room and sit for five to seven days because there is no placement, no community placement for us to help get them stabilized."

LEADERSHIP MEMBER, EAST TN

Policies
Some direct quotes on this topic below:

Regarding the decision on whether to pay a staff member more or staff the client with additional support
"If they just give you this reimbursement rate that only supports me having one staff.| Because it's just that person needs staff 24 hours a day around the clock. And when you look at the reimbursement rate, first of all, I can't just pay somebody $15 to work with somebody who's a group eight because like she was saying, they're going to go over here and work with this person. So you have to give an incentive for that staff member to be like, "Okay, I'm going to work here because I'm going to make $18 an hour." And so when you start looking at the rate that you're provided and you're paying your staff with benefits, $18 an hour, I can only put one staff over there."

Regarding the inflexibility of funding levels
"But on the DIDD side of things though, you got to take in consideration of cost cap now because even though you might need a different funding level for an individual, just for the individual that it fits, I truly feel like he needs to have individual funding. Well, he can't get approved for that because of his cost cap. And that's end of story. Sorry, there's no support for you."

LEADERSHIP, EAST TN

Regarding the new ECF waiver system compared to the 1915c waivers
"This population really needs a multidisciplinary approach on the DIDD side, on the old waivers, they have access to station MD, which is 24/7 access to board certified physicians. We don't have that over on ECF, we don't have that service, but that is something that we need."

CAREGIVER

When caregivers were asked, what is the single most important issue in keeping their children safe:

> *"I guess for me it comes down again to having trained, experienced staff and consistent staff and how to get that. I think there needs to be a different level of qualification for people to work with medically and behaviorally, complex people that have a higher standard, much more training. But the biggest thing to me is the turnover. Our kids are never going to get somebody who understands their communication, who understands their triggers to understands how to bring them down. It's just going to be a constant. And I really think that they need to pay a good wage and really invest in training some highly skilled people to work with our population."*

> *"Yeah, we were considering [residential placement] and one of the reasons why we have not taken her … is because I know that the staff will not have the skills to be able to support her. And I worry about her having negative interactions with law enforcement. We're Black just in case you don't know from my name and we're immigrants, so that's a huge concern for me. They had wanted to move her to Cookeville and I was like, "That's not going to happen." My child has indicated that she wants to be at home, she wants to live at home. She wants to live close to people who look and sound like her.*

Staff

> *"We have some very seasoned house managers, and one of the things that I've seen in the industry, in the different roles that I've been in, is that we've, always, had DSP turnover. That's, always, been a problem. It just is some years worse than others, but over the last, probably, five or six years, the more significant turnover is starting to happen in the mid-level manager area, the program manager, and the house manager area. When you lose that longevity, and you lose that historical ability to work with these individuals, then, the new people, coming in the door, aren't getting those tenured people to train them, and, then, they turn over because they don't feel supported, they don't feel trained, they don't feel equipped. And that goes back to… If you're familiar with the industry, we've done a lot of legislative work to get DSP wages raised, over the last few years, and that's great. But the thing that they need to start working on, and the next initiative we're kind of pushing through is that there needs to be rate increases tied to the state increases that the state employees get. And that's where you're going to tend to hang on to your longevity."*

"No offense, it's trash. And then, again, the behaviors, word of mouth on behaviors. Well, people that's been in the field, the accountability that'll be held if something goes wrong, that's a fear. And again, the pay. We're taking care of people and their lives. Their lives is basically in our hands for eight, maybe 16 hours or so, and that's valuable. If this life is valuable, then pay for how valuable this life is. So for the services that is provided for this life, that's how I see it."

DSP/STAFF HOUSE MANAGER, MIDDLE TN

"No matter how good of a trainer I got, or the training I'm doing, I still have to take care of the people too. I can't just focus all on training, but they want the home managers to be the only one training because they don't want to pay extra people. But if we pay a little bit of extra money, people might stay longer and get the right training."

DSP/STAFF, EAST TN

"Carly made me take another point that's very well-stated is that we have a high percentage of our staff are working a second job because one job won't provide for their family. So the stress level, the burnout, it becomes more likely when we can't pay people a livable wage. So, that's a factor, I think, we just have to always consider."

LEADERSHIP, WEST TN

"I think adequate compensation for staff. And in our son's house and I think a lot of places the agency's actually spending more because they don't have enough staff because people have to work time and a half. And the other part of that is our house manager often works 60 hours a week. She's 65 years old, she's wonderful. We're scared to death that one day she's going to say, "I want to have a life." And so it's not just they're driving the cost way up because people are perpetually working over time, but you tend to drive people out, because they don't want to work 60 hours a week. The only other thing I wanted to throw in is if you haven't talked to them, you ought to talk to the Tennessee Disability Coalition. They probably deal with more families with children with severe behavior issues than anybody else in the state."

CAREGIVER

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"I know that we touched on this earlier, but also there is an instance in which this individual made a claim that wasn't true and this person had to go on leave, and with that they also don't get paid during that time. And it's my understanding that this employee was unable to pay their rent and things like that, which is also a big concern. I think if I was in that position and that was a scenario, I'd be like, "That's too much for me. I'm out." Even just the risk of it, because even when you're doing the orientation, as soon as they say, "Okay, well if you mess up, you're going on leave." And even though I'm a therapist, I was like, "Man, I don't want that to happen to me." That's almost enough to make you want to reconsider."

LEADERSHIP

Policy

"I mean, I think that we have a couple of locations where it's been a safety issue. We have one individual that spits, and he spits on his housemates, the staff, on his bed, and so that's a huge safety concern for me because that's bodily fluids. And we have reached out to everybody that we can think of to get assistance, and we were offered the assistance of… to get folders, the plastic folders, and for staff to carry those around and the individuals to carry those around to block the spit, try to get individual funding for the gentleman, and we can't because of cost cap."

"I am excited that DIDD is actually working on a project like this because I know that I get a lot of pressure at my level to accept referrals that have intensive behaviors and needs. They're even in jail hospitalization and they're like, "Why can't you take them?" Well, first of all, I don't have staff to immediately work with them, so I don't have a training program that's going to prepare them for that. So it's traumatic for us when they're pressuring us to take those folks, then we're not in the position to do that."