
NEW JERSEY COMPREHENSIVE ASSESSMENT TOOL (NJCAT) SURVEY RESULTS

JULY 3, 2021

DEVELOPMENTAL DISABILITIES ADVOCACY NETWORK (DDAN)
Person-Centered/Self-Directed Services Committee

Executive Summary

Survey

The survey was designed for individuals with intellectual or developmental disabilities (I/DD) and their families. The purpose of this survey was to collect feedback on the New Jersey Comprehensive Assessment Tool (NJCAT). The survey was open for a month and a half, from October 12, 2020 to November 30, 2020, and it collected 1,046 responses. The results can be found in the later sections.

Recommendations

1. Provide support and create educational materials for individuals and families
 - a. The Division should review existing materials and identify the gaps. The target areas include but are not limited to:
 - How to provide comprehensive and accurate information on the unique needs of individuals with I/DD
 - Reassessment process
 - Rights of Appeal
 - b. The Division should make educational resources in various formats including webinar and factsheet
 - c. The Division should create a page where individuals, families, and professionals can easily find resources
2. Increase flexibility and choices
 - a. Individuals and families should have the choice of having a Division facilitator present
 - b. Individuals and families should be able to choose the most comfortable and efficient method for NJCAT including online, in-person, phone, or mail.
3. Revise and enhance the NJCAT to capture needs that are reported not accurately assessed
 - a. Expand or revise questions to address behavioral and self-care needs (see Figure 12)
 - How many staff are needed to support the individual during a crisis (e.g. aggressive behavioral episodes)?
 - b. Expand the timeframe from the last 6 months to 12 months
 - Significant and critical care needs should be reflected in the assessment as historical information, even it is beyond 12 months old.
 - c. Collect not only quantitative data but also qualitative data such as narrative and example of individuals' complex and unique needs
4. Promote family involvement and team approach
 - a. Parents, guardians, or other important parties who know individuals well must be invited to the assessment regardless of where they reside (e.g. group home)
5. Reconvene the Self-Directed Policy Committee under DDD in September 2021
 - a. Create a Division-wide initiative to promote and embrace Person-Centered Thinking and Planning within both Self-Directed Services and Provider Managed Residential Services
 - b. Revise the Division's webpage in regards to the Self-Directed Service to highlight its philosophy and increased flexibility
 - c. Offer and promote peer support and/or mentoring so that "best practice" can be shared
 - d. Establish a more robust education and training system for individuals and families

Acknowledgment

The Developmental Disability Advocacy Network (DDAN) Person-Centered/Self-Directed Services Committee thanks the individuals with intellectual/developmental disabilities and their families who participated in the survey to share their invaluable feedback and comments.

Special thanks to Kerry McGrath for analyzing the data and writing this report.

DDAN Person-Centered/Self-Directed Services Committee Members (alphabetical order)

- Mary Claire Gomeringer, Parent
- Liza Gundell, The Family Resource Network
- Joyce Jelly, The Boggs Center on Developmental Disabilities, Rutgers Robert Wood Johnson Medical School
- Mary Kneuer, Parent
- Ann Martinelli, Parent
- Melanie McGackin, Parent
- Peter Philipps, Parent
- Natalie Trump, Parent
- Lisa Weissbach, Parent

New Jersey Council on Developmental Disabilities (Support Staff, alphabetical order)

- Kyoko Coco, Family Support Coordinator
- Kerry McGrath, Former Social Work Intern, Seton Hall University (Current Rutgers University Student in the Master of Social Work Program)

Developmental Disability Advocacy Network

The [New Jersey Developmental Disability Advocacy Network \(DDAN\)](#) consists of self-advocates, family members, support providers, and disability stakeholders. There are 8 key issue committees including Person-Centered/ Self-Directed Services (PC/SD Services). The PC/SD Services committee conducted a survey to individuals with intellectual or developmental disabilities and their family members that have experience with the New Jersey Comprehensive Assessment Tool (NJCAT). The NJCAT is a standardized assessment tool used by the Division of Developmental Disabilities (DDD), the Department of Human Services “to determine eligibility for services and identify an individual's level of need for support in three main areas: self-care, behavioral health, and medical.”¹

The PC/SD Services Committee has received various comments and feedback from individuals and families on NJCAT including but are not limited to the following.

- Effectiveness and limitation on accurately assess individual's needs
- Validity and reliability of NJCAT
- New DDD facilitator's role
- Preferred method(s) for completing NJCAT

The committee conducted an online survey in order to collect feedback and recommendations on the above-listed areas from individuals and families.

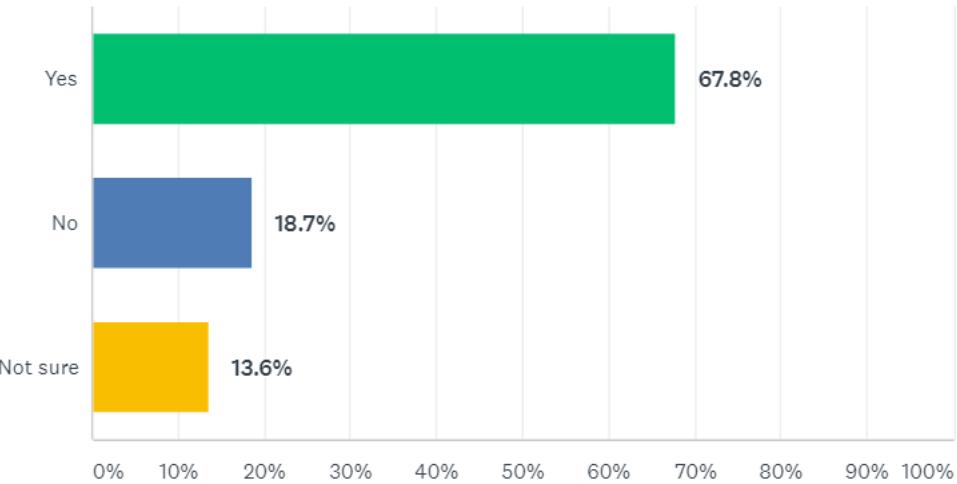
The survey was open for a month and a half, from October 12, 2020 to November 30, 2020, and it collected 1,046 responses. The survey was programmed to skip, show or hide certain questions depending on answers. For instance, if respondents answered that DDD facilitator was not present for NJCAT assessment, questions regarding their participation were skipped. For this reason, some questions below will have smaller response numbers than others.

The results from the survey can be viewed at <https://www.surveymonkey.com/results/SM-6D7SV8XP7/>.

¹ <https://nj.gov/humanservices/ddd/resources/njcat.html>, Accessed 12/31/2020

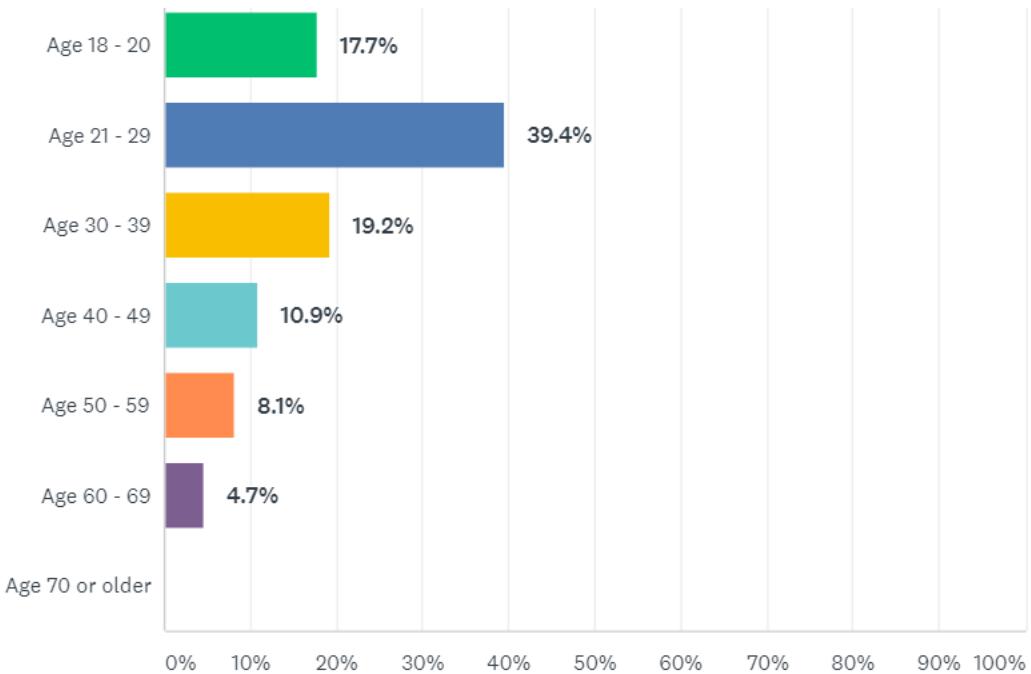
Survey results

Figure 1: Have you or your loved one with developmental disabilities completed the New Jersey Comprehensive Assessment Tool (NJCAT)?



Out of 1,039 responses, 704 responses (67.8%) were “Yes”, 194 responses (18.7%) were “No” and 141 responses (13.6%) were “Not Sure”.

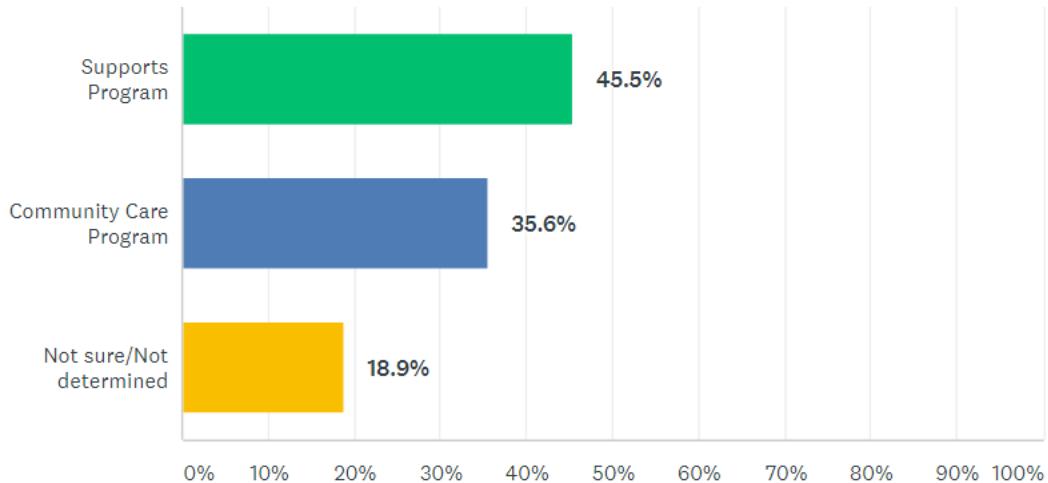
Figure 2: How old was the individual with Intellectual/ Developmental (I/DD) when he/she most recently completed the NJCAT?



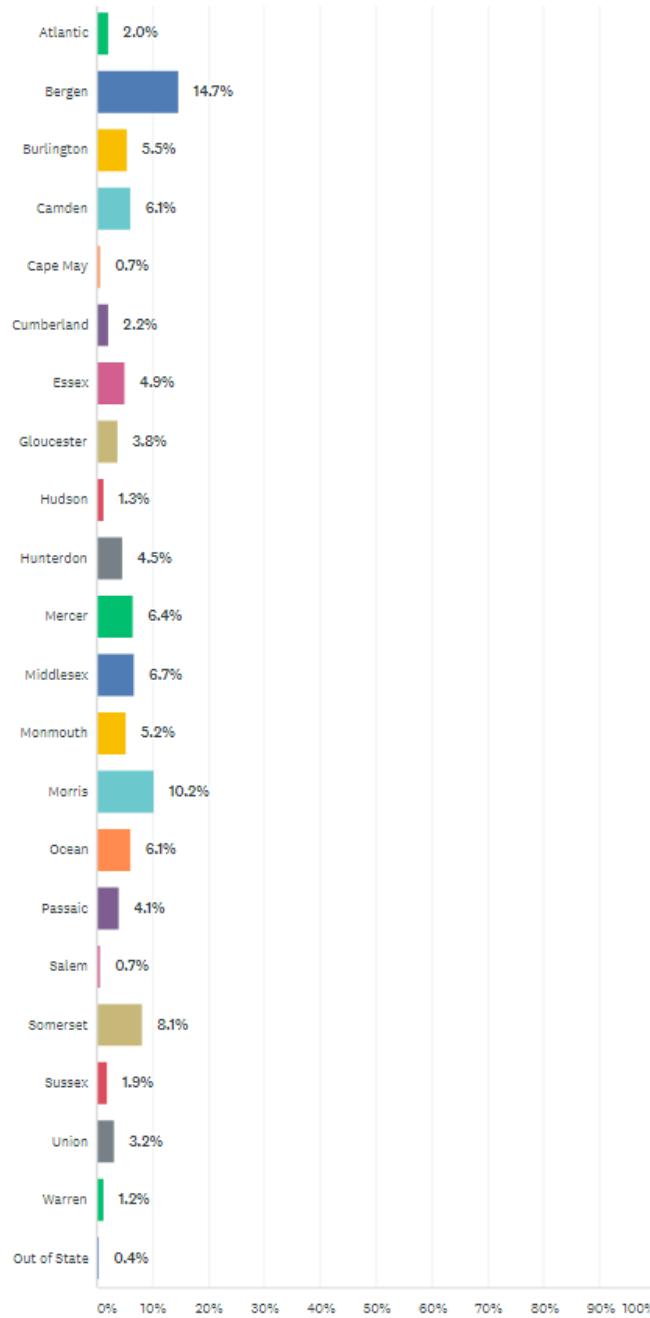
Out of 682 responses, the most common age range of individual with I/DD was 21-29, which received 269 responses (39.4%). This was followed by 30-39 (131, 19.2%); 18-20 (121, 17.7%); 40-49 (74, 10.9%);

and 59-59 (55, 8.1%). The final age ranges included 60-69 (32, 4.7%). There was no respondent reported age 70 or older.

Figure 3: Which DDD program is he/she enrolled (if currently receiving services)?

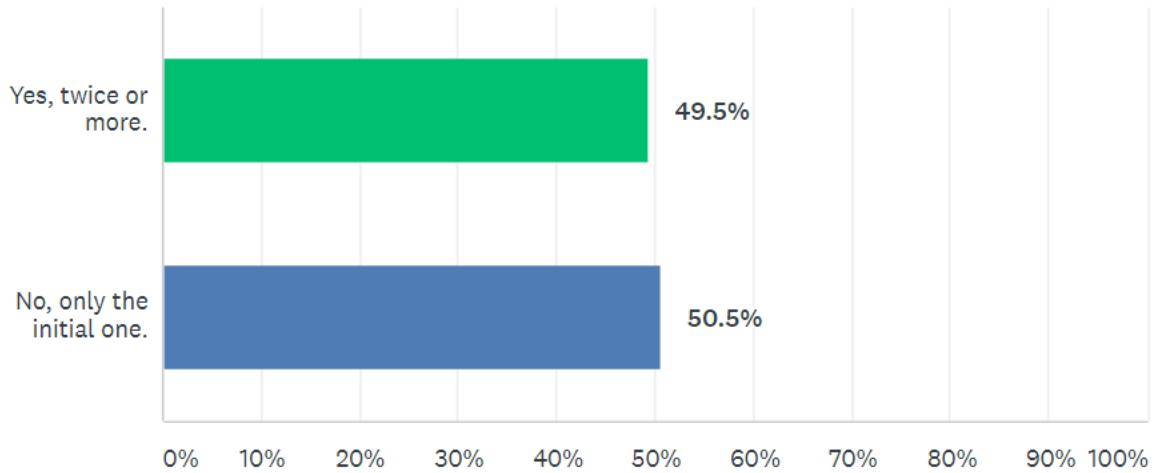


Out of 682 responses, 310 (45.5%) individuals receiving services through DDD are in the Supports Program and 243 (35.6%) are in the Community Care Program. The other 129 (18.9%) of the responses were for those who were not sure what program the individual with I/DD is in or they have not been enrolled in a program.

Figure 4: Which county does the individual with I/DD reside?

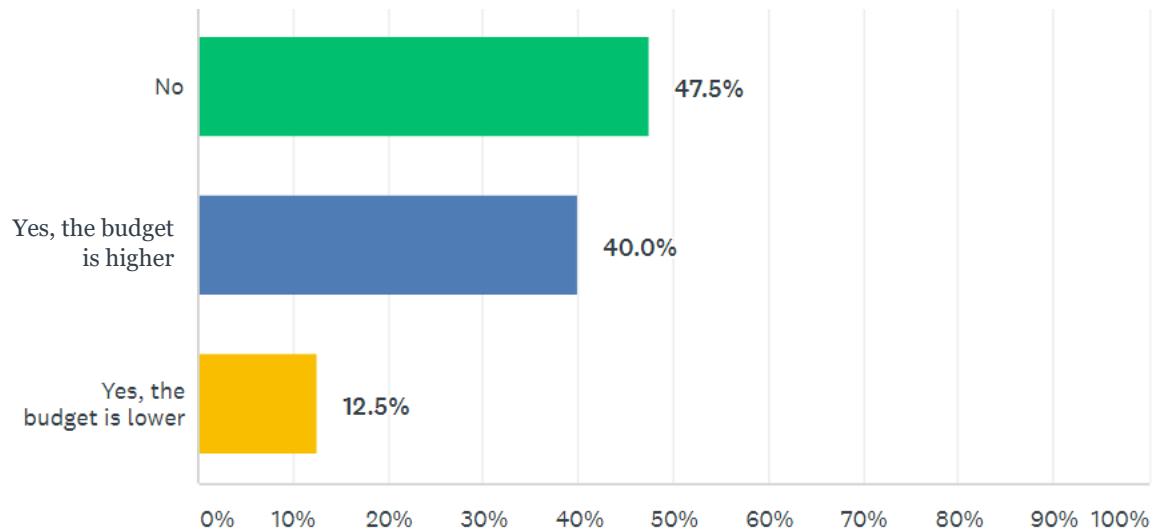
There were 688 responses for this question, 171 responses (24.9%) came from Bergen and Morris counties. Four of the six lowest counties to respond to the survey were from Salem, Cumberland, Cape May, and Atlantic counties, which together totaled 39 responses (5.6%). The other sixteen counties each represented four to six percent of the total respondents.

Figure 5: Has the individual with I/DD taken the NJCAT reassessment (not initial one)?

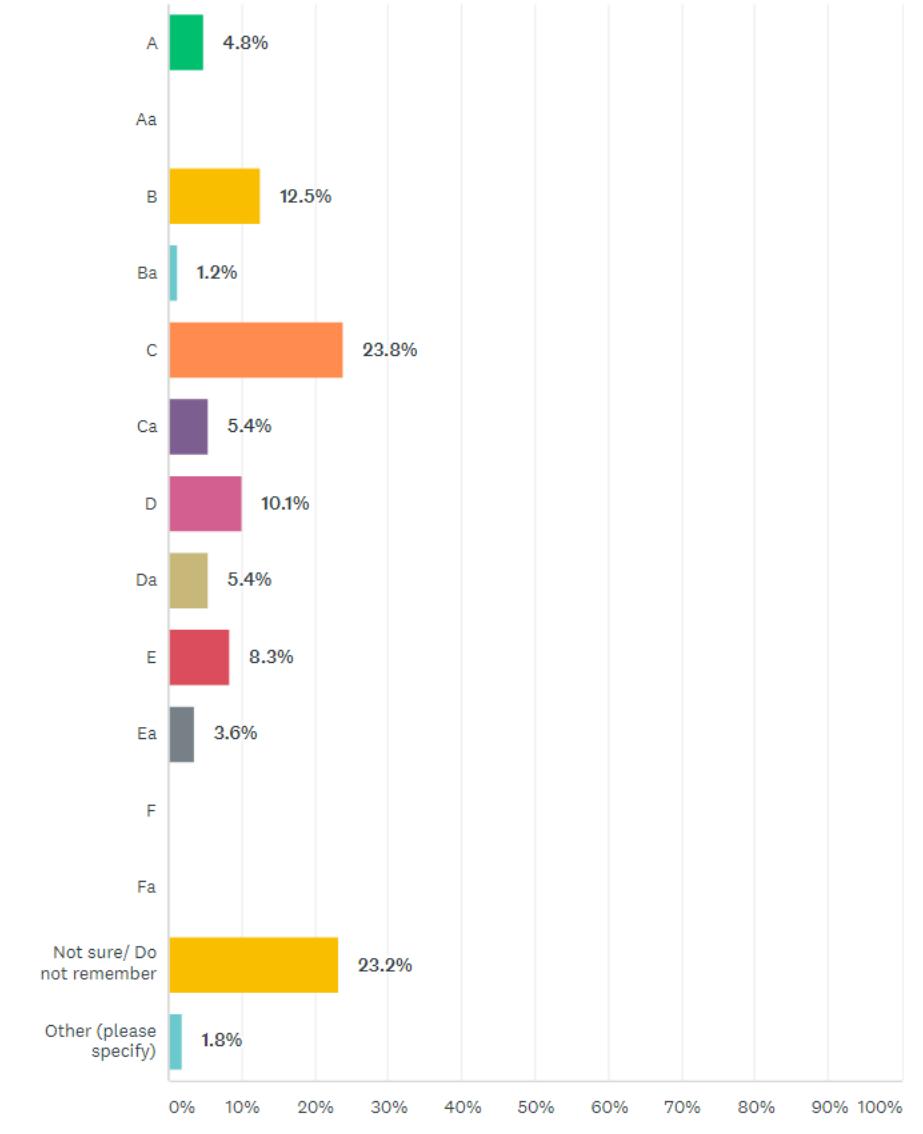


Out of 657 respondents, 325 (49.5%) had multiple assessments, while 332 (50.5%) reported completing NJCAT only once.

Figure 6: Has his/her tier (budget) changed after the last reassessment?

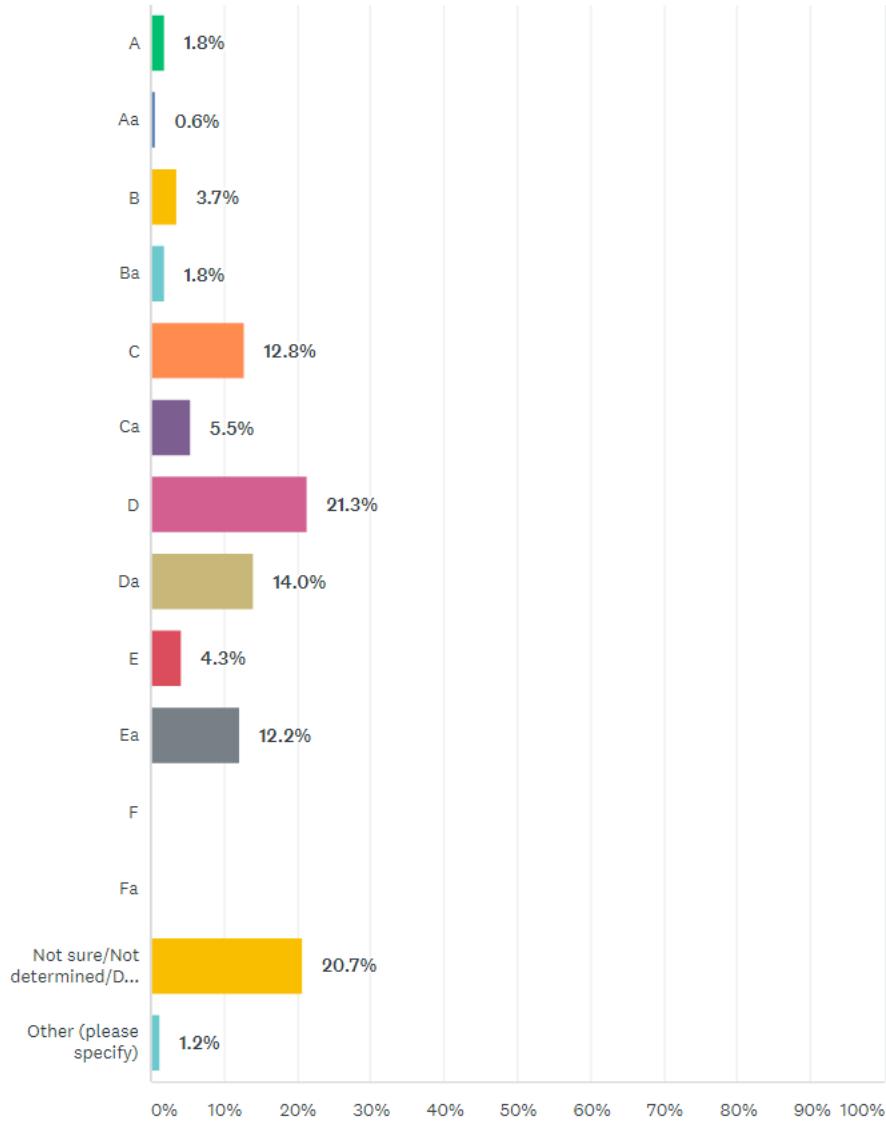


Out of 320 respondents who have taken multiple NJCAT, 152 (47.5%) reported that their tier did not change after the last assessment. One hundred twenty-eight (128, 40.0%) reported their tier became higher, while 40 (12.5%) shared that their tier became lower as a result of reassessment.

Figure 7: What was your previous tier?

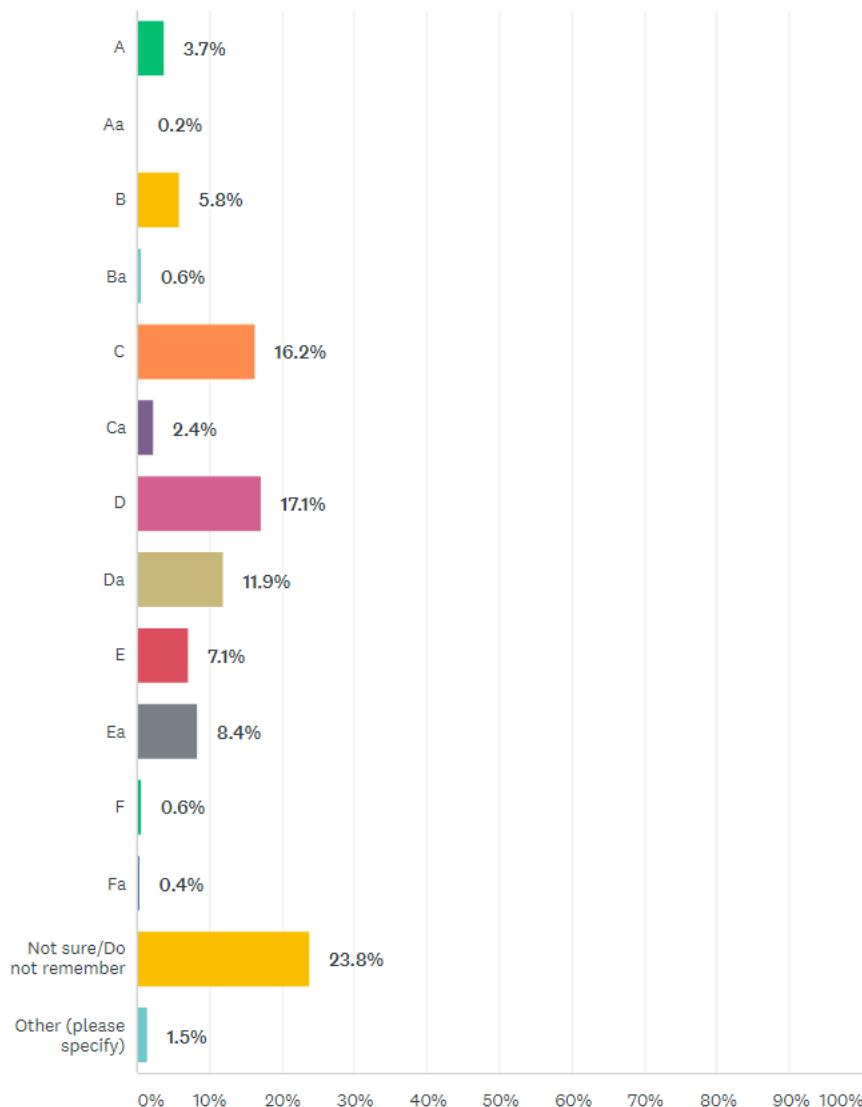
Among 168 respondents whose tier changed as a result of reassessment, the most common tier prior to reassessment was C (40, 23.8%), followed by B (21, 12.5%), and D (17, 10.1%). Another popular response was “Not sure/ Do not remember” with reported 39 (23.2%) responses. There were 3 responses under “Other” and they are as follows:

- *done before tier assigned - still in interim at the time*
- *10 or more years ago, when still in school and at home*
- *2018 reassessment resulted in Da; 6-2020 reassessment dropped to D*

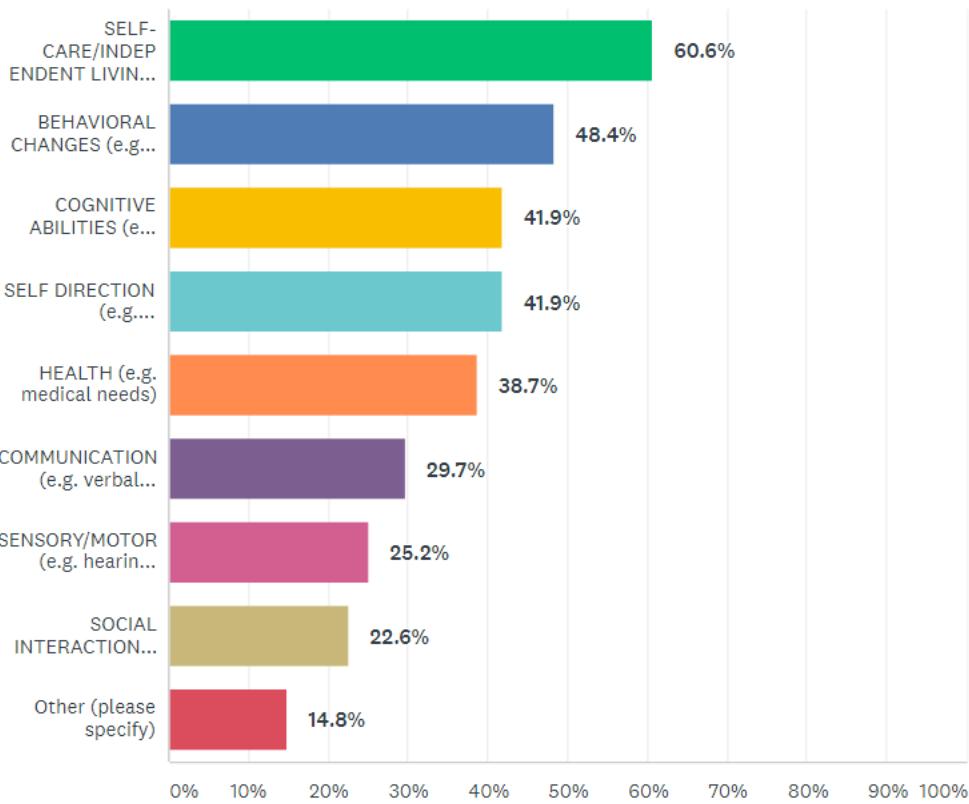
Figure 8: What is your tier after assessment?

Asked what their tier was after assessment, 35 respondents (21.3%) out of 164 respondents reported that tier D followed by Da (23 respondents, 14.0%), C (21 respondents, 12.8%), and Ea (20 respondents, 12.2%). Another popular response was “Not sure/Not determined/ Do not remember” (34 respondents, 20.7%).

Figure 9: What is your tier?



Among 462 respondents who have had only initial assessment, the top four tiers were D (79, 17.1%), C (75, 16.2%), Da (55, 11.9%), and Ea (39, 8.4%). The most common response was “Not Sure/ Do not remember,” which consisted of 110 responses (23.8%). There are 7 respondents (1.5%) who marked “other.” Most of them reported that their tier is not yet determined and one respondent shared that he/she was denied for services.

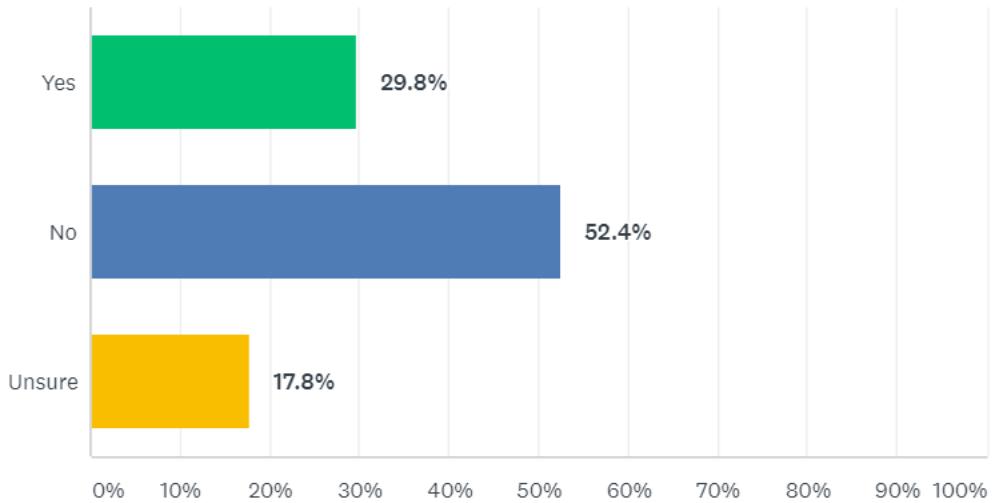
Figure 10: Areas that you believe affected the change in tier assignment (check all that apply)

One hundred sixty-eight (168) respondents who reported the change of tier after reassessment were asked which areas of needs they believed affected such change. The most common area was “Self-care/Independent Living Skills (e.g. feeding, bathing, hygiene, cooking, cleaning, navigation)” (94, 60.6%). The next three important areas of focus are “Behavioral Changes (e.g. elopement, behavioral needs, aggression towards self/others)” (75, 48.4%), “Cognitive Abilities (e.g. memory, concept of time and events, numbers, reading/writing, multi-step directions, etc.)” (65, 41.9%), and “Self-Direction (e.g. decision-making skills, judgment, identification of their needs and wants)” (65, 41.9%). The most commonly reported answer seen under “Other” (23 respondents) was the presence of a new diagnosis (7, 30.4%), followed by those who were unsure why the change occurred (5, 21.7%), and a better assessment because the questions were answered to better reflect the individual with I/DD (4, 17.4%). (See Table 1).

Table 1: Other Responses

Characterization	Number
New Diagnosis	7
Unsure/No Change	5
Better Assessment	4
Health Improvement	2
Nonspecific Questions	3
Other	2
Total Responses	23

Figure 11: Do you think the NJCAT accurately assesses your/your loved one's unique needs?



Among 534 respondents, 159 (29.8%) of them agree that NJCAT accurately assesses their/their loved one's unique needs, while 280 (52.4%) and 159 (29.8%) of them either disagree or are not sure of its accuracy, respectively.

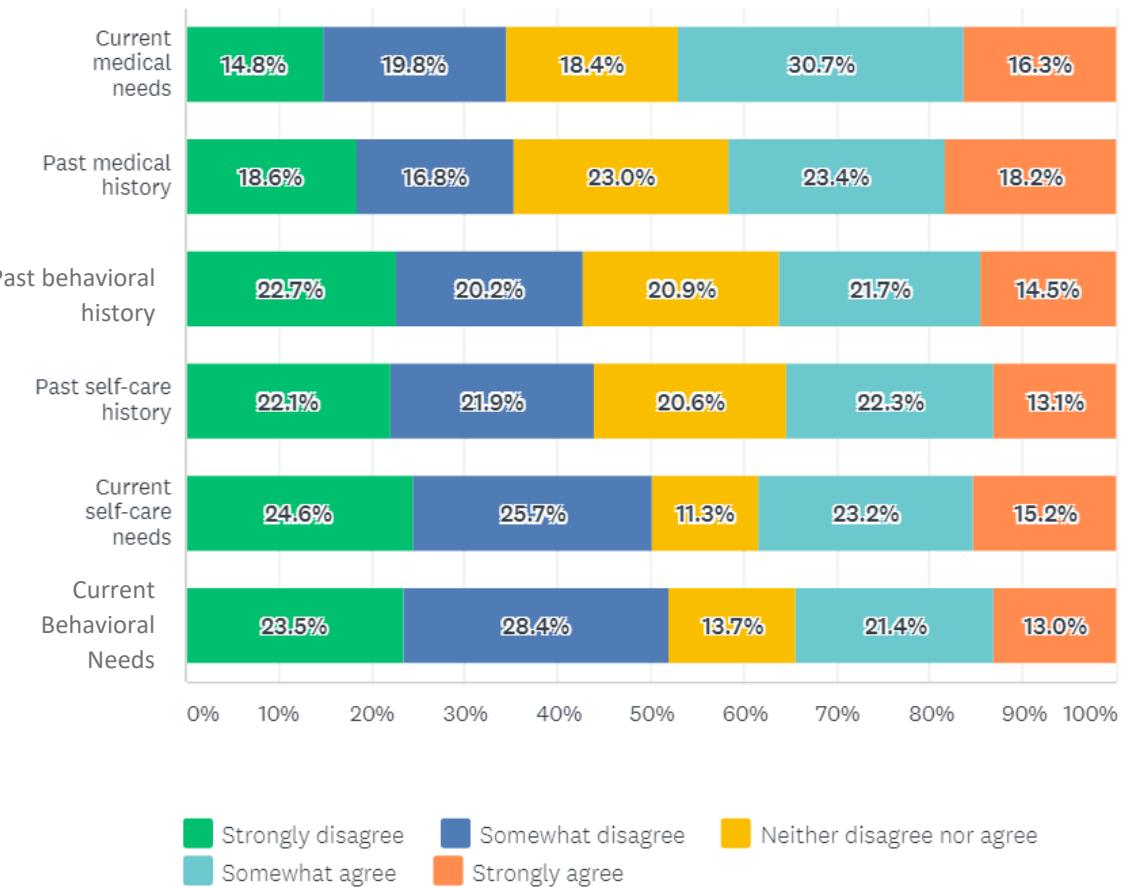
Figure 12: NJCAT accurately captures my/my loved one's following needs

Figure 12 shows the order of level of agreement on how NJCAT accurately captures the following six areas: past medical needs, current medical needs, past behavioral needs, current behavioral needs, past self-care needs and current self-care needs. The top means most positive feedback followed by less positive. This question was answered by 526 respondents.

Over 40% of respondents either strongly or somewhat agreed that NJCAT captured their/their loved one's **current and historical medical needs** (47.0% and 41.6%, respectively), while 18 – 23% of them "neither disagree nor agree" and around 35% of them disagreed (34.6% and 35.4%, respectively).

One hundred eighty-seven (187, 36.2%) respondents agreed that **past behavioral history** was accurately assessed, while 221 (42.9%) respondents disagreed and 108 (20.9%) respondents neither agreed nor disagreed.

Additionally, 229 (42.0%) disagreed that **past self-care history** was accurately assessed through the NJCAT, while 184 (35.4%) agreed.

Over half of respondents felt that their **current self-care needs and current behavioral needs** were not accurately captured (262 respondents, 50.3% and 272 respondents, 51.9%, respectively), while 200 (38.4%) and 180 (34.4%) respondents provided positive feedback, respectively.

New Jersey Comprehensive Assessment Tool (NJCAT) survey

The survey provided an opportunity for respondents to use their own words to describe what kind of needs and information are not properly addressed in the NJCAT, if any, in the following 4 areas: medical, behavioral, self-care and “other.” Among 356 respondents, 237 comments for behavioral, 220 comments for self-care, 181 comments for medical, and 77 comments for “other” were collected.

Figure 13: What kind of needs and information are not properly addressed in the NJCAT, if any? (Behavior)

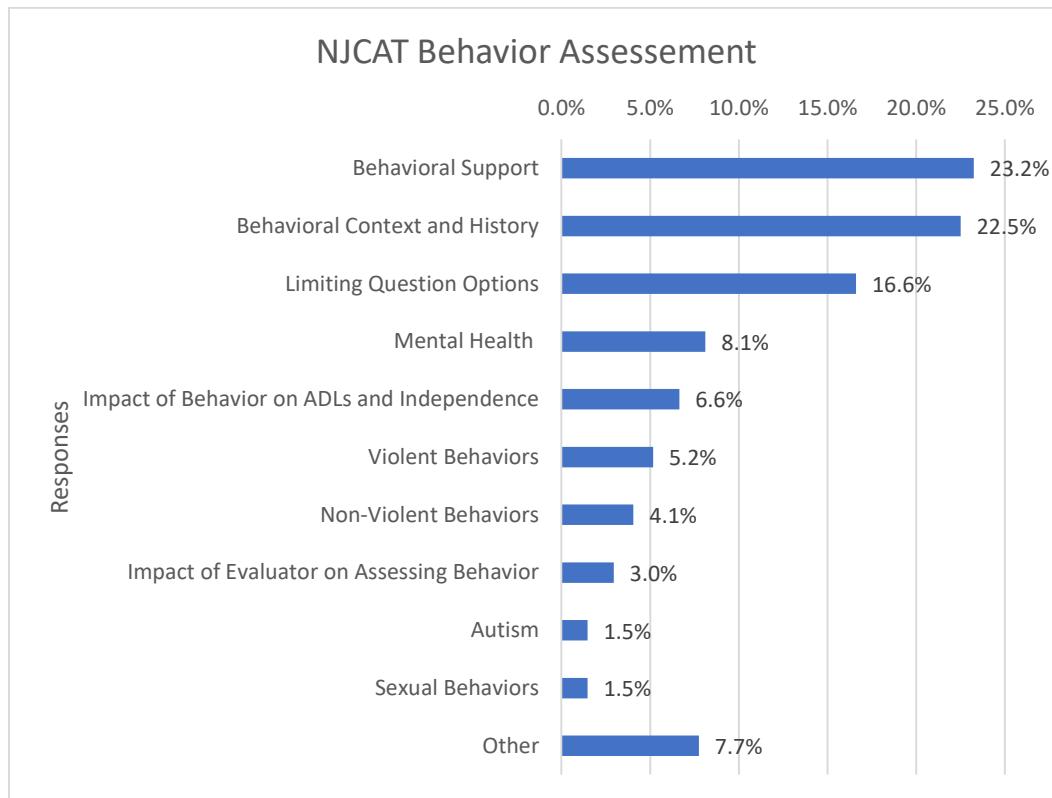


Table 2: What kinds of needs and information are not properly addressed in the NJCAT, if any? (Behavior)

Responses	Total	%
Behavioral Support	63	23.0%
Behavioral Context and History	61	22.3%
Limiting Question Options	45	16.4%
Mental Health	22	8.0%
Impact of Behavior on ADLs and Independence	18	6.6%
Violent Behaviors	14	5.1%
Non-Violent Behaviors	11	4.0%
Impact of Evaluator on Assessing Behavior	8	2.9%
Autism	4	1.5%
Sexual Behaviors	4	1.5%
Other	21	7.7%
Total Responses	271	

Among medical, behavioral, self-care and “other,” behavioral area received the most comments (237 responses). As some respondents provided multiple themes in his/her comments, the number of total responses in table 2 exceeds the number of respondents.

The most common theme mentioned was “Behavioral Supports” (63, 23.0%), which includes the need for trained staff, therapies, and need for constant supervision to prevent behaviors. This is followed by “Behavioral Context and History” (61, 22.3%), which addresses the NJCAT’s inability to capture an individual’s behavior history or the circumstances surrounding the behavior. The next common response was “Limiting Question Options” (45, 16.4%) and this relates to the questions being too black and white and that lack of a place to elaborate or explain. The responses categorized under “Mental Health” (22, 8.0%) related the effects that mental health issues have on behavior. Similarly, the responses categorized under “Autism” (4, 1.5%) addressed the effect that Autism has on an individual’s behaviors. The “Other” category (23, 8.4%) consists of comments including the behavior assessment does not pertain to all individuals with I/DD; the lack of appropriate programs to address behavior; and the effects of hormones.

Below are a few responses including the common themes:

- *Missing opportunities to define severity and frequency of behaviors like tantrums, outbursts, self-isolation and property destruction. Missing key questions related to behaviors presented by individuals with Autism Spectrum Disorder--frequency of perseverative and ritualistic behaviors that interfere with skill development and ADLs. (Behavior Context and History, Limiting Question Options, Autism, Impact of Behavior on ADLs)*
- *My loved one has anxiety and depression. He only requires reminders for eating and bathing; however, when alone he just paces the apartment and talks to himself. He is alone every night and all day Tuesday and Thursday. His budget can only afford 11 hours of supports. He should not be alone. He was denied PCA/PPP services. (Behavior Supports, Mental Health)*
- *The behavioral related questions focus only on the actual negative behaviors the person has experienced within the very recent past (30 days/90/120). If the individual has achieved SUCCESS at managing mental health or other behavioral challenges WITH SUPPORT the NJCAT does not take the person’s history into account at all. This promotes a system in which inadequacy in assessment prompts lower tier rating which means a lower level of support available which means supports in place to help the person succeed will need to be withdrawn which means the person will be at risk of decompensation (i.e. crisis). And only when the person experiences the crisis may he be eligible to be assessed at a higher Tier level and then re-gain the supports he needed to begin with... The assessment does not adequately capture the level of support a person needs to remain well or to remain integrated in their community. (Behavior Supports, Limiting Question Options, Mental Health)*
- *The time frame is too short. Some individuals do well for months and then have a few bad months. (Limiting Question Options)*

Figure 14: What kind of needs and information are not properly addressed in the NJCAT, if any? (Medical)

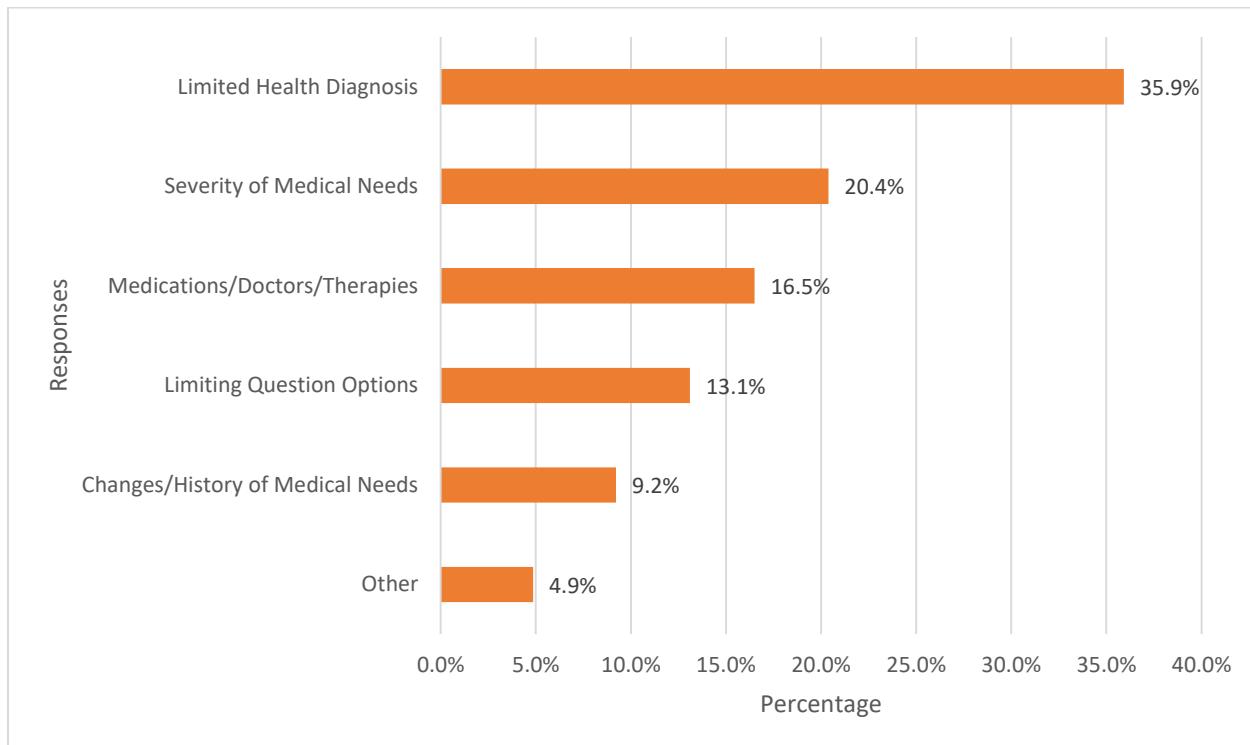


Table 3: What kind of needs and information are not properly addressed in the NJCAT, if any? (Medical)

Responses	Total	%
Limited Health Diagnosis	74	35.9%
Severity of Medical Needs	42	20.4%
Medications/Doctors/Therapies	34	16.5%
Limiting Question Options	27	13.1%
Changes/History of Medical Needs	19	9.2%
Other	10	4.9%
Total	206	

There were 181 responses about the needs and information not properly addressed in the NJCAT regarding medical. The most common response was “Limited Health Diagnosis” (74, 35.9%), which express concerns that certain diagnoses were not being considered. Some of the health issues that were mentioned were cancers, cardiac issues, food allergies, dementia, and mental health. This was followed by “Severity of Medical Needs” (42, 20.4%), which addresses the complexity of care needed to maintain medical needs, such as trained staff, specialists, or the 24-hour monitoring and care needed to manage the health issues. The next theme commonly mentioned, “Medication/Doctors/Therapies” (34,16.5%), pertained to the individual with I/DD finding doctors, making appointments, safely administering medications, and the frequency of therapies. “Limiting Question Options” (27, 13.1%) addressed the

respondent's interest in having a place to explain or elaborate on medical needs and supports. The "Other" category (10, 4.9%) consists of comments relating to lack of self-control, costs of medical supports, and the lack of consistency in medical diagnoses that the NJCAT focuses on.

Below are some responses that consist of the common themes:

- *My son has severe CP, gtube, trach, vent and oxygen dependent. He is dependent for all care and has unexpected medical needs of seizures, respiratory distress, infections. All this is not well addressed by the NJCAT as it currently exists.* (Limited Medical Diagnoses, Severity of Medical Needs)
- *It is the nature of the questions--all very limited and designed for limited answers. A seizure is something that can happen at any time. And there is NO MEDICAL basis that if there was no seizure last month, they will not have one this month. Yet, frequency was the concern. 1 Seizure can disrupt life for an entire month(s) all recovery varies.* (Limited Health Diagnoses, Limiting Question Option, Changes/History of Medical Needs)
- *Can not take care of own basic medical needs. No place on survey to accurately describe all medical conditions and their affect or potential affect (sic) on individual if care is not properly monitored. An example would be failure to take daily medication. One day without medication can put individual's health and safety in jeopardy.* (Severity of Medical Needs, Medications/Doctors/Therapies, Limiting Question Options)
- *Wording of questions don't allow for full picture of individual's needs. Wording is also unclear and confusing and even misleading at times.* (Limiting Question Options)

Figure 15: What kind of needs and information are not properly addressed in the NJCAT, if any? (Self-Care)

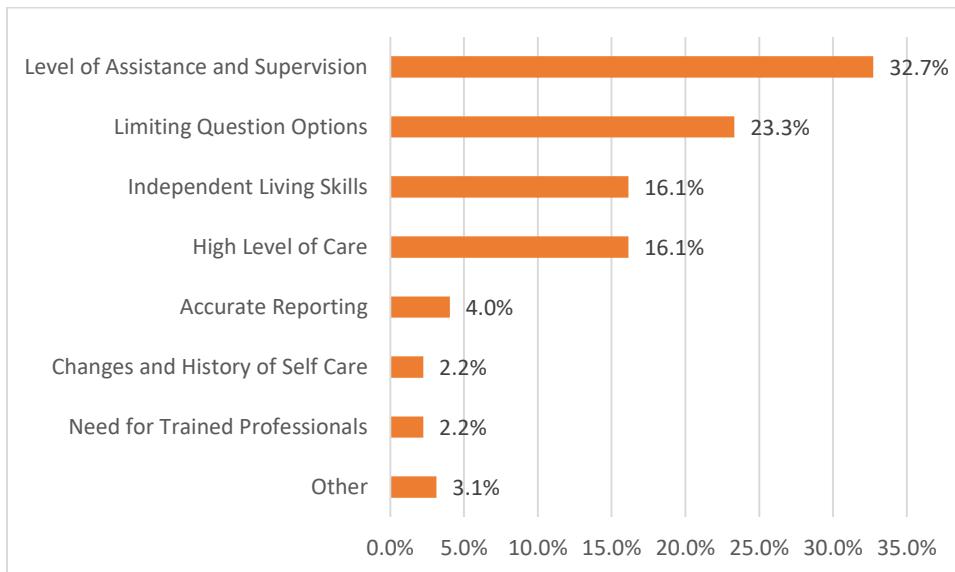


Table 4: What kind of needs and information are not properly addressed in the NJCAT, if any? (Self-Care)

Responses	Total	%
Level of Assistance and Supervision	73	32.7%
Limiting Question Options	52	23.3%
High Level of Care	36	16.1%
Independent Living Skills	36	16.1%
Accurate Reporting	9	4.0%
Changes and History of Self Care	5	2.2%
Need for Trained Professionals	5	2.2%
Other	7	3.1%
Total	223	

There were 220 responses submitted regarding needs and information not addressed relating to self-care. The most common theme mentioned in the survey comments for this section was “Level of Assistance and Supervision” (73, 32.7%), which consists of comments made about individuals with mild or moderate I/DD, who are not completely dependent or independent. The next common theme was “Limiting Question Options” (52, 23.3%), which mentioned wanting to elaborate or explain the level of assistance and supervision needed or wanted more specific questions asked. This was followed by the theme “High Level of Care” (36, 16.1%), which were comments that pertained to individuals with severe I/DD and are dependent on others for their self-care. The category “Accurate Reporting” (9, 4.0%) consists of comments where the respondent mentioned that they overestimated the amount of assistance that their loved one needs, which led to an inaccurate assessment. The “Other” category contains comments regarding the effect individual’s cognition and intellect level and capturing ongoing self-care needs.

Below are some comments that consist of the common themes:

- *Questions are too vague. Are they potty trained. There's no answer for partial. In my case, partial would mean they can get themselves to the bathroom and know when they have to go but they can't wipe themselves, clean themselves etc. another ex: can they cook? Well they can put water in a pot, they can stir food but they can't turn stove on etc. (Limited Question Options, Level of Assistance and Supervision)*
- *There are finer points that are not covered such a feeding themselves, he can feed himself but can't purchase or cook food, can't cut food so that he doesn't choke, doesn't limit the portion so he doesn't overeat, but the question is can they feed themselves (Limited Question Options, Level of Assistance and Supervision, Independent Living Skills)*
- *My son needs CONSTANT care and reminders that have to do with self-care, regulate shower temperature, cooking with assistance (sic), making shopping lists, budgeting, laundry, shopping, banking, Medical,. He needs constant reminders to take a shower, does he have a towel, check shampoo and soap, check for toiletries before going to the bathroom, brushing your teeth, etc. I have to do everything regarding appointments (Level of Assistance and Supervision, Independent Living Skills)*

Figure 16: What kind of needs and information are not properly addressed in the NJCAT, if any? (Other)

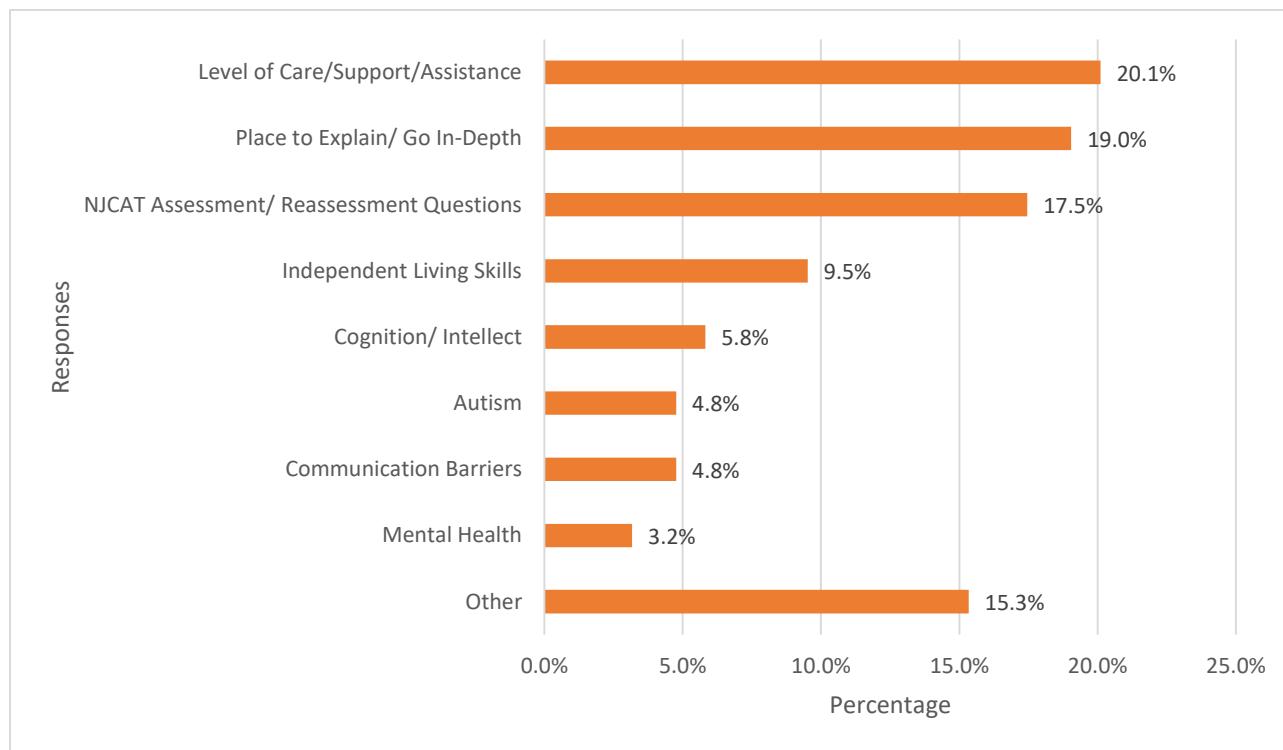


Table 5: What kind of needs and information are not properly addressed in the NJCAT, if any? (Other)

Responses	Total	%
Level of Care/Support/Assistance	38	20.3%
Place to Explain/ Go In-Depth	36	19.3%

NJCAT Assessment/ Reassessment Questions	32	17.8%
Independent Living Skills	17	9.1%
Cognition/ Intellect	11	5.9%
Communication Barriers	9	4.8%
Autism	9	4.8%
Mental Health	5	2.7%
Other	29	16.1%
Total	187	

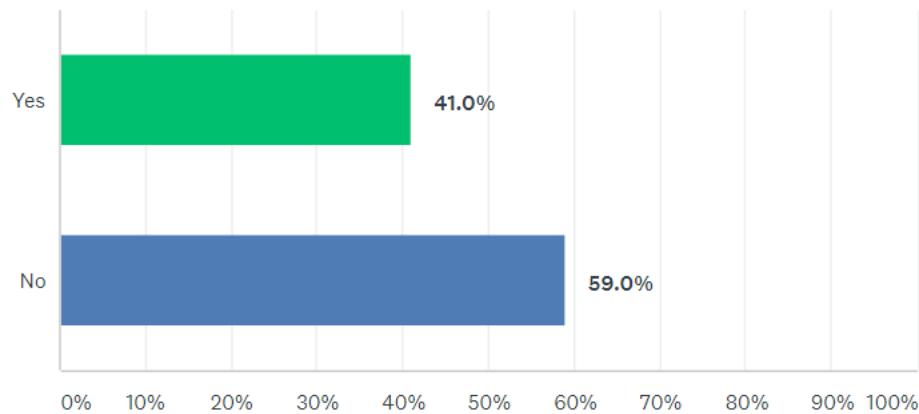
One hundred seventy-seven (177) respondents provided their comments in “Other” section. The most common response among the comments was “Level of Care, Support, Assistance” (38, 20.3%), including the need of trained professional staff to address a loved one’s needs and the amount of assistance or supervision that the parent needs to provide their child, and the equipment needed for daily activities. This was followed by “Place to Explain/ Go In-Depth” (36, 19.3%); “NJCAT Assessment/ Reassessment Questions” (33, 17.8%); and “Independent Living Skills” (17, 9.1%). The “Independent Living Skills” category consists of respondents, who felt that topics such as, transportation, housing, cooking, cleaning, budgeting, administering medication, and emergency decision making, were not being properly captured. The category “Other” pertains to responses that address the familial stress of having an individual with a disability; the fact that some questions or sections do not pertain to all individuals with I/D; lack of capturing an individual’s history, the extent of sensory issues; and struggle to find medical professionals (doctors or nursing staff) to help with medical needs.

Below are some responses that contain common themes:

- *In general questions seemed primarily designed for people with physical disabilities. Not enough focus on executive function deficits. Definitely not autism, or DD/MI.no questions addressing clients with complex needs and pragmatic language deficits or real skills or supports needed to function safely and successfully in the community (Level of Care/Support/Assistance, Mental Health, Autism, Communication, Independent Living Skills)*
- *The NJ-CAT does not capture the needs of people who are so called “high functioning” well at all. It does not consider the supports a person might need to achieve or maintain a high degree of independence. It does not consider mental health conditions that do not currently have major behavioral manifestations (in the somewhat limited examples of behavioral manifestations that are given in the CAT such as aggression and property destruction). It does not examine the types of higher level supports a person may need to be a contributing member of the community or to establish or maintain a lifestyle like that of other citizens. (Level of Care/Support/Assistance, Mental Health, NJCAT Assessment/Reassessment Questions)*
- *There is just so much more to the complexity of our loved one’s inability to care for herself that is present on her assessment. In no way can she live alone, as she ages, it’s harder for older family members to provide care that keeps her safe since her behavior is so rampant. (Place to Explain and Go In-Depth)*
- *It is the way the test is done more than the content it is asking for. The test asks questions about all of the areas but it is very cumbersome to take and is a snapshot of moment in time. The*

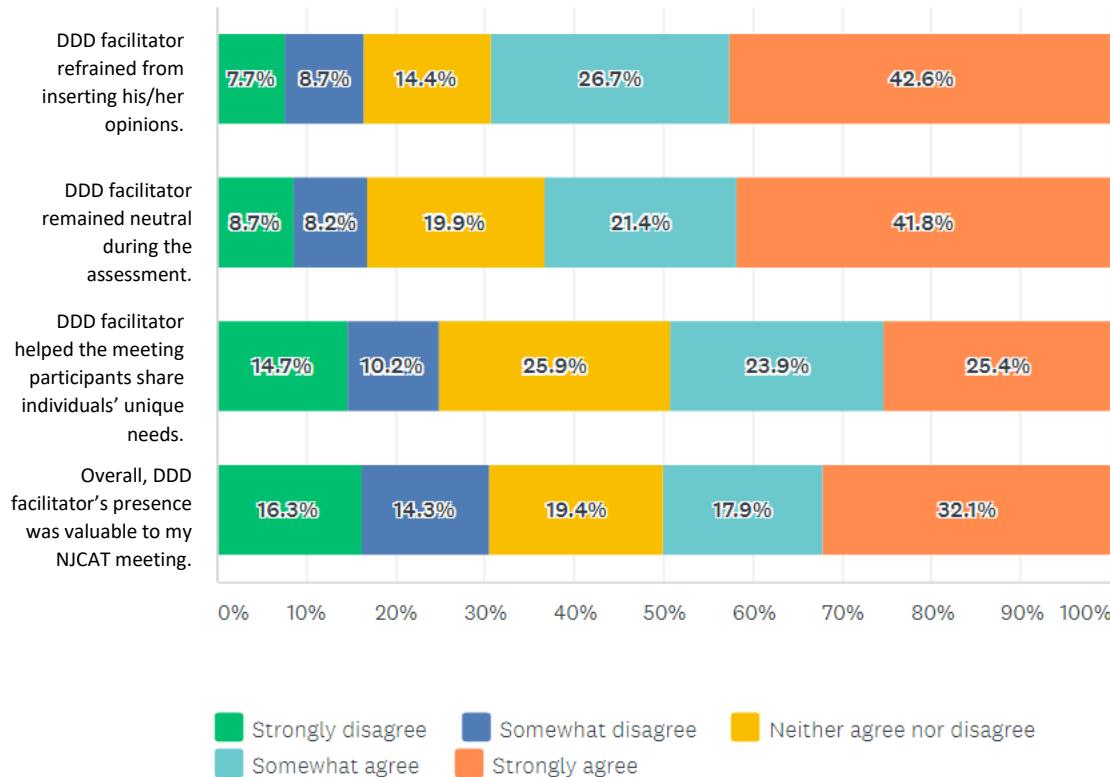
wording of many of the questions leaves the test taker struggling to figure what it means and which one to choose. (NJ CAT Assessment/Reassessment)

Figure 17: Was a DDD facilitator present for NJCAT assessment?



Out of the 510 respondents, 209 (41.0%) had a DDD facilitator in their NJCAT assessment. For those 209 respondents were given an additional question to provide their feedback on the DDD facilitator's involvement.

Figure 18: What is your opinion on the following statements?



Out of the 195 respondents, 135 (69.3%) strongly or somewhat agreed that the facilitator refrained from inserting his/her opinions, which compares to the 32 respondents (16.4%) who strongly or somewhat disagreed. One hundred twenty-four (124, 63.2%) agreed that the facilitator remained neutral during the assessment, but 33 (16.9%) disagreed. In regard to the facilitator helping the participants share the individual's unique needs, 97 (49.3%) respondents agreed, and 49 (24.9%) respondents disagreed. The overall consensus about the value of the DDD facilitator was mostly positive (98, 49.0%).

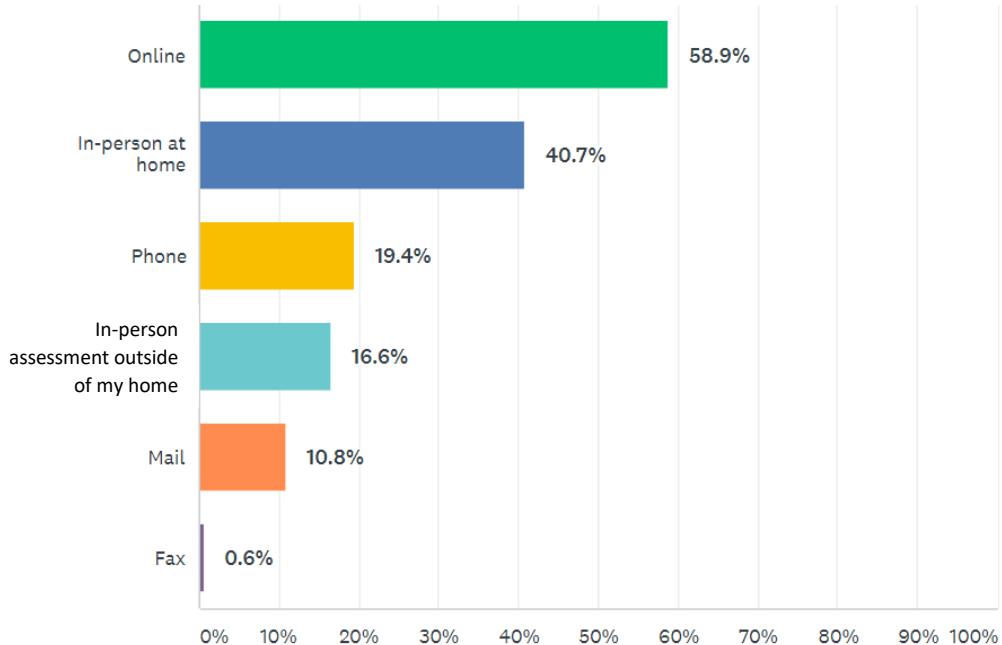
Asked to provide positive and/or negative experiences of having a DDD facilitator in the NJCAT assessment, 149 respondents left a total of 170 comments. Out of those 170 comments, 112 included positive aspects (75.2%) and 58 showed areas of improvement (38.9%).

The respondents mostly appreciated that the facilitator was supportive, knowledgeable, and was able to clarify confusing questions. The concerns included that the facilitator guided answers, ignored the participants' answers, tried to contradict information being given by participants, and was unknowledgeable and cold.

Some of the responses are included below:

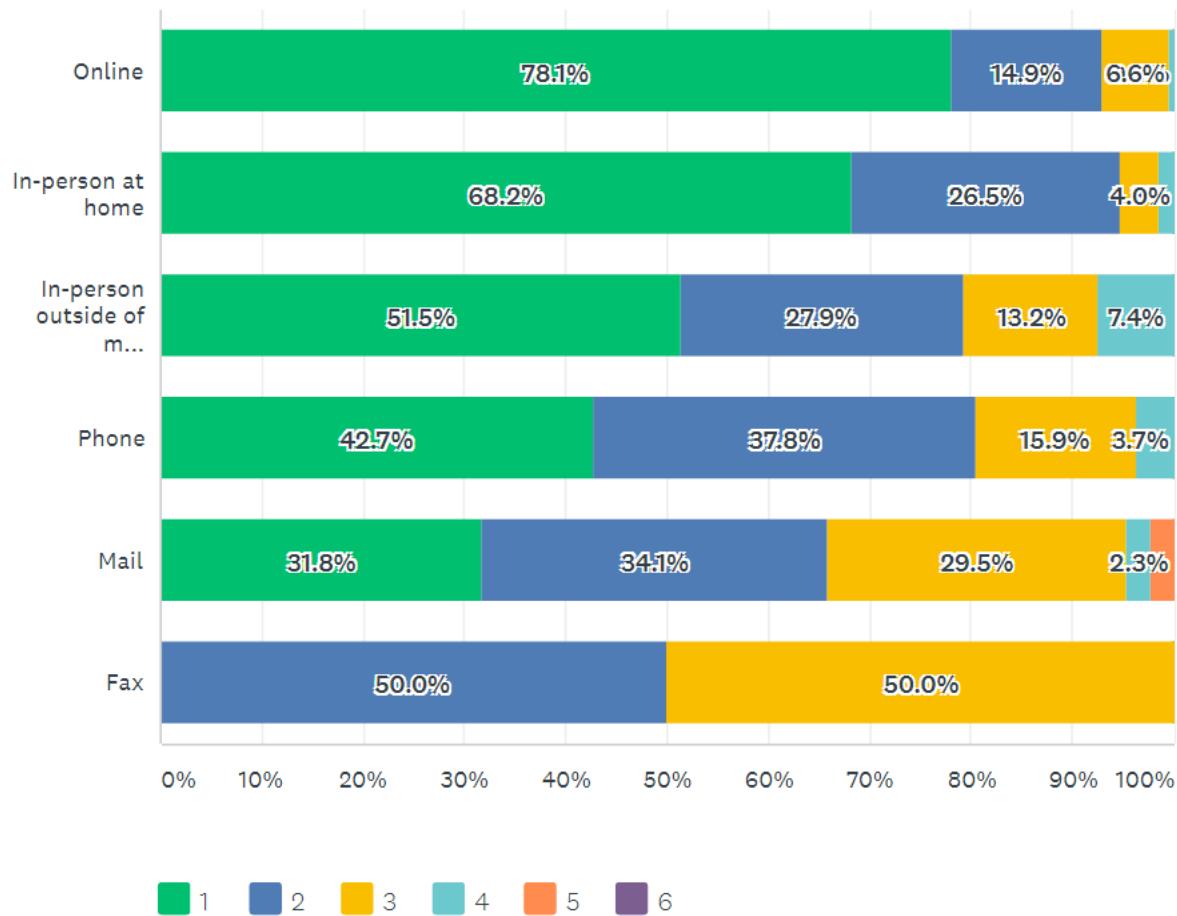
- *It was helpful to have her there because it allowed me to get clarification and give more specific answers to questions and give explanations.*
- *The facilitator's presence was tremendously positive and helped us give a much more accurate picture of what our son's PRESENT and RELEVANT needs and conditions are.*
- *They do not know our individuals and tend to choose options based on their perception of the answers, not real-life experiences.*
- *She gave us her interpretation of some questions, even though we had documentation contrary to her interpretation*

Figure 20: What is/are your preferred method(s) for completing the NJCAT? Please check all that apply.



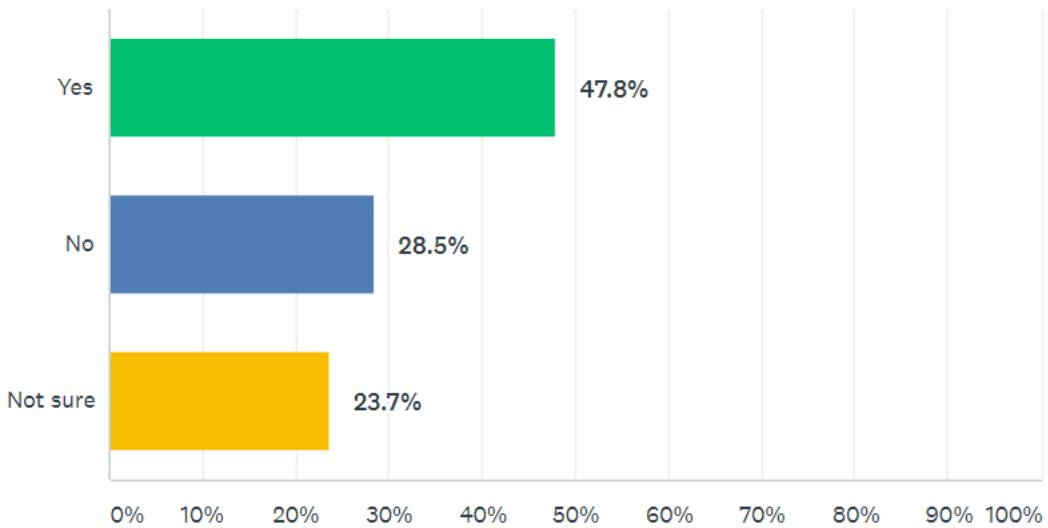
There were 501 responses, but there was overlap in some categories due to the ability to check off multiple answer options. Out of 501 responses, more than half (295, 58.9%) chose “online” as a preferred NJCAT method followed by “In-person at home” (204, 40.7%).

Figure 21: Please rank the methods in order of your preference



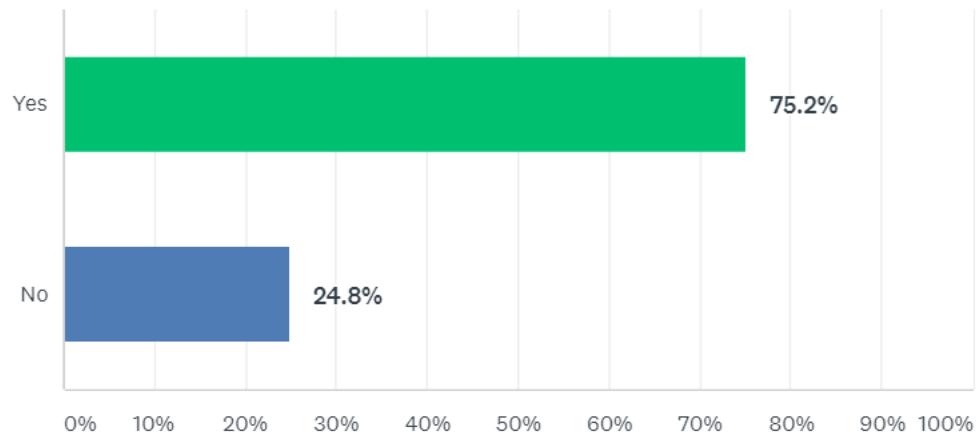
In this following question, respondents were asked to change the order of chosen methods by their preference. The number (from 1 to 6) shows the order of preference with 1 meaning the most preferred. Out of 228 responses, 178 (78.1%) chose “Online” as the most preferable option for completing the NJCAT assessment and another 34 (14.9%) chose it as their second preference. Out of 151 responses, 103 (68.2%) chose “In-person at home” as the first chose and 40 (26.5%) chose it as a second preferable. The “Phone” option had 82 responses and 35 (42.7 percent) was the first choice and 31 (37.8 percent) was a second choice. There are 3 respondents who chose fax as one of the preferable options, but none of them chose it as the most preferable compared with other methods.

Figure 22: Do you feel the need for a reassessment every five years?



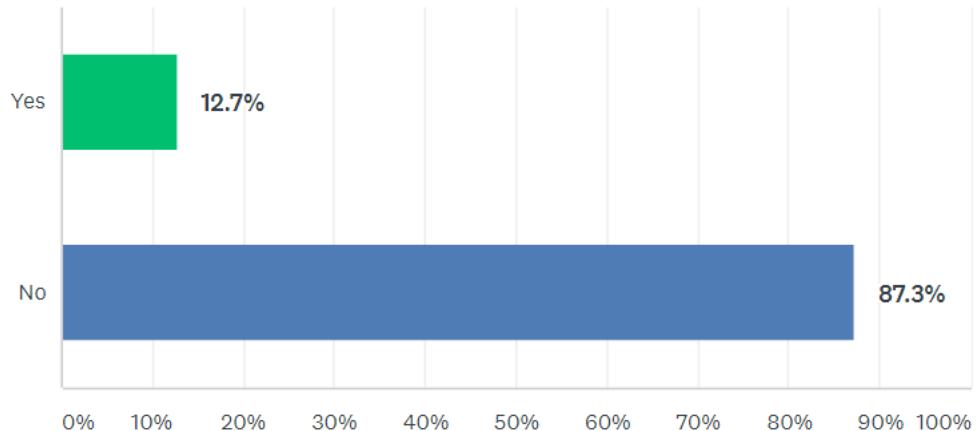
Out of 481 respondents, 230 (47.8%) felt the need for a reassessment every 5 years, while 137 (28.5%) disagreed and 114 (23.7%) said: "Not sure." It should be noted that this survey was conducted before the DDD announced the elimination of 5-year reassessment requirement.

Figure 23: Are you aware that you can request a reassessment for a change in circumstances?



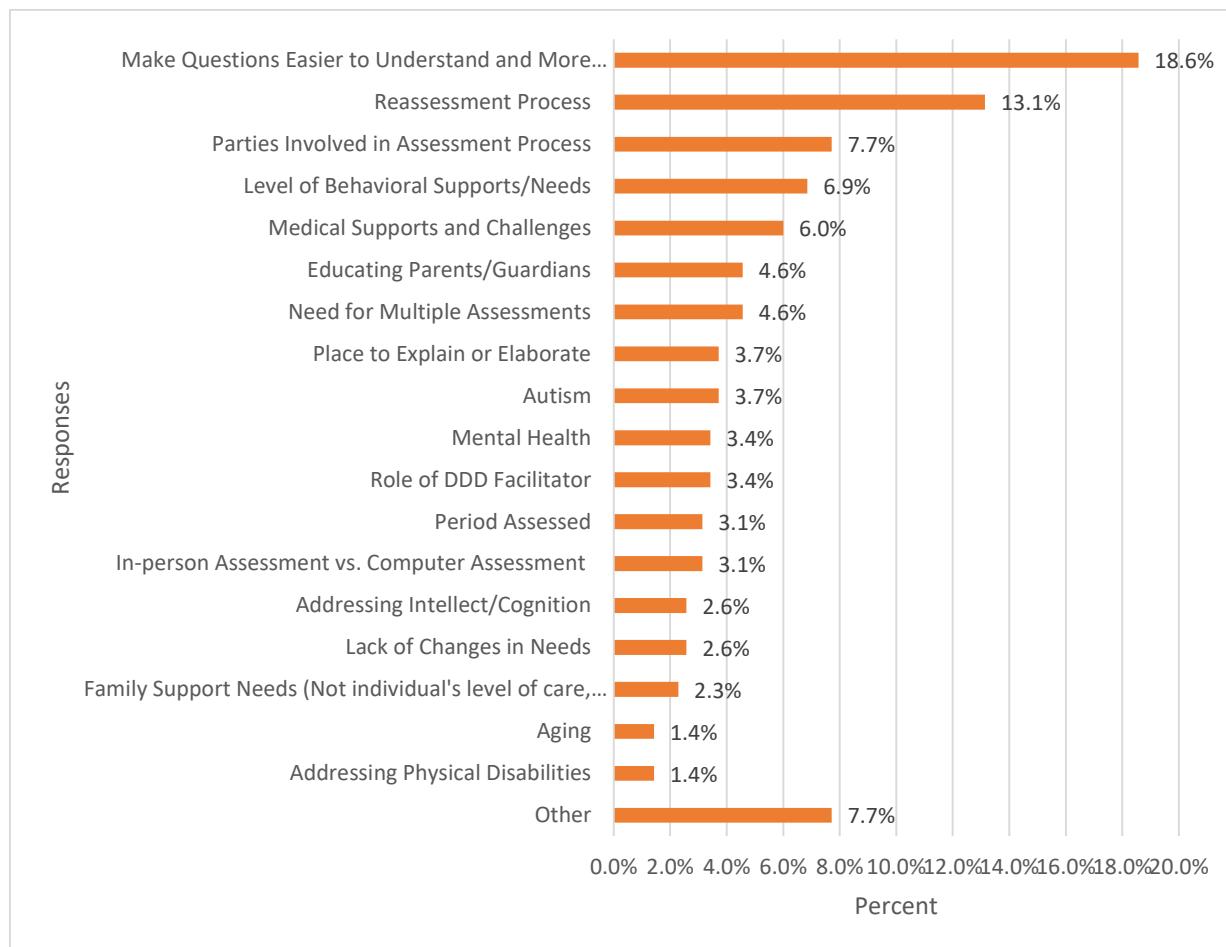
Out of 484 respondents, 364 (75.2%) were aware of their rights to request the reassessment, while 120 (24.8%) were not.

Figure 24: Have you requested a reassessment that was not granted?



Out of 480 respondents, 61 (12.7%) of them requested a reassessment but was not granted.

The survey also asked respondents to provide additional feedback and comments. There were 274 responses and further analysis of those responses found that some comments addressed multiple topics, which is why the total in *Table 6* is 351. Due to the vast number of themes mentioned in this question, the themes were divided into positive areas and areas for improvement.

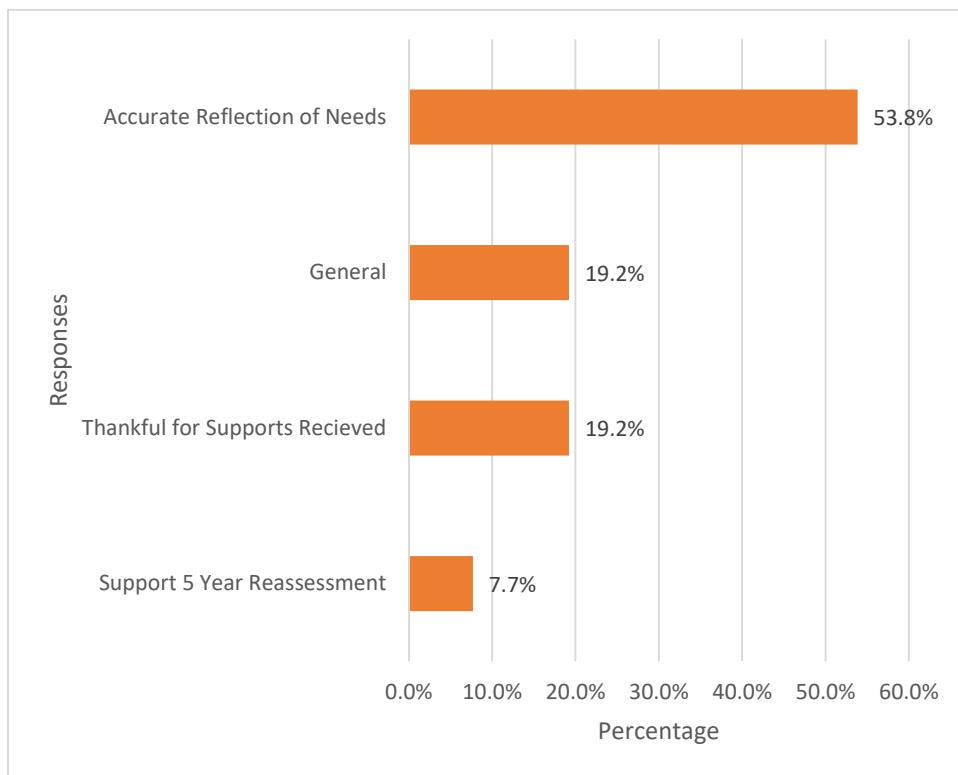
Figure 25: Additional Comments and Feedback on the NJCAT: Areas for improvement*Table 6: Additional Comments and Feedback on the NJ CAT: Areas for improvement*

Responses	Total	Percentage
Make Questions Easier to Understand and More Thorough	65	18.6%
Reassessment Process	46	13.1%
Parties Involved in Assessment Process	27	7.7%
Level of Behavioral Supports/Needs	24	6.9%
Medical Supports and Challenges	21	6.0%
Need for Multiple Assessments	16	4.6%
Educating Parents/Guardians	16	4.6%
Autism	13	3.7%
Place to Explain or Elaborate	13	3.7%
Role of DDD Facilitator	12	3.4%
Mental Health	12	3.4%
In-person Assessment vs. Computer Assessment	11	2.1%

Period Assessed	11	2.1%
Lack of Changes in Needs	9	2.6%
Addressing Intellect/Cognition	9	2.6%
Family Support Needs (Not individual's level of care, but families)	8	2.3%
Addressing Physical Disabilities	5	1.4%
Aging	5	1.4%
Other	27	7.7%
	350	

The most common theme in the areas of improvement was, “Make Questions Easier to Understand and More Thorough” (65, 18.6%), which consisted of comment made about the NJCAT questions being too confusing, unclear, and tricky, as well as the assessment asking too broad of questions. All of the comments in this category mentioned the questions inaccurately capture the needs and issues of individuals with I/DD, which has caused individuals to receive the wrong tier. This was followed by the “Reassessment Process” (46, 13.1%). The respondents explained the difficulty they experienced in requesting a reassessment.

The next commonality in these responses was “Parties Involved in the Assessment Process” (27, 7.7%); “Level of Behavioral Supports/Needs” (24, 6.9%); and “Medical Supports and Challenges” (21, 6.0%); “Need for Multiple Assessments” (16, 4.6%), which expressed concern about the ability of one assessment to properly assess all three areas effectively. Also, this category consisted of comments made about sections of the NJCAT not pertaining to some individuals. There were 16 comments that related to parents underestimating their loved ones’ needs and overestimating their abilities, which resulted in their loved one receiving an incorrect tier. The category “Other” is represented by comments claiming that the NJCAT is not user-friendly and questioning the algorithm used to assign the tiers.

Figure 26: Additional Comments and Feedback on the NJCAT: Positive*Table 7: Additional Comments and Feedback on the NJCAT: Positive areas*

Responses	Total	Percentage
Accurate Reflection of Needs	14	53.8%
Thankful for Supports Received	5	19.2%
General	5	19.2%
Support 5 Year Reassessment	2	7.7%
Total	26	

Out of 274 responses, 34 of them represented positive feedback for the NJCAT assessment. The most common positive remark pertained to the NJCAT's accuracy in reflecting needs (14, 53.8%). This is followed by "Thankful for Supports Received" (5, 19.2%); General positive remarks (5, 19.2%), and "Support 5-year Reassessment" (2, 7.7%). Some of the improvements suggested were to include a fact sheet explaining the appeal process, expand the parties involved in the NJCAT assessment, allow parents to review the copy bring sent to DDD in order to prevent misreporting, and allow for a place to explain one's responses.

Below are comments that relate to some common themes:

- *There needs to be a better method for appealing the results of an NJCAT reassessment if you feel they should have an acuity but didn't meet the scores to have one because the questions didn't*

support the individual. I complete several for my agency and many of them do not qualify for additional funding to provide more supports to ensure stability and progress. Supervision needs to be increased at times and the budgets do not support more staff, although we add staff but only because it is the right thing to do but not because we are being supported for it.

(Reassessment Process, Make Questions Easier to Understand and More Thorough)

- *The assessment process should be reviewed and self-advocates should be consulted for recommendations on how the assessment process can be more person-centered. Additionally people with disabilities should be empowered to decide if they would like to be part of their own assessment and how they would like their assessment to be reviewed annually (i.e. one-on-one vs a full team for example). ((Reassessment Process, Make Questions Easier to Understand and More Thorough, Parties Involved in Assessment Process)*
- *The NJCAT attempts to do an enormous amount of assessing with one tool and can be easily manipulated by the taker or facilitator. If a person's situation has not changed there is no reason to re-assess an individual which a chronic, lifelong disability. If there is a need for 5 year re-assessments, they should be that, re-assessments and not approached as a person re-applying. There should also be MUCH MORE AND MUCH BETTER coordination from Performcare and DDD so individuals in the system move over and do not re-apply from step one. Evaluations should move with the person, services etc. Parents should not feel so pressured to pick a correct answer on a test that forces them to put their child into one of five boxes, it's not that simple and often none of the choices make sense. (Educating Parents/ Guardians on NJCAT, Multiple Assessments Needed, Make Questions Easier and More Thorough, Role of DDD Facilitator, Lack of Changes in Needs)*
- *Limiting medical or behavioral issues to only 3 to 6 months back for display of these, does not give a complete picture of the individual's needs. "History of", is key and understanding a persons (sic) behaviors and medical condition and these can erupt at any time. Therefore, limiting to only going back 3-6 months completely throws off a true picture of care needs. (Behavioral Supports and Challenges, Assessment Period, Medical Supports and Challenges)*
- *NJCAT is a fair tool. I feel there need to be the ability for explanation (blank space) and not just number or letter answer. Each individual is so unique with certain needs/no two alike. There explanation can make a huge understanding in the level of care necessary. There is no way to make these daily needs known if unable to add to the question...leaves answer actually incomplete. (Accurate Reflection of Needs, Suggestions for Improvement)*
- *An awful lot rides on the assessment, and parents can easily be tripped up, and I have heard that challenges to tier rating are tough -- nor formal rules/procedures to request review of tier rating. A formal document explaining appeal rights would be helpful.*

Recommendations

DDAN Person-Centered and Self-Directed Services Committee recommends as follows.

1. Provide support and create educational materials for individuals and families
Some respondents expressed that NJCAT questions are confusing and ambiguous. Others showed their need for general support to go through the assessment process. More robust and various resources should be available for individuals and families.
 - a. The Division should review existing materials and identify the gaps. The target areas include but are not limited to:
 - How to provide comprehensive and accurate information on the unique needs of individuals with I/DD
 - Reassessment process
 - Rights of Appeal
 - b. The Division should make educational resources in various formats including webinar and factsheet
 - c. The Division should create a page where individuals, families, and professionals can easily find resources
2. Increase flexibility and choices
Before the COVID-19 pandemic, the Division implemented two changes to the NJCAT assessment protocol: Change to in-person method and assignment of DDD facilitator. This survey shows that online was the most preferred method followed by in-person (figure 21). Most of the respondents agreed that the DDD facilitator remained neutral and the half of respondents found their involvement helpful and valuable (see Figure 18). However, a few respondents reported that their presence negatively impacted the assessment. Some advocates also raised their concern that the Division staff's participation raises the conflict of interest.
 - a. Individuals and families should have the choice of having a Division facilitator present
 - b. Individuals and families should be able to choose the most comfortable and efficient method for NJCAT including online, in-person, phone, or mail.
3. Revise and enhance the NJCAT to capture needs that are reported not accurately assessed
The half of respondents felt that current behavioral and self-care needs are not accurately assessed (see figure 12). Respondents also expressed their desire to provide describe individuals' unique needs instead of selecting multiple choices.
 - a. Expand or revise questions to address behavioral and self-care needs (see Figure 12)
 - i. How many staff are needed to support the individual during a crisis (e.g. aggressive behavioral episodes)?
 - b. Expand the timeframe from the last 6 months to 12 months
 - i. Significant and critical care needs should be reflected in the assessment as historical information, even it is beyond 12 months old.
 - c. Collect not only quantitative data but also qualitative data such as narrative and example of individuals' complex and unique needs
4. Promote family involvement and team approach
The Committee believes that ensuring the participation of "key players" would be critical to capture individuals' unique and complex needs. It is a concern of this committee that once individuals started to live out of their family's home (e.g. group home), parents, guardians, or other important parties are not always invited to the NJCAT assessment.
 - a. Parents, guardians, or other important parties who know individuals well must be invited to the assessment regardless of where they reside (e.g. group home)
5. Reconvene the Self-Directed Policy Committee under DDD in September 2021

In order to achieve a truly person-centered system, it is important to not only improve the assessment tool but also create long-term goals in other areas. The goals and objectives should be created and prioritized by individuals and families.

A few years ago, the Division had a Self-Directed Policy Committee. Multiple subcommittees worked tirelessly and submitted the proposals to the Division. As the administration changed, the proposals, unfortunately, got lost and invaluable input and recommendations were not fully put into practice. The DDAN SD/PC Committee recommends that the Self-Directed Policy Committee be reconvened with the following focus:

- a. Create a Division-wide initiative to promote and embrace Person-Centered Thinking and Planning within both Self-Directed Services and Provider Managed Residential Services
- b. Revise the Division's webpage in regards to the Self-Directed Services to highlight the philosophy of Person-Centered Thinking and Planning and to increase flexibility.
- c. Include Person-Centered Thinking and Planning training and resources available to not only individuals and families but to Division staff, Support Coordination and Provider Agencies.
- d. To bring back the importance and focus of the Tenants of Self Direction which are:
 - i. Freedom-Freedom to choose the services/supports that work best for the individual,
 - ii. Choice-a choice of a variety of opportunities of how to live their best lives,
 - iii. Control- of their resources and supports,
 - iv. Confirmation-by having self -advocates at the table when creating policies that impact them, and
 - v. Contribution-The freedom and supports for individuals to make their contribution as citizens in their local communities
- e. Offer and promote peer support and/or mentoring so that "best practices" in Person-Centered Thinking and Planning and Self-Directed Services can be shared and implemented for all people served including those in provider managed residential settings in order to create systemic change. Non-disability specific activities are not being included as part of someone's ISP when they are living in a group home
- f. Establish a more robust Person-Centered and Self-Directed education and training system for individuals and families, DDD professionals as well as all service providers