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Quality of Care for IDD Adults Living in Florida: A Pilot Study

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Table of Contents

Executive Summary

As the Founder and CEO of Research Analytics Consulting, LLC, I agreed to co-design a survey to provide a snapshot of the quality of services as experienced by IDD adults in the state of Florida. This was at the request of several parents I have met, who have at least one adult child born with an Intellectual or other Developmental Disability (IDD), given my role as Guardian Advocate and Representative Payee for a 46-year-old IDD woman, whom I love dearly. She has lived independently, in her own apartment, with the support of a full-time live-in caregiver for almost two years now. She first lived with one housemate. She now lives with two. She is also supported by a coach and by us, as her family, and attends an Adult Day Training (ADT) program each day. It is my desire to help her live her best life that prompted me to agree to take this on.

This report reflects the opinions of 157 IDD adults, over the age of 21, based on their self-report or that of their family member. Most of these adults live in SW Florida. This is because these opinions were solicited via a survey distributed to families served by a high-quality reputable agency that provides Waiver Support Coordinators (WSC). Families who received the survey were asked to forward it to any parent group that might be interested in completing it. Therefore, while the sample includes many FL counties, these results are highly reflective of the views of families in SW Florida. In addition, most, if not all, families that responded to this survey are likely receiving funds from the Agency for Persons with Disabilities (APD) in the state of Florida, given the distribution method. This is because once an IDD adult is approved to receive funds from APD, the first step a family must take is to select a WSC.

This limits the generalizability of these results. Therefore, we consider this report to reflect the results of a pilot study. To truly understand what is happening across the state we would want to retool some of our measurement instruments, our surveys, based on what we learned in this pilot study. Nevertheless, I find these results to be reflective of what I have experienced personally, over the past two years, as I have learned to navigate these systems.

Our survey asked respondents to evaluate how they, or the IDD adult in their family, felt about their job, their vocational coach, their roommates, their caregiver(s), their Supported Living Coach, and their Adult Day Training (ADT) program. While all these resources theoretically exist for IDD adults, the results indicate that most IDD adults in this sample are supported by Adult Day Training (ADT) programs and Live-in Caregiver support. Approximately 50% of the IDD adults, whose perceptions are provided in this report, attend an ADT program and approximately 50% live outside of the home with one or more housemates. 75% of adults that live outside the family home are support by a full-time live in caregiver.

Only 17% of IDD adults, whose opinions are reflected in this report, currently work to supplement their income and only 10% of respondents work with a vocational job coach. Those that worked, expressed pride, happiness, and enjoyment with their job and expressed a desire to work more hours consistently. A few respondents, reflecting the perceptions of adults that currently attend an ADT program, reported a desire to find meaningful work out in the community, with little support provided by ADT program staff.

Less than 25% of IDD adults, whose opinions are reflected in this report, work with a Supported Living Coach (SLC). IDD adults living independently are most likely to be working with an SLC. 71% of adults living independently work with an SLC, compared to only 30% of those living in a licensed group home and only 7% of those living at home with family. When asked what they typically spent time doing with their SLC most reported going shopping or supporting medical and other healthcare needs. Almost half reported going out in the community, typically for a meal.

Approximately half, 48%, of the IDD adults, whose opinions are reflected in this report, reported attending an Adult Day Training (ADT) program. Less than half of IDD adults living at home, about 40%, attend an ADT program, whereas more than two-thirds, 69%, of those living in a licensed group home attend an ADT program. Only 39% of IDD adults living independently attend an ADT program. This makes one wonder what these adults are doing each day since only 16% of adults living independently reported that they worked.

Respondents were asked a series of questions, designed to evaluate how they, or the IDD adult in their life, felt about the quality of each of the supports available to them. These questions could be grouped into two categories – those reflecting learning new things and how to become more self-sufficient and those reflecting feelings or emotions towards their support person. Regardless of the type of support provided, the lowest scored items on our scales consistently pertained to the former, while higher scored items pertained to feeling cared about by their support person.

Taken as a whole, the evidence in this report suggests that the system of care provided to IDD adults lacks a focus of helping them transition to greater levels of self-sufficiency, if they are able. There is a lack of a coherent, aligned, progressive system of training for IDD adults over the age of 21. Most funds are being used to support a system of learned helplessness, as opposed to empowerment.

I believe we can do better.

Results

Demographics

There were 157 survey respondents in total. Figure 1 illustrates the age breakdown of the IDD adults, whose perceptions are reflected in the results. As the figure illustrates, most of these IDD adults are between the ages of 22 and 49. Slightly more IDD males (54%) are reflective in these results than females (46%).

Figure 1: Age Group of Respondents (n =157)

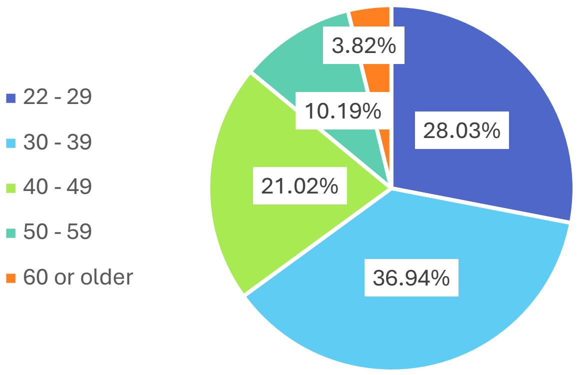
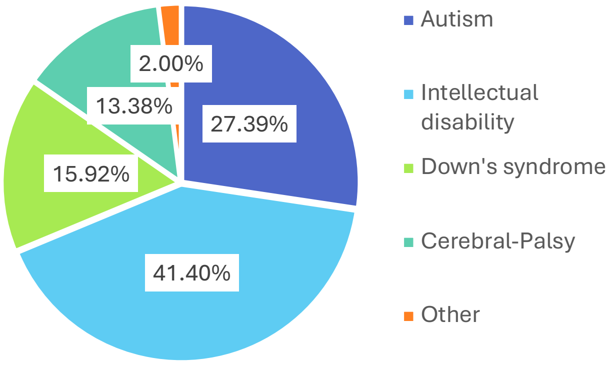


Figure 2 illustrates the primary disability status for the sample of the respondents. As the figure illustrates, Intellectual Disability had the highest percentage of respondents (41%) followed by Autism (27%).

Figure 2: Primary Disability of Respondents



A slight majority of respondents reported that the IDD adult had a Guardian or Guardian Advocate (62%).

A little over half of the respondents reported the IDD adult still lived at home with their family (55%), while the majority of those that do not still live at home with their family live in a licensed facility, such as a group home. Only 16% of respondents reported the IDD adult lived in their own home or apartment, either with or without roommates.

When asked who helped the IDD adult manage their money an overwhelming number of respondents (86%) stated that it was a Family member/Guardian/Guardian Advocate.

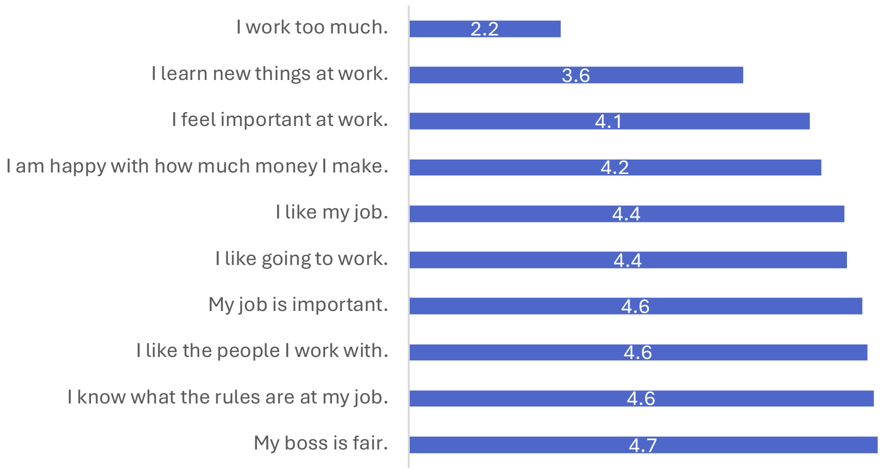
Table 1 depicts the counties that respondents reported living in. As the Table illustrates, the top counties represented in this report include Sarasota (25%) and Manatee (14%). However, a total of 31 counties had representation from at least one family.

Table 1: Counties in which IDD Adults Reside

County	N	Percentage
Sarasota	40	25%
Manatee	22	14%
Saint Lucie	12	8%
Indian River	11	7%
Hillsborough	10	6%
Brevard	8	5%
Lee	6	4%
Pasco	5	3%
Pinellas	5	3%
Polk	4	3%
Broward	3	2%
Collier	3	2%
Duval	3	2%
Palm Beach	3	2%
Charlotte	2	1%
Citrus	2	1%
Martin	2	1%
Miami-Dade	2	1%
Osceola	2	1%
Bradford	1	1%
Clay	1	1%
DeSoto	1	1%
Gadsen	1	1%
Hernando	1	1%
Lake	1	1%
Leon	1	1%
Marion	1	1%
Orange	1	1%
Saint Johns	1	1%
Sumter	1	1%
Walton	1	1%

Employment

Figure 3: Means of Job Satisfaction Items



Only 17% (n = 27) of the respondents reported that the IDD adult worked to supplement their income. Figure 3 illustrates the average response to each item on our job satisfaction scale, sorted from low to high. Responses to each item ranged from 1 (Never) to 5 (Always). This scale was designed to measure IDD adults' perceptions of their job. As the figure illustrates, the lowest scored item was that the IDD adult worked too much. Understandably, many IDD adults are limited in the number of hours they work because if they earn too much money, they will lose their SSDI benefits. However, a review of the qualitative comments demonstrates that many IDD adults report inconsistency in scheduling, only working a few hours one or two days per week, which is far below what they are allowed to work within this system. This was followed by an item focused on learning new things at work, presumably because the tasks assigned to IDD adults are often repetitive and monotonous activities, as demonstrated in the qualitative comments.

A total of 13 respondents provided written qualitative comments on the perceived quality of the job held by the IDD adult and these written qualitative comments are provided in Appendix A. A thematic analysis was conducted on these responses, and three major themes emerged. First, 50% of those that provided feedback (n = 5) expressed pride, happiness, or enjoyment with their job and expressed a desire to work more hours more consistently. However, 50% of these same respondents expressed challenges and skills gaps at work. Specifically, keeping pace and staying focused at work were expressed as concerns, as was the lack of variety of tasks assigned on the job. Some concerns were also expressed about process barriers that exist in the Vocational Rehabilitation process. However, one specific program, Customized Employment, which included a discovery process with a VR vendor was cited as the “best thing ever” by one respondent.

Only 10% (n = 16) of the IDD adults whose perceptions are provided in this report stated that they worked with a Vocational Job Coach. Figure 4 illustrates the average response to each item, designed to measure IDD adults’ perceptions of their job coach, sorted from low to high. Responses to each item ranged from 1 (Never) to 5 (Always). As the figure illustrates, there was less variability in these survey items. However, interestingly, the three lowest rated items on this scale have to do with learning.

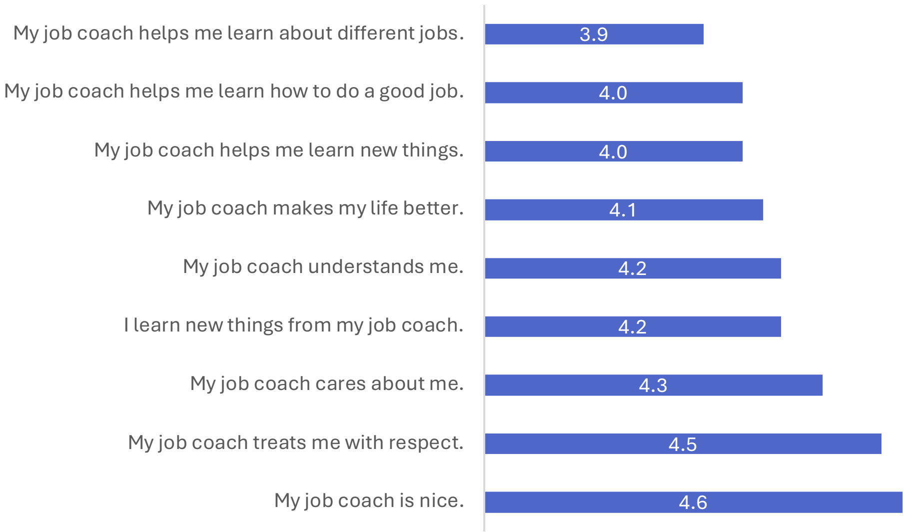


Figure 4: Means of Job Coach Satisfaction Items

Only six respondents provided written qualitative comments about the quality of their job coach.

Therefore, a thematic analysis was not conducted. These comments are provided in Appendix A.

Current Living Situation

Roommates

As stated previously in this report, a little over half of the IDD adults whose responses are reflected in this report currently live at home with family. Those who do not live at home with family (n = 71) were asked if they lived with one or more roommates and 86% (n = 61) of these IDD adults reported that they did. Those that reported living with roommates were asked if they were able to select their roommate and only 14 respondents reported that they were.

Figure 5 illustrates the average response to each item, designed to measure IDD adults' perceptions of their relationship with their roommate, sorted from low to high. Responses to each item ranged from 1 (Never) to 5 (Always). As the figure illustrates, the lowest scored items pertained more to roommates helping each other out, while higher scored items pertained to positive emotions or feelings between roommates. It should be noted that the items on this scale were scored considerably lower, in general, than the items on any of the other scales.

Figure 5: Means of Roommate Satisfaction Items

Respondents were asked to comment on their relationship with their roommates and these written qualitative comments are provided in Appendix A. A total of 38 respondents provided a response to this question. A thematic analysis was conducted on these responses, and four major themes emerged:

1. Mutual respect or friendship was expressed by 9 respondents.
2. Friction between roommates was expressed by 7.
3. Little to no meaningful interaction between roommates was expressed by 6.
4. More concerning, expressed aggression, taunting, inappropriate behaviors, or feeling unsafe in their environment was expressed by 4.

Clearly it is not uncommon, even with neurotypical adults, to struggle with roommate and housemate situations, for the very same reasons – due to differences in abilities, personalities, and/or interests. However, the lack of choice that many IDD adults have, with respect to selecting their own roommate, likely exacerbates the situation. This data helps to demonstrate the importance of implementing the theoretical values and goals that underlie person-centered planning and community integration. These values and goals serve as the guiding principles for the Agency for Persons with Disabilities (APD) and the federal standards for Home and Community Based Services (HCBS) and include the following:

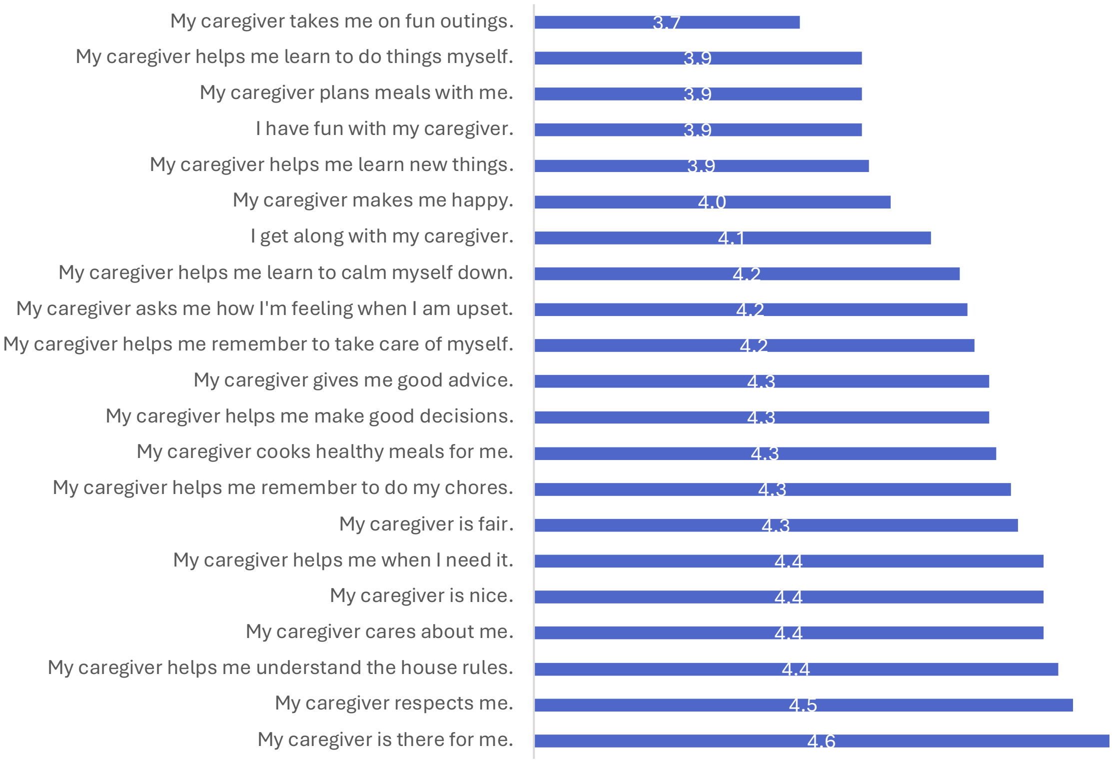
- **Choice and Control**: IDD adults should have meaningful choice over where and with whom they live.
- **Dignity and Privacy**: IDD adults should have private space and/or compatible roommates and housemates that respect their autonomy and personal comfort.
- **Community Inclusion:** IDD adults should be able to choose living arrangements that support their self-determination and their participation in community life.

Theoretically, when individuals with IDD are given control over their roommates or the opportunity for independent living their satisfaction, stability, and engagement should increase. Sadly, the data from this survey demonstrates that this is not the case for many IDD adults who are not living at home with family.

Live-in Caregiver

Recall that a little under half, 48%, of the IDD adults whose responses are reflected in this report currently live out in the community. 75% (n = 53) of these IDD were reported to live with a full-time life in caregiver. Figure 6 illustrates the average response to each item, designed to measure IDD adults' perceptions of their relationship with their live-in caregiver, sorted from low to high. Responses to each item ranged from 1 (Never) to 5 (Always). As the figure illustrates, the lowest scored items pertained to caregivers helping the IDD adult they care for plan meals, go out for fun or learn new things. On the other hand, higher scored items pertained more to positive emotions or feelings between IDD adults and their caregivers.

Figure 6: Means of Caregiver Satisfaction Items



A total of 22 respondents provided qualitative comments on their relationship with their live in caregivers and these written qualitative comments are provided in Appendix A. A thematic analysis was conducted on these responses, and four major themes emerged.

1. Overall satisfaction and a positive relationship with their caregiver(s) were expressed by 9.
2. Four (4) respondents stated that caregivers needed better training to understand the needs of the IDD adult that they served.
3. Three (3) respondents stated that caregivers provided a very limited teaching of life skills.
4. Finally, 3 respondents reported that caregivers tended to provide physical care but limited emotional or social engagement.

This data highlights the importance of stable and compassionate caregivers. Nearly one in five respondents reported that IDD adults that do not live with family had inconsistent caregiving staff that turned over frequently, which undermines trust and continuity of care.

Supported Living Coach (SLC)

All respondents, those living at home with family as well as those living in a group home or in a supported living environment, were asked if they worked with a Supported Living Coach (SLC). This is a very important support position for IDD adults, theoretically, living outside of their family home. According to a document, entitled A Guide to Supported Living in Florida, published by the Florida Developmental Disability Council (FDDC) in 2003, this role is central to helping IDD adults live independently in the community. Specifically, the role of a SLC is to assist IDD adults achieve and maintain independent, self-sufficient living arrangements. They are meant to help their clients make informed choices, develop daily living skills, and access community resources so they can live successfully outside institutional settings. However, less than 25% (n = 35) of all respondents reported working with an SLC. This implies that a large majority of IDD adults, including half of those living outside of a family members' home, are not working with a SLC. More importantly, it is unlikely that without such support an IDD adult who has only lived at home with family will ever be able to learn how to move to a more independent living environment, perhaps eventually gaining the skills and confidence to enable them to live without a full-time caregiver, which is one of the highest costs associated with an IDD adult living in the community.

Figure 7: Means of SLC Satisfaction Items

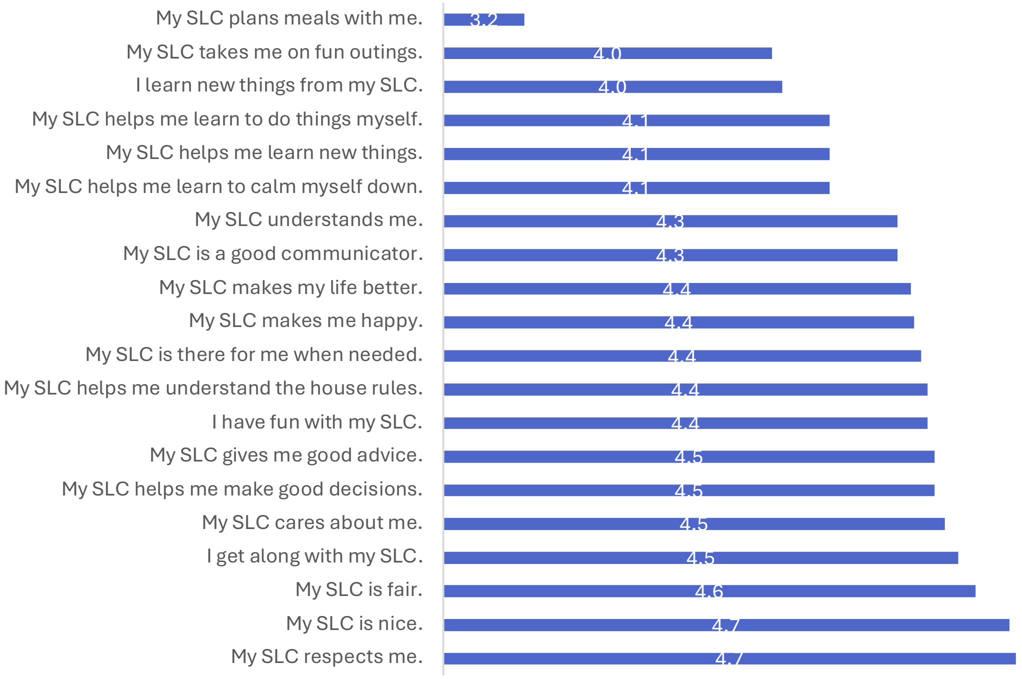


Figure 7 illustrates the average response to each item, designed to measure IDD adults' perceptions of their SLC, sorted from low to high. Responses to each item ranged from 1 (Never) to 5 (Always). As the figure illustrates, the lowest scored items pertained more to SLCs planning meals with their clients and helping the IDD adult they care for go out and have fun or learn new things. This is unfortunate, because their very role is described as helping IDD adults maintain their independence and integrate into the community. Yet it would appear as if IDD adults do not always have a say in the food that they eat since one of the lowest scored items for both support roles (caregiver and SLC) was working with IDD adults to plan meals. Therefore, the very things we expect those to do for our loved ones living out in the community, the things we do with our loved ones as a family – planning meals together and doing fun things out in the community – are the lowest scored items by those currently utilizing the system of supported care.

A total of 13 respondents provided qualitative comments on their relationship with their SLCs, and these written qualitative comments are provided in Appendix A. A thematic analysis was conducted on these responses, and three major themes emerged.

1. Overall satisfaction and a positive relationship with their SLC were expressed by 7 respondents.
2. However, roughly 4 respondents mentioned challenges, such as inconsistency, lack of initiative, or confusion about their role.
3. Three (3) respondents stated that they were unaware of the role an SLC could play in an IDD adult's life.

Respondents were asked what they typically did when they spent the day with their SLC. These written comments are provided in Appendix A. A total of 19 respondents provided a response to this question. A thematic analysis was conducted on these responses, and three activities emerged that most respondents reported doing with their SLC.

1. Thirteen (13) respondents reported that the IDD adult spent their time with their SLC grocery, clothing, or personal shopping.
2. Eleven (11) respondents reported that their time was spent on medical and health care support, and it is unclear what type (if any) of medical training is needed to serve as an SLC.
3. Finally, 9 respondents, reported going out with their SLC on a community outing, typically for a meal or a walk for recreation.

Only 2 respondents mentioned emotional or personal support being provided by their SLC, although presumably it may be embedded in other activities. However, the mental and emotional well-being of IDD adults, many of whom have faced past trauma, is just as important, if not more so, as it is for neurotypical adults. In addition, only three respondents mentioned employment types of activities, which is interesting since IDD adults that are well-placed in a work position report being extremely happy with their jobs. This might signal a potential area of growth for SLCs, who have the potential to serve such an important role in the lives of IDD adults – enabling them to live their lives as independently as feasible.

Key insights from this evidence are that SLCs are indispensable to independent living. Many IDD adults currently rely on them for their shopping and health care needs. Therefore, they play an instrumental role in the support of IDD adults living out in the community. However, the data also show that less than half of those living out in the community have such support. In addition, the data point to the need for additional training, support, and onboarding of SLCs, who, theoretically, should provide coaching in daily living skills **and** emotional regulation. Therefore, this training should emphasize relationship-building and empathy training, in addition to skill building and community integration.

Adult Day Training (ADT) Programs

All respondents, those living at home with family, as well as those living in a group home or in a supported living environment, were asked if they attended an Adult Day Training program. Approximately half of the respondents, 48%, reported that they did. ADT programs are designed to help adults with IDD develop or maintain the skills needed to participate in daily life and the community. They provide recreational and other activities that improve social development and increase skills in daily living. They typically operate on the same schedule as a school (e.g., 9 to 2:30) in a center or other community-based setting. They are certified by APD and subject to periodic reviews and quality assurance models.

Figure 8: Means of ADT Satisfaction Items

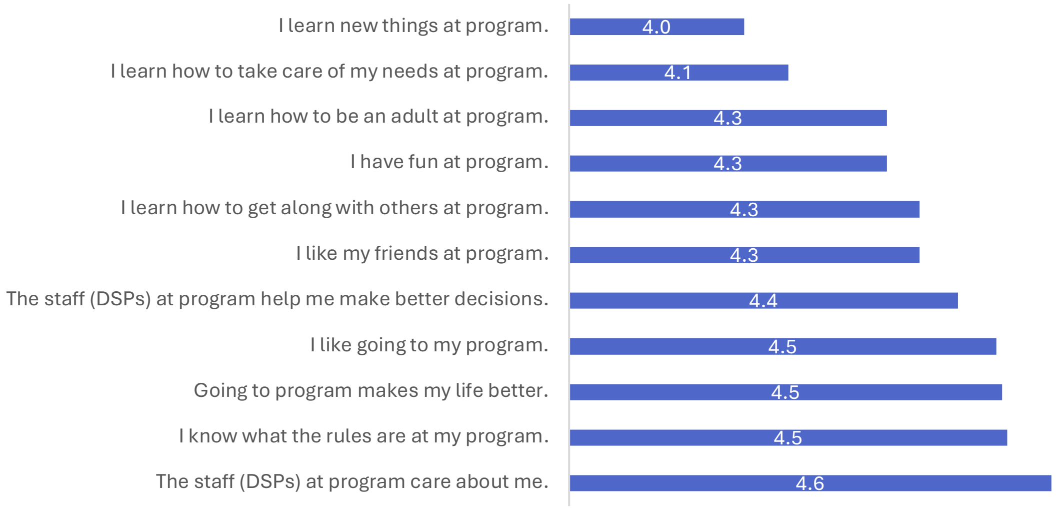


Figure 8 illustrates the average response to each item, designed to measure IDD adults' perceptions of their ADT program, sorted from low to high. Responses to each item ranged from 1 (Never) to 5 (Always). As the figure illustrates, the lowest scored items pertain more to learning new things and how to take care of their own needs although ADTs very role is described as helping IDD adults develop or maintain the skills needed to participate in daily life and the community. How can this be occurring if learning new things only happens some of the time at program, which is what a lower mean implies. Once again, the highest scored items pertain to feeling cared about.

A total of 29 respondents provided qualitative comments on the quality of their ADT program, and these written qualitative comments are provided in Appendix A. A thematic analysis was conducted on these responses, and three major themes emerged.

1. Twelve (12) respondents mentioned the quality of staff. Respondents value caring and stable staff. However, high turnover and poor-quality programs erode trust.
2. Nine (9) respondents mentioned meaningful engagement and skills development, or the lack thereof, in their ADT program.
3. Eight (8) respondents mentioned a sense of social belonging and emotional well-being.

One family, that likely reflects a perception shared by all, is that the iBudget waiver is essential for access to ADTs and HBCS and improving the quality of life of IDD adults.

Non-neutral written comments were also classified as either positive or negative and 62% of comments that could be classified were positive (n = 18) while 38% were classified as negative (n = 11). A review of the positive comments indicated that families are most satisfied when programs offer consistent, caring staff in a safe and socially engaging environment. A review of the negative comments indicated that dissatisfaction with ADT programs centers around the lack of individualized, purposeful programming, pathways to employment, and constant staff turnover.

Key takeaways from this data indicate that ADT programs that invest in staff stability, individualized care, and social inclusion are viewed as highly successful by families who utilize these services. However, there is a strong need for more meaningful skills-based program that lead to employment opportunities for IDD adults. Given the fact that the lowest scored items on the ADT satisfaction scale pertained to learning new things, it is unclear how an IDD adult might "graduate" from an ADT program to pre-employment and then employment. As one self-advocate states *I want to work, not go to a day program. No one helps me with this*.

Appendix A: Qualitative Comments

Q11. Feel free to explain why the IDD adult is, or is not, satisfied with their current job placement. What makes it good? What could make it better?

1) He has a work study position at a college
2) He is slower than his coworkers and often gets criticized for this.
3) More hours needed
4) We completed the Discovery process with a VR vendor. Customized Employment has been the best thing ever!
5) I recommend looking into the VR onboarding process, which takes 6 -12 months and it expires less than 1 year. If it expires, the individual has to re-apply for the duplicate/ inefficiency process to join the VR again. At the point, the individual lose 1-2 year opportunities to gain experience.
6) She works cleaning at the Haven where she lives. She would like to possibly work off campus occasionally to broaden her friend base and meet new challenges.
7) Only works 2 hours a week. Often called out as he does food prep at a Dunkin Donuts. If the truck does not come in, they feel as if he does not have anything to do so they call him out.
8) She has been working for Publix for 30 years. She works only 1 evening a week from 4-8pm.
9) I love to work it keep me happy
10) Struggles to keep up work assigned and stay focus
11) He overall likes his job and workplace. He does interact somewhat with his co-workers.
12) It is good because any requested time off is given. It is bad because sick people come close. Some variety in tasks would make it better.
13) All good

Q15. Feel free to explain why the IDD adult is, or is not, satisfied with their current or past relationship with their job coach. What makes it good? What could make it better?

1) help get more hours
2) Job coach is a good person but seems to be stuck in the old view of jobs for jobseekers with IDD to food, filth, flowers
3) Starts a otj training and then stops working and nothing happens after that it seems

4) Job coach attends weekly and has a great relationship with Kyle. Jobs are limited for those with special needs and I feel like Kyle should have had more options at applying at various places and that hasn't happened.
5) Needs to have help completing job applications and opportunity to role play prior to job interview. I need regular follow-up. I always text coach to ask for help. I don't feel like anyone is helping me get a job.
6) Job coach keeps management happy

Q21. Feel free to explain why the IDD adult is, or is not, satisfied with their roommate(s). What makes it good? What could make it better?

1) My daughter has private room as does most of her housemates . She prefers to spend Saturdays with her mother than the fun outings her group home goes on bc she is fearful that I am old (not really, 72) and might die soon. Her Dad did at 58.
2) Having a friend. Being by myself. I like being by myself - doing my own routine s.
3) Due to her own disability some days she is not happy and tends to take out frustation on both roomates and staff!
4) She is non verbal therefore I have to answer the above questions based on her behaviors. She appears happy and she willingly goes back to the home from visits with me. Residents and her interact pleasant with each other.
5) There are 5 roommates - the one she shares a room with is a good friend, most of the time! The others are "iffy" most of the time, but they do celebrate each others' birthdays, Christmas, etc. together.
6) There is 3 housemates. Only 1 agitates me. I think the only way to make it better is for the 1 housemate to move out.
7) One usually taunts him with a Chuckie Mask. My son has Tourettes and they yell at him and make it worse. He has even felt he will come in his room and endanger him.
8) A roommate is just sharing a room of the unit and each of us has an independent life.
9) Incompatibility of interests, age gap, difference in outings preferences and lack of understanding in the disability of each other.
10) If her boyfriend was her roommate.
11) You may have a choice of roommate, but there is not a choice on who lives with you in a group home.
12) We ensured that they would be good matches by trials of living together and interviews.

13) Profound autism and intellectual disability plus aggression make living situations very challenging but group homes have 5-6 people and private room very hard to find as well as adequate staffing and understanding of the disability

14) As her mother/guardian I'm not sure how she feels about her roommates. She has been in this group home for a short time.

15) Lack of interaction. There is no difficulty with the roommate he just does not have comfortable conversation.

16) There are 6 men with totally different disabilities, 3 have 10% ability for common interests; Come visit and see for yourself.

17) wants to live on her own with no room mates

18) They both respect each others space a individual need for private time

19) Current roommate just moved out so she is in a room by herself at the moment. I answered the question using the previous roommate

20) She lives in a group home setting. Has a good relationship with all of her room mates.

21) I love my roommate she is very nice and she helps me

22) Female lives her male friend per their choice

23) She has housemates, no roommate.

24) He is not social and does not interact with housemates

25) Sometimes there personalities crash.

26) Everything is good

27) his roomate is blind, nonverbal and nonambulatory. they share a room but zero interaction. two other housemates are female, one is mostly bedridden and the other stays in her room. There is a 4th male housemate who is high functioning but they go to different day programs and may only see each other at meals. they do not do any other activities together.

28) He sexually acts out so has his own room

29) The roommates help my child feel "normal", accepted and loved, unlike living in the general community where she feels rejected, misunderstood and invisible.

30) One in one. With care giver.

31) We are good friends.

32) Roommate is a support companion.

33) Roommate is non verbal, self destructive, unable to interact.

34) She is unable to speak so they don’t converse. The other girls are similar age and nice to each other. It’s a good environment and they are well cared for and loved.

35) Around the same age & abilities.

36) Sometimes the roommate talks too much, bothering the IDD adult. Is usually best to have their own room/no roommate whenever possible.

37) He is autistic and does not socialize one on one. Parallel socialization, at best. He is not bonded to anyone in the home except the staff (maybe!).

38) 2 roommates and three living in the apartment are quiet different in their likes and dislikes. Godd caregivers with family support keeps all moving forward positively. Better would be individual apartments but the same level of support and activities.

Q25. Feel free to explain why the IDD adult is, or is not, satisfied with their current caregiver. What makes it good? What could make it better?

1) She is non verbal, therefore answers are based on behaviors that I observe when I visit at the group home. She has a companion during the day during the week that she goes out with. The caregivers in the home interact and provide 24 hr care and assistance with all ADL's.

2) There are several caregivers at the group home. She is closer to some than others.

3) This is a group home with 4 different caregivers. I sometimes have a problem with 1 of the caregivers

4) Lack of teaching life skills, doing the minimum possible, lack of taking out to outside activities to integrate in the community, lack of cleaningness. Good: no abuse nor neglect nor stealing.

5) It is imperative to ensure that the caregiver is trained by family and willing to listen, learn, and follow through. Our caregiver has been with my son since 2013 and it has been terrific. A caring heart and giving person is needed to provide live in status.

6) Needs to have a car

7) Staff/ caregivers in group home don’t speak English and struggle to keep house safe and do not check on residents with any regularity most left on their own

8) The caregiver is very thoughtful and aware of all the difficulties he faces. She’s patient with him. He can be stubborn and demanding. He wants to make some of his meals. They do not sit down together for meals.(the 3 of them)

9) There are a group of caregivers, OJT (except for house manager); the food is mediocre; these are largely mentally disabled roommates. My son can clean and cook but the staff has to control this and the turnover is high. low pay, tough environment. each client has very unique requirements.

10) Group home has round-the-clock staff, who are kind and attentive and we are so thankful for.

11) The house manager is wonderful not there all the time.

12) I enjoy having a caregiver that helps me in my apartment she keeps me safe. She teach me how to call emergency numbers.

13) Caregivers take care of him, meals, health needs etc.

14) My caregiver allows me to be apart of my community living a meaningful life with supervision. I have my own bedroom make my own decision and go out to have fun with my caregiver. I live in my own house with assistance and I have privacy.

15) caregivers are group home provider and staff. They are all outstanding and do support my son above and beyond others he has had. It would be nice if DSPs could interact with my son beyond hygiene needs and meal prep (i.e. read to him, watch a show together, play a game or cards, etc.) Beyond the day program and our weekend visits he stays to himself in his room watching tv or playing video games. He doesn't complain about this but it limits his social communication to 40 hrs a week at day program.

16) My child recently had a bad experience with a caregiver in a group home and was transferred to another home and it is working out well now. She did not feel "heard" in the previous home and the caregiver was in my opinion lazy, lacked common sense, empathy and poor judgement in training other staff, but was a person who was reliable showing up for work.

17) Takes very good care of me

18) My care giver cares about me.

19) Adult person is not stabilized on medication so could not ask this person these questions.

20) They love the girls as family and take great care of them

21) For the most part there are good staff working in the group homes. Sometimes personalities clash or the staff aren't well fit for this type of work.

22) Again, no bond with caregiver but 100% relies on their care. Does not care for self.

Q29. Feel free to explain why the IDD adult is, or is not, satisfied with their relationship with their Supported Living Coach. What makes it good? What could make it better?

1) Not sure what an SLC is . I answered questions as if survey was referring to Waiver Support Coordinator. WSC

2) Lack of accessibility, requires too many follow ups and reminders, late for medical appointments, don't learn about my medical treatments nor conditions. Way better initiative and getting to know me and all my medical aspects.

3) I believe my son is fond of the SLC. He can complain a lot but He trusts her.
4) Money issues
5) Wish he was able to come more often and a set schedule
6) Extremely understanding and supportive of Bradley
7) I enjoy working with my coach she respect me and educate me about my feel and emotional we have a good relationship.
8) SLC had limited hours , but always willimg to help me.
9) She teach me a lot of things to have my home. She is happy and I like to learn from her.
10) Person does not like SLC as reported to me.
11) SLC is very new and we have not developed a relationship yet, she is also trying to help me find a job but I'm not sure she understands what I'm able to do.
12) My support living Coach is wonderful without Melissa. I would not know what I would do without her support respect and understanding any questions or concerns. I have about my life. She explains everything to me and makes me feel wonderful that things will be OK for my future. Thank you, Melissa Thank you thank you thank you you
13) SLC is dedicated and reliable.

Q30. What does the IDD adult typically do when they are with their Supported Living Coach?

1) Hair cuts and medical appointments. SLC don't take me to groceries nor other outings.
2) Walks
3) Grocery/clothing shopping, meal planning, cooking, banking, out for lunch, meds
4) shop, bank, medical appt.
5) Cooking help, shopping, trips out in our community
6) Medical appointments, make grocery list, go shopping, budget my money
7) Makes sure he has all of his chores done for the day, checks to be sure he has good hygiene, dressed appropriately for the weather, takes him out on both necessary and social outings.
8) call my bus for work help to apply for food stamp help to get a job and maintain job take me to the doctor and help me with paying all my bills go shopping, pick up medications.
9) Assisted with budget for expenses and keeps on track not to over spend money

10) Medical appointments, grocery shopping, pays monthly bills. Leisure activities like bowling, shopping, to the movies, out to eat, picnic, plays basketball and walks in the park.
11) My coach comes over help me pay my bills, she helps me to read, take me to the store to shop, we go to the doctor teach me about my medication, teach me how to call 911, fire drill, have my cellphone charge.
12) takes me to post office, assist with mail, banking, medical appointments, keeping my home in good shape
13) Go to stores like Walmart or McDonald's etc.
14) They food shop, read books, look for a job on the computer,
15) Shop for groceries and transport to doctors' appointments.
16) She asked me questions about things that are bothering me and how she can make them better. Most of the time in John aren't bothering me since she came into my life.
17) Takes care of buying personal toiletries etc. Organizes lunches out with other clients.
18) Shop, prep meals, cook , laundry
    Gardening, physical fitness , read etc
19) shop, eat out

Q35. Feel free to explain why the IDD adult is, or is not, satisfied with their current ADT program. What makes it good? What could make it better?

1) Very dedicated and caring staff. Feels like extended family. Trusts them . Likes the staff across campus by that I mean administration, teachers, caregivers, med staff, transporters even if they are not specifically her own, but serving others. Remarkably small turnover
2) This ADT Program is run by owner of Group Home she lives in so there is consistency.
3) The Rise program in Vero is amazing. Very satisfied with the care my daughter receives there.
4) Loves the people running the program and all the friends I've made there
5) They attend a private pay ADT
6) I like my ADT very much. I will love to have more outings to the community and to learn more life skills while participating in it.
7) The choices above reflect Rachel's reaction to most things. Her response is typically lukewarm.
8) Better programming

9) I want to work, not go to a day program. No one helps me with this.

10) The staff is attentive and always looking out for the clients.

11) She has been in the program a short time. On our visits with her she has said she like the program. I know it makes her life better because she likes being out at something during the day.

12) This is a godsend. Also, my son worked at Publix 5 years! had to quit due to behavior issues and publix management changes unable to adapt to a disabled person at his specific location. These adults are extremely vulnerable to verbal and psychological abuse, repeatedly. Safety is the main concern.

13) Jessica enjoys being with her peers.

14) At times, my adult daughter is afraid of loud situations that from time to time occur at the ADP. She may choose to stay home the day after something upsets her. Then she is ready to return w a smile. She does avoid the louder clients. Her ADP appreciates her fears and works in common sense ways to deal with the fear.
She sometimes 'chooses' not to learn.
She looks forward to her day program w great excitement.

15) If it was not for her iBudget waiver which funds her group home care and her ADP she would have no life. The iBudget waiver is a blessing from god.

16) to do more vocational skills, actual skills, hands on skills, not just talking about skills. But putting them into "practical use"

17) I get to do Karaoke on Fridays with my friends. We go out on volunteer at several companies. we also goes to the library

18) Cannot say enough GOOD about the RISE program in Jensen Beach. Very well organized, professional, caring and kind. They assist him with PT every day, work with him on social skills and encourage him to take responsibility for his choices and actions. WE and HE love them!

19) My son's IQ is hood a toddler, and he has many medical and physical issues .

20) Outings should be more meaningful - example, if going to Publix to shop for anything it shouldn't just be for the sake of going &biying 2 or 3 items because that's all the time you have…it should be to shop for items on a recipe and make recipe upon returning to adt. It can be as simple as buying 5-6 items for a salad …. Saliant!

21) Some activities are not stimulating enough for my child.

22) There very caring

23) This program is wonderful and not only are the staff great but they offer so many different opportunities for the adults.

24) I have friends and I like attending my ADT

25) Help me get a job. Job skills.

26) It is My Son staple it is his constant. He knows all the people care for him deeply there and look for his best interest and he feels safe and secure.

27) Too much staff turnover. There's always new faces. At the Gh's as well.

28) Just started at this program in the last six months. The program needs to do a better job at identifying and coordinating goals for future jobs and independent living. We are scheduling a meeting

29) The ADT does not meet the needs of autistics. Basically, warehousing.