GEORGETOWN UNIVERSITY
Thrive Center for Children, Families, and Communities

Advancing Cultural and Linguistic Competence, Diversity, Equity, and Inclusion: OPWDD-Georgetown University NCCC Partnership for Systems Change Project

Report of Listening Sessions and Interviews of
Persons with Intellectual and Developmental Disabilities and Families
Residing in New York State

Submitted by:
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Executive Summary

The New York State Office for People With Developmental Disabilities (OPWDD) partnered with the Georgetown University National Center for Cultural Competence (NCCC) to conduct a statewide data collection initiative as part of the *Advancing Cultural and Linguistic Competence, Diversity, Equity, and Inclusion: OPWDD-Georgetown University NCCC Partnership for Systems Change Project*.

The purpose of this initiative was to better understand the experiences of persons with intellectual and developmental disabilities (IDD) and their family members when seeking or receiving supports and services through OPWDD. Through listening sessions and structured interviews, this initiative gathered perspectives on the availability, accessibility, acceptability, quality, and utilization of OPWDD supports and services, particularly as they relate to families' cultural beliefs, practices, and preferred languages. The initiative took place from February 18 to December 16, 2025. This report presents overall findings and recommendations from the listening sessions and interviews, as well as systems recommendations from the NCCC. These data are essential to the ongoing efforts of OPWDD, in collaboration with people with IDD, their families, providers, and other constituency groups, to advance policies and practices of cultural and linguistic competence across all components of New York State's developmental disabilities system.

Methods

To collect this information, the NCCC Research and Evaluation Team (R&E Team) implemented a mixed-methods approach that included a registration survey, listening sessions, and individual interviews. The R&E Team chose to use the term *listening sessions* because it is both disability- and family-friendly, culturally acceptable, and what both groups expressed needing – to be listened to. Although the term "listening sessions" was used, the R&E Team adhered to all relevant protocols for conducting focus groups. Identified participants included persons with IDD; family members currently receiving supports and services; family members who had received supports and services in the past but were not currently receiving them; and family members who had not yet obtained supports and services. This data collection initiative was granted exemptions on January 23, 2024, by the Georgetown University Institutional Review Board (IRB) after review of the protocols and related materials. Categories of exempt research are stipulated in Federal Regulations 45 CFR46.101 (b)(1-6).

Persons with IDD and families were invited to participate in listening sessions and interviews conducted between February 18 and December 16, 2025. Listening session activities included: 1) facilitated sessions designed to gather collective input from family members about their experiences accessing supports and services through OPWDD; and 2) semi-structured interviews that were intended to elicit more in-depth qualitative feedback on individual experiences, barriers, and met and unmet needs. Listening sessions and interviews were offered in multiple languages, as required by the New York State Language Access Law, to

ensure participation and accessibility by persons with IDD and families who speak languages other than English. American Sign Language (ASL) and other technologies were employed to ensure accessibility in compliance with federal statutes for web-based communication.

Phone interviews were conducted with 24 persons with IDD, providing one-on-one attention and ensuring accessibility. Additionally, a total of 330 family members participated in this data collection initiative – 53 family members were interviewed, and 277 participated across 33 listening sessions held using Zoom™ and ThoughtExchange™. Zoom™ is an online communication platform that supports video conferencing, voice calls, and chat functions. ThoughtExchange™ is an online survey and engagement platform that allows users to respond to both closed- and open-ended questions anonymously and to rate the responses of others. Interviews were conducted as an alternative data-collection method for families who indicated less familiarity or comfort with these online platforms.

Data collection and analysis were guided by the *NCCC Disabilities Disparities Framework* (Goode, 2017), which provided a structured approach to examine disparities in access to and use of supports and services among all people with IDD and their families. The *NCCC Disabilities Disparities Framework* organizes inquiry across five interrelated categories:

- ***Availability*** of supports and services, including the array, type, and intensity.
- ***Accessibility*** of supports and services such as geographic distribution, hours of delivery, technology, language access, accommodations, and universal design.
- ***Acceptability*** which principally involves system capacity to plan, provide, and evaluate culturally and linguistically competent supports and services across the life course to diverse population groups.
- ***Quality*** of supports and services provided across diverse populations and communities. Quality, as defined in this framework, includes, but is not limited to, appropriateness, effectiveness, dependability, respectfulness, inclusiveness, person- and family-centeredness, satisfaction, and safety. Quality ensures responsiveness to the cultures and languages of the diverse populations receiving supports and services in the communities in which they live.
- ***Utilization*** are rates for populations' access and use of supports and services that can be measured collectively and by specific racial, ethnic, cultural, and linguistic groups.

These five framework categories were used to develop quantitative and qualitative questions for persons with IDD and their family members. Data collection experiences for both groups were designed to assess participants' perspectives about supports and services based on:

- their cultural beliefs and practices,
- their preferred language(s), and
- how supports and services align with their own interests, needs, and circumstances, or those of their family members with IDD.

The listening sessions, interviews, and a survey were conducted using a protocol grounded in the five framework categories for: (Group A) family members of persons with IDD who were currently receiving supports and services, and (Group B) family members of persons with IDD who previously received supports and services but were not currently receiving them. Group C consisted of family members of persons with IDD who were never successful in accessing supports and services. Therefore, for Group C, three of the five framework categories (*availability, accessibility, and utilization*) were presented to respondents. *Utilization* was limited to questions regarding the OPWDD website. The interview protocol for persons with IDD was also informed by the framework. It included questions specifically centered on how supports and services aligned with cultural, racial, and ethnic identities and languages spoken. The way respondents answered questions reflected perspectives on *accessibility, acceptability, quality, and utilization*, but not on *availability*.

The survey included both closed-ended and open-ended items. Closed-ended items captured respondents' overall perceptions of access to and usefulness of supports and services, while open-ended questions elicited detailed qualitative feedback about experiences, factors influencing access, and needs that were met and unmet.

Listening sessions and interviews with family members were conducted in five languages: English (81%), Chinese (12%), Spanish (4%), Korean (2%), and Russian (less than 1%). Respondents represented family members of persons with IDD across varying levels of supports/service engagement. None of the persons with IDD requested language interpretation services.

Quantitative data were analyzed using descriptive statistics, including frequencies and percentages, to identify patterns across survey responses. Qualitative data from open-ended survey responses, listening sessions, interviews, and ThoughtExchange™ comments were analyzed using structured thematic coding processes. These methods allowed the R&E Team to identify key experiences, concerns, and recommendations shared by respondents.

Findings

Persons with IDD

Respondents expressed varied perspectives regarding the *accessibility and acceptability of supports and services*. This was particularly evident in the importance respondents attributed to whether staff shared their racial, ethnic, or cultural background or spoke the same language as they did. Most respondents indicated that it was "very important or important" for staff to speak their language, as they viewed this as essential for effective communication. A slight majority of respondents indicated that it was "not too important" or "not important at all" that staff share their racial, ethnic, or cultural identities. These respondents emphasized respectful communication, helpfulness, and quality of supports. Those respondents who found it "very important, important, or somewhat important" valued shared cultural experiences and origins and felt that staff would better understand them.

"I like to meet new and different people, and I can teach them about my cultural beliefs, and they can teach me about theirs."

"I'm fortunate enough to speak English but a lot of people speak Spanish in my neighborhood. So, I think it's important to have people that are somewhat relatable to my culture, like understand the different nuances of my culture. Even if it's not for me personally and it's for others in my neighborhood."

Supports and services that respondents viewed as high in *quality* included respectful communication and staff listening to understand and tailoring supports to each person's unique interests, needs, and lived experiences. Respondents emphasized that providers/staff should take the time to learn about and understand their cultural backgrounds, and engage them in meaningful ways in their day-to-day lives.

Respondents reported both positive and challenging experiences related to *utilization* of supports and services. Findings reflected positive experiences of being listened to, making their own decisions, or being engaged in shared decision-making. Conversely, other findings revealed minimal involvement with decision makers; barriers related to communication and power dynamics; and limited opportunities for meaningful participation.

"I feel like they talk about us with disabilities and not to us... I should have a choice in how my plan is written. I'm a disabled person, and my disability informs every decision I make..."

"Being able to share what's important to me feels very, very important."

"I'm in self-direction. When I get home tonight, we're having a plan meeting. I determine what the goals are, what the activities are, and what I need to get them done..."

Family Members

When discussing *availability*, the majority of respondents from Groups A and B indicated that the supports and services were available that met the needs of their family member with IDD and were responsive to their cultures. However, the percentages of respondents who reported either "yes or no" that supports and services were available when they needed them or in the amount that they needed were almost equal. Those who responded "yes" stated that they had positive experiences with providers that were supportive and timely. Respondents who said "no" indicated long wait times, complex processes to obtain supports and services, a lack of clear guidance, and feelings of frustration and lack of support in navigating the system. Group C respondents shared the reasons they thought supports and services were not available to them, including waiting lists, denials, and a lack of clarity about required documentation. Additionally, Group C indicated what they thought would make supports and services available to them and in ways that considered their cultural beliefs, practices, and preferred language. Suggestions included clearer guidance and culturally and linguistically competent staff.

"We are receiving family support service, respite care, and assistive technology which is what we want and need."

"Supports are available, but the amount provided does not match what our family needs."

"… A required service is not available unless it fits into one of a handful of narrowly defined categories."

"The OPWDD process takes too long, and services are not approved in time to meet our needs."

"No available service providers, long wait lists, and months and years of waiting."

When discussing *accessibility*, family members from Groups A and B described multiple challenges when attempting to access supports and services, including difficulty navigating application processes, limited awareness of available programs, and difficulty communicating with service providers and systems. Some respondents noted that supports and services were difficult to access due to administrative requirements, lack of clear guidance, uncertainty about eligibility requirements and next steps, and significant delays between applying for supports and services and actually receiving them. The OPWDD website was described by many as being inaccessible and very difficult to navigate and understand. Group C respondents indicated what they thought could make supports and services accessible, including follow-up from social workers, improved attitudinal and professional staff behavior during interactions, and clarification of service options for their family members.

"The case manager comes to our home or meets with us over the phone or Zoom, so that works and the services my son receives are accessible by subway or bicycle."

"CM and broker helped locate programs with good reputations among Chinese families."

"It is better than before … but OPWDD allows only limited program options, which restricts his opportunities for progress."

"My main language is Spanish, and I had no translations."

When discussing the *acceptability and quality* of supports and services, respondents in Groups A and B emphasized the importance of staff who demonstrate cultural understanding, communicate respectfully (in English and other languages), take the time to listen to understand persons with IDD and families, and offer the types and quantity of supports and services needed and preferred. The majority of family respondents, once they were able to secure supports and services, rated them relatively highly. A small minority of family respondents indicated inconsistent and insufficient supports and services overall, and OPWDD's or system providers' lack of capacity to respond to their cultural and linguistic needs. Group C was not presented with items on acceptability or quality.

"The com hab and respite care support have been excellent and very sensitive to our family's cultural needs."

"There is almost no accommodation of my brother's cultural practices when they differ from those of his housemates."

"We do not have the support we need, either in quantity or quality."

The majority of responses from families regarding *utilization* revealed that the process to use supports and services ranged from difficult to very difficult. Families indicated frustration with excessive paperwork and forms, long wait times, repeated and lost document requests, inconsistent responsiveness, and a website that was difficult to navigate. While some families reported that the approval process itself could be bureaucratic, time-consuming, or overwhelming, once supports and services were approved, they were easy to use.

"It was difficult to apply and get approved for OPWDD, but after we were accepted everything was much easier."

"It's a long and difficult process. It took us years. Also, once you are approved, that's just part one … It's been 4 years since our front door session and we are just now utilizing services. It shouldn't be this difficult."

Limitations

The NCCC solicited voluntary statewide participation in the listening sessions initiative. A total of **354** people, persons with IDD and family members, participated. Although the respondent group included all OPWDD Regions, the total number of respondents is not a representative sample of the population of people residing in New York who are eligible for, receive, or want to receive supports and services. This does not, however, invalidate the experiences and recommendations of these respondents and the implications for supports and services.

It is important to note that some respondents may not have understood the meaning of culture as used in the questions posed to them. For example, a number of these responses stated that culture was not relevant, culture did not apply to them, or that they identified as "typical American." As a result, cultural influences on how disability is understood and preferences for culturally-informed supports and services are present but may be underrecognized or underreported in the data gathered in this report.

Recommendations

Respondents offered recommendations to improve the experiences of people with IDD and families across the five framework categories – *Availability, Accessibility, Acceptability, Quality, and Utilization.* The following recommendations are categorized by persons with IDD, family members of persons with IDD, and the Georgetown University National Center for Cultural Competence.

Persons with IDD

Persons with IDD offered recommendations to OPWDD to:

- Improve supports and services based on their lived experiences;
- Ensure clear, consistent, and timely communication across all components of the developmental disabilities system, including better follow-through and advance notice of changes;
- Integrate cultural and linguistic competence into person-centered planning to ensure responsiveness to their diverse interests and needs;
- Recognize and respect persons with IDD as decision-makers regarding the supports and services they want and need and support their active role in developing and approving their life plans; and
- Ensure that staff who provide supports and services are culturally and linguistically competent.

Family Members of Persons with IDD

Family members of persons with IDD offered recommendations to OPWDD to:

- Improve the overall experience of persons with IDD and family members when applying for supports and services. This includes having: a) an accessible website; b) easy to understand eligibility criteria, application forms, and diagnostic protocols and processes; c) professional and courteous interactions with OPWDD staff; and d) effective communications;
- Expand outreach, engagement, and information sharing across all people, families, and communities in need of and receiving supports and services;
- Strengthen cultural and linguistic competence among providers and their staff; and
- Create more opportunities for persons with IDD and families to share feedback about their experiences, including meeting with policy makers who make decisions about the supports and services that they receive across the life course.

NCCC Project Team

Recommendation 1. Convene statewide public forums to discuss the findings from this report.

As stated previously, a total of **354** people, persons with IDD and family members, participated in the listening sessions. Although the respondent group included all OPWDD Regions, the total number of respondents is not a representative sample of the population of people residing in

New York who are eligible for, actually receive, or want to receive IDD supports and services. This, however, does not invalidate the experiences and recommendations of these respondents or the implications for supports and services. Therefore, it is recommended that OPWDD collaborate with self-advocacy and family organizations, the network of voluntary service providers, and other constituents and organizations concerned with IDD supports and services to discuss the implications of the findings of this report statewide, including the following respondent demographics.

Table ES-1.
Ethnicity of respondents with IDD (n=24).

Ethnicity	Percentage*	Number of Participants*
Hispanic or Latino	8%	2
non-Hispanic or Latino	92%	22

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

Table ES-2.
Racial background of respondents with IDD (n=24).

Racial background	Percentage*	Number of Participants*
White	67%	16
Black or African American	25%	6
Other (please specify)	8%	2

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

For respondents who selected *Other (please specify)*, only one response indicated "Hispano."

Table ES-3.
Ethnicity of family members of persons with IDD (n=330).

Ethnicity	Percentage*	Number of Participants*
Hispanic or Latino	18%	61
non-Hispanic or Latino	82%	269

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

Table ES-4.

Racial background of family members of persons with IDD (n=330).

Racial background	Percentage*	Number of Participants*
White	46%	151
Black or African American	13%	44
Asian	24%	80
Native American or Alaska Native	1%	3
Two or more races	7%	22
Other	9%	30

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

For respondents who selected *Other (please specify)*, illustrative responses included: "Puerto Rican," "Latino of African/European/Indigenous decent," "Latino Indigenous (mestizo)," "Jewish," "Indigenous," "I am Ashkenazi and my son is Native Central American," "Guyanese East Indian," "Bavarian," "Ashkenazi."

Table ES-5.

Language preferred for participating in listening session by family members of persons with IDD (n=330).

Language Preferred for Participating in Listening Session	Percentage*	Number of Participants*
English	81%	266
Chinese	12%	41
Spanish	4%	12
Korean	2%	8
Russian	0.3%	1
Other	1%	2

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

For respondents who selected *Other (please specify),* two responses indicated "English or Spanish" and "English and ASL or closed-caption in English."

<u>Recommendation 2.</u> Consider the sociocultural and political contexts that affect data collection across New York State's diverse communities.

As stated previously, participation in the listening sessions initiative was voluntary and conducted during a highly sensitive time for immigrant families and communities in New York and across the United States. This sociocultural and political environment may have impacted the willingness of some persons with IDD and families to participate. Future data collection will need to take these factors into consideration in efforts to engage New York's diverse immigrant communities.

<u>Recommendation 3.</u> Establish a statewide structure and process to evaluate supports and services delivered directly by OPWDD and by its network of voluntary IDD providers.
Given OPWDD's priority of working to advance cultural competence, linguistic competence, and equity within New York State's system, it is recommended that OPWDD:

- Improve the overall experience of persons with IDD and family members when applying for supports and services. This includes having: a) an accessible website; b) easy to understand eligibility criteria, application forms, and diagnostic protocols and processes; c) professional and courteous interactions with OPWDD staff; and d) effective communications.
- Offer additional opportunities to engage in data collection across all demographic groups in the state and continue to gather data, such as those captured in this report.
- Make a concerted effort to elicit the experiences of persons with IDD and family members who speak languages other than English (including ASL or other sign languages). It is important to note that this recommendation is made because the number of listening session respondents (i.e., persons with IDD and families) is not representative of the languages spoken in the state or those mandated by the New York State Language Access Law.
- Invest in a statewide structure and processes to evaluate supports and services from the user perspective – people with IDD and their families across the life course – from the diverse cultural and linguistic groups residing in the state.
- Partner with people with IDD, their families, other key constituency groups, and organizations to inform data analysis and dissemination strategies of the findings.
- Create a solutions-oriented statewide action coalition to address disparities in availability, accessibility, acceptability, quality, and utilization of supports and services as identified for future data collection efforts.

Summary

The findings from this data collection initiative provide important insights into how supports and services delivered by OPWDD and system providers are experienced by the diverse populations who live in New York State. The documented experiences, cultural perspectives, and recommendations of persons with IDD and their families are essential to guide policymaking and service design. These recommendations, coupled with those of the NCCC, can help inform needed systems-change efforts. These recommendations were offered to strengthen system capacity to ensure that OPWDD's (a) eligibility and applications processes, (b) supports and services, (c) community engagement, and (d) communication strategies demonstrate cultural and linguistic competence, and that supports and services are equitably accessed, provided, and evaluated.

Introduction

The New York State Office for People With Developmental Disabilities (OPWDD) partnered with the Georgetown University National Center for Cultural Competence (NCCC) to conduct a statewide data collection initiative as part of the *Advancing Cultural and Linguistic Competence, Diversity, Equity, and Inclusion: OPWDD-Georgetown University NCCC Partnership for Systems Change Project*.

Purpose

The purpose of this initiative was to better understand the experiences of persons with intellectual and developmental disabilities (IDD) and their family members when seeking or receiving supports and services through OPWDD. This initiative gathered perspectives through listening sessions and structured interviews from persons with IDD and family members about supports and services based on:

- their cultural beliefs and practices,
- their preferred language(s), and
- how supports and services align with their own interests, needs, and circumstances, or those of their family members with IDD.

These data are essential to the ongoing efforts of OPWDD, in collaboration with people with IDD, their families, providers, and other constituency groups, to advance policies and practices of cultural and linguistic competence in all components of the developmental disabilities system of New York State.

Data collection and the analysis were guided by the *NCCC Disabilities Disparities Framework*, (Goode, 2017), which provided a structured approach to examine disparities in access to and use of supports and services among all people with IDD and their families. The *NCCC Disabilities Disparities Framework* organizes inquiry across five interrelated categories:

- ***Availability*** of supports and services, including the array, type, and intensity.
- ***Accessibility*** of supports and services such as geographic distribution, hours of delivery, technology, language access, accommodations, and universal design.
- ***Acceptability*** which principally involves system capacity to plan, provide, and evaluate culturally and linguistically competent supports and services across the life course to diverse population groups.
- ***Quality*** of supports and services provided across diverse populations and communities. Quality, as defined in this framework, includes, but is not limited to, appropriateness, effectiveness, dependability, respectfulness, inclusiveness, person- and family-centeredness, satisfaction, and safety. Quality ensures responsiveness to the cultures and languages of the diverse populations receiving supports and services in the communities in which they live.
- ***Utilization*** are rates for populations' access and use of supports and services that can be measured collectively and by specific racial, ethnic, cultural, and linguistic groups.

This report presents summary findings by framework categories, and where applicable, by group. Findings are intended to inform persons with IDD, families, OPWDD, system providers, and other constituents about perceived strengths, gaps, and barriers in the current system of supports and services, centered on cultural and linguistic competence. The final section of this report provides recommendations to inform decisions at policy-making and programmatic levels to increase capacity for cultural and linguistic competence within New York State's developmental disabilities system.

Methods

The NCCC Research and Evaluation Team (R&E Team) implemented a mixed-methods approach that included a registration survey, listening sessions, and individual interviews. The R&E Team chose to use the term *listening sessions* because it is both disability- and family-friendly, culturally acceptable, and what both groups expressed needing – to be listened to. Although the term *listening sessions* was used, the R&E Team adhered to all relevant protocols for conducting focus groups.

Persons with IDD and families were invited to participate in listening sessions and interviews conducted between February 18 and December 16, 2025. Listening session activities included: 1) facilitated sessions designed to gather collective input from family members about their experiences accessing supports and services through OPWDD; and 2) semi-structured interviews that were intended to elicit more in-depth qualitative feedback on individual experiences, barriers, and met and unmet needs. Listening sessions and interviews were offered in multiple languages, as required by the New York State Language Access Law, to ensure participation and accessibility by persons with IDD and families who speak languages other than English. American Sign Language (ASL) and other technologies were employed to ensure accessibility in compliance with federal statutes for web-based communication.

Formats for Listening Sessions and Interviews

The listening sessions, interviews, and a survey were conducted using a protocol grounded in the five framework categories for: (Group A) family members of persons with IDD who were currently receiving supports and services and (Group B) family members of persons with IDD who previously received supports and services but were not currently receiving them. Group C consisted of family members of persons with IDD who were never successful in accessing supports and services. Therefore, for Group C, three of the five framework categories (*availability, accessibility, and utilization*) were presented to respondents. *Utilization* was limited to questions regarding the OPWDD website.

All interviews with persons with IDD were conducted in English as preferred. Listening sessions and interviews with family members were conducted in five languages: English (81%), Chinese (12%), Spanish (4%), Korean (2%), and Russian (less than 1%) (Table 11). Respondents represented family members of persons with IDD across varying levels of supports/service engagement. None of the persons with IDD requested language interpretation services.

Phone interviews were conducted with 24 persons with IDD, providing one-on-one attention and ensuring accessibility. Additionally, a total of 330 family members participated in this data collection initiative – 53 family members were interviewed, and 277 participated in listening sessions held using Zoom™ and ThoughtExchange™. Zoom™ is an online communication platform that supports video conferencing, voice calls, and chat functions. ThoughtExchange™ is an online survey and engagement platform that allows users to anonymously respond to both closed- and open-ended questions and to rate the responses of others.

Listening sessions and interviews were organized to accommodate different participant groups and levels of comfort with technology. Separate formats were used for persons with IDD and for family members, with additional session types based on families' experience with OPWDD supports and services. Format assignments were as follows:

For persons with IDD:

- One-on-one interviews conducted via Zoom™ or phone.

For family members:

- Zoom™ listening session with ThoughtExchange™ included (large-group discussions)**:**
    - Designed for participants who were comfortable using technology and were currently receiving supports and services from OPWDD (Group A).
- Zoom™-only listening sessions for each of the three groups: (These sessions were for smaller groups, and ThoughtExchange™ is best conducted in groups greater than 10 participants).
    - Group A: Families currently receiving services from OPWDD
    - Group B**:** Families who previously received services from OPWDD but were not currently receiving services
    - Group C: Families who have never received services from OPWDD
- Phone interviews:
    - Conducted for participants across all family groups (Groups A, B, and C) who were not comfortable using technology.

As indicated above, the R&E Team conducted one-on-one virtual interviews using Zoom™ for persons with IDD. All questions were asked verbally, and sessions were recorded and transcribed. The team convened a series of listening sessions and interviews for families of persons with IDD based on the previously listed categories – Group A, B, or C. The listening sessions were conducted virtually on Zoom™ with the R&E Team. During the listening sessions, the R&E Team provided an overview followed by a link to a Qualtrics™ survey. Respondents

were provided 20 minutes to complete this survey while logged into Zoom™. After respondents completed the Qualtrics™ survey, the R&E Team launched four open-ended questions via ThoughtExchange™ for groups with greater than 10 participants.

Of the 33 listening sessions, 28 were conducted using Zoom™ only, and five were conducted using both Zoom™ and ThoughtExchange™ to allow respondents to anonymously provide answers to the four open-ended questions. Each session began with real-time instructions from R&E Team members. A link was provided in the Zoom™ chat, and respondents used it to access ThoughtExchange™ and submit their responses. The four open-ended questions were asked verbally during the 28 sessions conducted only using Zoom™. The R&E Team used Zoom™ to conduct one-on-one interviews over the phone. All questions were asked verbally, and sessions were recorded and transcribed.

Data Collection Tools

Data collection tools were aligned with the *NCCC Disabilities Disparities Framework* (Goode, 2017), which provided a structured approach to examine disparities in access to and use of supports and services among all people with IDD and their families. The *NCCC Disabilities Disparities Framework* organizes inquiry across five interrelated categories: availability, accessibility, acceptability, quality, and utilization.

Data Analysis

Data analysis was also guided by the NCCC Disparities Framework. Microsoft Excel™ was used for quantitative analysis, and Dedoose™ was used for qualitative analysis. All Qualtrics™ survey data were exported and prepared for both quantitative and qualitative analysis. Quantitative items were analyzed using Microsoft Excel™, for which the R&E Team generated descriptive statistics, including frequencies and percentages. These results were visualized through graphs. Open-ended responses from Qualtrics™ were imported into Dedoose™ for qualitative analysis.

For open-ended questions asked through ThoughtExchange™, the platform's built-in analytic tools were used to categorize respondents' experiences, comments, and recommendations into themes. Open-ended questions asked verbally during Zoom™ sessions were transcribed and uploaded into Dedoose™ where they were coded using a collaborative, iterative approach. The R&E Team divided the dataset, and each member coded independently by examining each individual's response for its manifest content. The codes for each question were geared at emphasizing, on a surface level, the content of each question's responses, without assigning latent themes based on the interpretation of R&E Team members. Subsequently, these codes underwent review, refining the coding structure and, where applicable, merging codes with significant similarities.

The R&E Team met weekly to review coding decisions, refine code definitions, and resolve discrepancies through discussion and consensus. This process helped ensure consistency in how codes were applied and strengthened the validity of the final thematic findings. Qualitative data from the interviews with persons with IDD were coded by a single evaluator using the codes

developed during the iterative team-based process.

Recruitment and Registration

Flyers and emails were designed by the NCCC R&E Team and disseminated by this team, OPWDD, and provider organizations to recruit persons with IDD and families for interviews and listening sessions. To ensure inclusion of persons with IDD and families who speak languages other than English, the NCCC collaborated with community-based and ethnic-specific disability and advocacy organizations to recruit potential participants. In addition, the R&E Team collaborated with Care Coordination Organizations (CCOs) to disseminate recruitment materials to persons with IDD and their families. Flyers included information on the purpose, duration, participation criteria, technology requirements for participation and registration, and a $25 gift card as a participation incentive. Flyers also included a link directing interested parties to a Qualtrics™ registration form where they could schedule a listening session or interview.

The registration process for persons with IDD first asked whether they needed assistance completing the form or participating in the interview. Those who indicated a need for assistance were prompted to provide contact information for the person who would provide them with support. The R&E Team followed up directly with the identified support persons to complete the registration process. Persons with IDD who indicated they did not need assistance completed the remaining registration items, which included contact information, types of supports and services they received, demographic items such as race/ethnicity and preferred language, and any accommodations they required. At the start of each session, the R&E Team reviewed the consent process by describing the purpose, procedures, potential risks and benefits, confidentiality, and voluntary nature of participating in the data collection initiative. The R&E Team also asked periodic check-in questions to ensure understanding by each participant. Verbal consent was obtained from each participant before beginning the interview questions.

The registration process for family members of persons with IDD first prompted them to sign an electronic consent form. This consent form contained information such as the purpose, procedures, potential risks and benefits, confidentiality, and voluntary nature of participating in the data collection initiative. Next, family members completed the remaining registration items, which included contact information, the types of supports and services they received for their family member with IDD, demographic items such as race/ethnicity and preferred language, and any accommodations they required. After the consent and registration processes were complete, the R&E Team reviewed the responses, assigned families to Group A, B, or C, and scheduled them for a listening session or an interview.

Data Cleaning Process

As part of the registration process, the R&E Team conducted a comprehensive data quality review that involved removing duplicate responses, out-of-country responses, IP addresses

outside of the New York tri-state area, suspicious or duplicate IP addresses, chatbot (bot) entries designed to simulate human responses, and content identified as likely scams. Additionally, bot detection and relevant ID features were enabled in Qualtrics™ to assist with identifying bot-generated and duplicate responses.

After each listening session or interview, the R&E Team divided the survey responses and independently reviewed participants' survey data. The team then met to discuss and resolve any inconsistencies and to cross-check respondent information. This review included examining IP addresses to identify those outside the New York tri-state area, assessing potential fraud risks using Scamalytics™, reviewing Zoom™ attendee analytics, checking participant activity within the OPWDDListens email system, and confirming whether registration information matched survey responses (e.g., region and supports and services received). Team members also reviewed the open-ended responses, flagging entries that contained vague, repetitive, inconsistent, or unclear language.

Institutional Review Board (IRB)

This data collection initiative was granted exemption on January 23, 2024, by the Georgetown University Institutional Review Board (IRB) after review of the protocols and related materials. Categories of exempt research are stipulated in Federal regulations at 45 CFR46.101 (b)(1-6) and include: Research and demonstration projects which are conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine public benefit or service programs.

Findings

Quantitative and qualitative findings are presented in the report sections that follow and are organized by the *NCCC Disabilities Disparities Framework* categories of *Availability, Accessibility, Acceptability, Quality*, and *Utilization,* and by respondent group. Figures present the quantitative findings, and illustrative quotes are included to highlight key themes and patterns emerging from the qualitative findings.

Persons with IDD: Respondent Demographics

Interviews were conducted with n=24 persons with IDD recruited through emails sent to provider agencies. Fifty percent (50%) of the respondents were persons with lived experience of intellectual disability (Table 3). The majority of the respondents, 88%, were persons currently receiving supports and services (Table 1), and 52% reported receiving supports and services for more than six years (Table 7). Thirty-three percent (33%) of respondents were from Region 4 (Metro, Brooklyn, Staten Island, & Bernard Fineson) (Table 2). Ninety-two percent (92%) of the respondents identified as non-Hispanic or Latino (Table 4), and 67% identified as White (Table 5). None of the persons with IDD requested language interpretation services. Most of the respondents, 54%, were 25-44 years of age (Table 6). Tables 1-7 present the frequencies for these demographic variables.

Status of Supports and Services

Table 1.

Status of respondents with IDD on receiving supports and services through OPWDD (n=24).

Status of Receiving Supports and Services	Percentage*	Number of Participants*
Yes, I am now receiving supports and services	88%	21
No, I have never received supports and services before, but I tried to	8%	2
No, I have never received supports and services before and I did not try to	4%	1

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

Region

Table 2.

Reported OPWDD region of respondents with IDD (n=24).

Region	Percentage*	Number of Participants*
Region 1: Western New York & Finger Lakes	4%	1
Region 2: Central New York, Broome & Sunmount	25%	6
Region 3: Capital District, Taconic & Hudson Valley	13%	3
Region 4: Metro, Brooklyn, Staten Island & Bernard Fineson	33%	8
Region 5: Long Island	17%	4
Missing (did not disclose)	8%	2

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

Disability Type

Table 3.

Reported disability type of respondents with IDD (n=24).

Disability type	Percentage*	Number of Participants*
Person with lived experience of intellectual disability	50%	12
Person with lived experience of other developmental disabilities	42%	10
Other	8%	2

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

Ethnicity

Table 4.

Ethnicity of respondents with IDD (n=24).

Ethnicity	Percentage*	Number of Participants*
Hispanic or Latino	8%	2
non-Hispanic or Latino	92%	22

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

Racial Background

Table 5.

Racial background of respondents with IDD (n=24).

Racial background	Percentage*	Number of Participants*
White	67%	16
Black or African American	25%	6
Other (please specify)	8%	2

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

For respondents who selected *Other (please specify)*, there was only one response that indicated “Hispano.”

Age Range

Table 6.

Age range distribution of respondent with IDD (n=24).

Age Range	Percentage*	Number of Participants*
18 - 24	17%	4
25 - 34	25%	6
35 - 44	29%	7
45 - 54	17%	4
55 - 64	4%	1
65 - 74	4%	1
75 - 84	4%	1

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

Length of Time Receiving Supports and Services

Table 7.

Length of time receiving supports and services of respondents with IDD (n=24).

Length of Time receiving supports and services	Percentage*	Number of Participants*
1 - 2 years	5%	1
3 - 4 years	14%	3
Less than a year	10%	2
More than 6 years	52%	12
Other	19%	5

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

Findings for Persons with IDD (n=24)

Presentation of Findings by Framework Category

The interview protocol for persons with IDD was informed by the framework and included questions specifically centered on how supports and services were aligned with the cultural, racial, and ethnic identities and languages spoken. The way in which respondents answered questions reflected perspectives on accessibility, acceptability, quality, and utilization but not availability. For that reason, the sub-sections below examine qualitative findings for persons with IDD across four of the five framework categories—Accessibility, Acceptability, Quality, and Utilization. For each question, one to four representative comments were selected to illustrate respondent perspectives, except in instances where limited or no comments were provided within a category. The questions presented to respondents are included in the appendices. For ease of reference and to provide context for the data presented, each question is also provided within the findings section.

Persons with IDD - Findings by Framework Categories: *Accessibility* and *Acceptability*

This section presents quantitative and qualitative findings related to *Accessibility* and *Acceptability*, beginning with what providers can do to demonstrate understanding that people with developmental disabilities come from many backgrounds. Findings emphasize the importance of relationship-building, cultural awareness, respectful communication, and providers' efforts to learn about and respond to the diverse lived experiences of persons with IDD.

Respondents were also asked to rate the importance of staff speaking the same language and sharing their racial, ethnic, or cultural background and to explain their ratings. Responses reflected varied perspectives. Most respondents indicated that it was "very important" or "important" for staff to speak their language, emphasizing that shared language is essential for effective communication. In contrast, a slight majority of respondents indicated that it was "not too important" or "not important at all" for staff to share their racial, ethnic, or cultural identities. These respondents emphasized respectful communication, helpfulness, and the quality of supports over shared identity. At the same time, respondents who rated shared racial, ethnic, or cultural background as "very important," "important," or "somewhat important" highlighted the value of shared experiences and expressed that staff with similar backgrounds may better understand their needs and perspectives. Illustrative responses are provided below.

What Providers Can Do to Show Understanding of Diversity of Backgrounds

Respondents were asked, "What can providers of supports and services do that show they understand that people with developmental disabilities come from many backgrounds?"

"Talk with them about what their interests are, where the background is, and try to get a better understanding of where they came from. Get involved with some of the activities that they get or cultures they're involved with."

"Just speaking to them and try to get to know them, try their culture."

"Visit the town, see for themselves. Build relationships and transparency."

"Be more sympathetic… don't pass on them because they come from a different background."

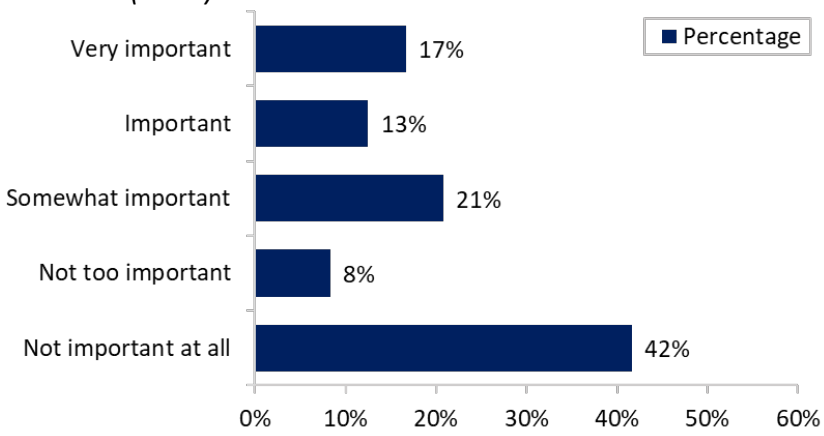
"Have a translator and language papers. Explain culture to staff."

Importance of Staff Sharing the Same Racial, Ethnic, or Cultural Background

Respondents were asked, "How **important** is it to you that staff are from the same racial, ethnic, or cultural group as you?"

The percentage of respondents who indicated *Not important at all* (42%) was the highest. Figure 1 presents the results for this item.

Figure 1.
Respondents' answers to how important it is to them that staff are from the same racial, ethnic, or cultural group as them (n=24).



Why Shared Racial, Ethnic, Cultural Background Is **Very Important**

Respondents were asked, "You said staff being from the same racial, ethnic, or cultural group as you is **very important**. Please tell us why."

"Because it is important to know that each person has their own origins."

"So that we can work better with the people we're dealing with."

Why Shared Racial, Ethnic, Cultural Background Is **Important**

Respondents were asked, "You said staff being from the same racial, ethnic, or cultural group as you is **important**. Please tell us why."

"Probably they would understand where I come from and understand certain things that I would have that I am going through. But I accept everybody for who they are. You know, it doesn't matter to me what racial background they come from. As long as you're helping me. It really is a good helping hand for me."

"As long as they can help you get to the services that you do need."

Why Shared Racial, Ethnic, Cultural Background Is **Somewhat Important**

Respondents were asked, "You said staff being from the same racial, ethnic, or cultural group as you is **somewhat important**. Please tell us why."

"So you have a lot of the same experiences, maybe celebrate some of the same holidays, have stuff to talk about."

"I'm fortunate enough to speak English but a lot of people speak Spanish in my neighborhood. So, I think it's important to have people that are somewhat relatable to my culture, like understand the different nuances of my culture. Even if it's not for me personally and it's for others in my neighborhood."

"I feel like some people don't like to share their culture, and we shouldn't force them to talk about their culture if they don't want to."

Why Shared Racial, Ethnic, Cultural Background Is **Not Too Important**

Respondents were asked, "You said staff being from the same racial, ethnic, or cultural group as you is **not too important**. Please tell us why."

"Not so important. It doesn't matter to me what race, nationality, color, skin color, whatever you are. You're there to help me. As long as you provide the service, and you provide the service good."

"As long as they're there to help me, or help people, I think that's more of an easier thing for them to do if they can be just flexible."

Why Shared Racial, Ethnic, Cultural Background Is **Not Important at All**

Respondents were asked, "You said staff being from the same racial, ethnic, or cultural group as you is **not important at all**. Please tell us why."

"Judge people based on the content of their character, not where they come from. Not the color of their skin."

"I just want somebody who cares."

"I like to meet new and different people, and I can teach them about my cultural beliefs, and they can teach me about theirs."

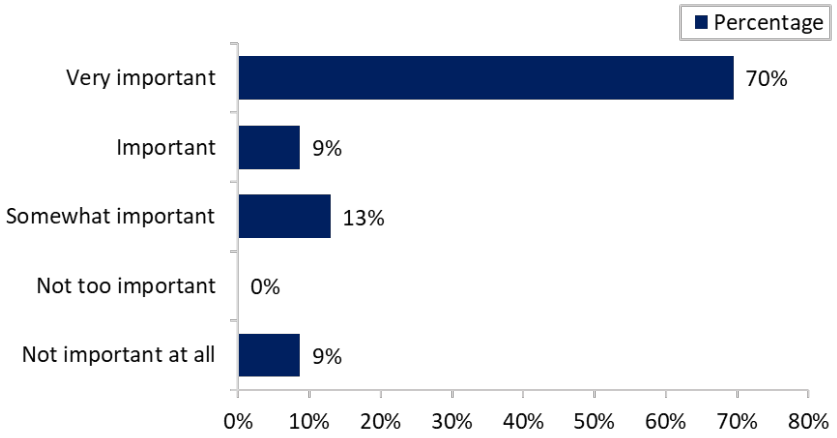
"I don't see it as something that's important."

Importance of Staff Speaking the Same Language

Respondents were asked, "How **important** is it to you that staff speak the same language as you?"

The percentage of respondents who indicated *Very important* (70%) was the highest. See Figure 2 for the graphic representation of this item.

Figure 2.
Respondents' answers to how important it is to them that staff speak the same language as them (n=23).[*]



*Due to rounding, percentages and respondent numbers may be higher or lower than expected

Why Staff Speaking the Same Language Is **Very Important**

Respondents were asked, "You said staff speaking the same language as you is **very important**. Please tell us why."

"So we could be on the same page, so they can understand what you're explaining to them. Because if they're not, it would probably not be as helpful, and maybe they may not understand. So, if it can be the same understanding of what you're going through, it would go a long way."

"So, they can understand me, understand my wants and needs, and what my issues are, and my behavior plan."

"Trying to explain something when the other person doesn't understand what I'm saying makes it more difficult."

"If someone speaks another language, I'm not going to understand what they're saying to me."

Why Staff Speaking the Same Language Is **Important**

Respondents were asked, "You said staff speaking the same language as you is **important**. Please tell us why."

There was only one response coded to this question and the respondent said:

"To get my point across, they would have to listen very carefully to me and make sure that what I say does matter."

Why Staff Speaking the Same Language Is **Somewhat Important**

Respondents were asked, "You said staff speaking the same language as you is **somewhat important**. Please tell us why."

"Even when people speak the same language, you can still be disconnected. It's more about finding a way to communicate."

"They have to speak the same language I do to communicate with me, but that doesn't have to be the only language they speak."

Why Staff Speaking the Same Language Is **Not Too Important**

Respondents were asked, "You said staff speaking the same language as you is **not too important**. Please tell us why."

There were no comments presented with this response.

Why Staff Speaking the Same Language Is **Not Important at All**

Respondents were asked, "You said staff speaking the same language as you is **not important at all**. Please tell us why."

"I don't care what language you speak, as long as you understand me and I understand you."

Persons with IDD - Findings by Framework Category: *Quality*

In the next set of inquiries under the framework category of *Quality*, respondents were asked to provide suggestions on what staff can do to show understanding of the importance of culture and what can be done to improve supports and services. Findings highlight that supports and services perceived as high in quality were characterized by respectful communication and staff listening to understand, as well as tailoring supports to each person's unique interests, needs, and lived experiences.

What Staff Can Do to Show Understanding of Importance of Culture

Respondents were asked, "What can the staff who support you do that shows they understand what is important to you about your culture?"

"Just be understanding and helpful. Look in the life plan of what they have and what I have said. People don't seem to understand that if people are provided with opportunity, they can make it on their own."

"Mainly spend some time with my family. Understand that my family is everything to me and understand that I really want the respect to be given back."

"Just being respectful, even when we have our differences. Having an open dialogue and maintaining mutual respect for each other's interests and likes. I identify as LGBTQ. It's finding a balance between it being your home and their workplace. They deserve to be respected in the workplace."

"Culture… religion's very sensitive. My peace and my well-being, my mental health is the most important thing. I don't really bring that up."

Suggestions for Improving Supports and Services Based on Culture and Language

Respondents were asked, "Thinking about your culture and language, is there anything you want to tell us that can make the services and supports you receive better?"

"Keeping a constant schedule for me is good. Making sure that I have a constant knowing of what is coming next. I don't like when things are sprung on me at the last minute—it alters my brain. I don't get enough notification about it. I really want staff to give us a heads up about schedule changes and keep in contact with me. Keeping that line of communication open is a really good assurance."

"I don't think so. I'm speaking from our own experience, but I think the state does the best it can for people in need, and that support comes in different layers."

"I feel like they talk about us with disabilities and not to us. The paperwork is one-size-fits-all. I should have a choice in how my plan is written. I'm a disabled person, and my disability informs every decision I make. We need disabled people at the top of OPWDD, not just consulted."

Persons with IDD - Findings by Framework Category: Utilization

The phrase "Nothing About Us Without Us" has long been a guiding principle within the disability rights movement, emphasizing the importance of full inclusion of persons with IDD in all aspects of community life. This section of the report on *Utilization* presents quantitative and qualitative findings related to respondents' experiences with the use of supports and services, including whether they felt heard, how they communicated their preferences, and what supports or changes might strengthen their ability to share their interests and needs with staff and decision-makers.

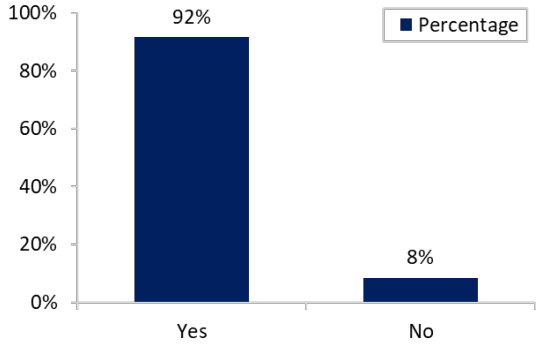
Respondents reported both positive and challenging experiences. Findings reflected positive experiences of being listened to, making their own decisions, and being engaged in shared decision-making. Conversely, other findings indicated minimal involvement with decision-makers, barriers related to communication and power dynamics, and limited opportunities for meaningful participation. Illustrative responses are provided below.

Ability to Tell Staff What Is Wanted and Needed

Respondents were asked, "Have you been able to tell staff who support you about what you want and need?"

The percentage of respondents who indicated *Yes* (92%) was higher. See Figure 3 for the graphic representation of this item.

Figure 3.
Respondents' answers to whether they have been able to tell staff who support them about what they want and need (n=24).



How Respondents Were Able to Tell Staff What They Want and Need

Respondents were asked, "Have you been able to tell staff who support you about what you want and need? If yes: tell me how this happened."

"Yes, I have been able to tell my support team what I need or want and how to improve my services. If I have problems, I know who to go to. I also tell my mom, and at my life plan meetings I tell my whole team what I need in my services and what I want to add."

"I'm in self-direction. When I get home tonight, we're having a plan meeting. I determine what the goals are, what the activities are, and what I need to get them done. It's person-centered planning. My goal is to continue to live in my own home. I know I can't go to the basement and do the laundry, so I need somebody to do the laundry or mop the floor. I get to schedule the services when I want them."

What Respondents Would Tell Staff They Want and Need and How They Would Want to Share It

Respondents were asked, "Have you been able to tell staff who support you about what you want and need? If no: what would you tell staff that you want and need? How would you want to do this?"

There was only one response coded to this question and the respondent said:

"I'm not sure. I never hear about that."

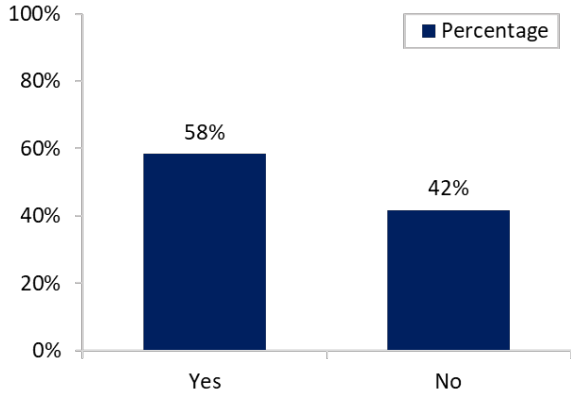
Whether Providers Asked Respondents to Share What Is Important to How They Want to Live

Respondents were asked, "Has your provider ever asked you to come to a meeting to tell staff what is important to how you want to live?"

The percentage of respondents who indicated *Yes* (58%) was higher. See Figure 4 for the graphic representation of this item.

Figure 4.

Respondents' answers to whether their provider has ever asked them to come to a meeting to tell staff what is important to how they want to live (n=24).



What Participants Said About How They Want to Live

Respondents were asked, "Has your provider ever asked you to come to a meeting to tell staff what is important to how you want to live? If yes: what did you say?"

"A few years ago, I went as part of a self-advocate group to a meeting to tell staff that a clinic was important and shouldn't close. I shared that I was a patient there, others said the same, and the clinic stayed open."

"Yes, for life plans. We do those once every six months and once every year. I talked about things I want to work towards and my social skills."

"Yes, I do that all the time in multiple agencies. I talk about being person-centered and giving people basic choices. I structure my conversations around options, like choosing when to shower or what to wear or eat."

What Respondents Would Say About How They Want to Live

Respondents were asked, "Has your provider ever asked you to come to a meeting to tell staff what is important to how you want to live? If no: what would you say?"

"They don't call unless you call them. If you don't follow up, you don't get updates. When you ask for services, they tell you what you don't need or say your child doesn't need it, even when doctors recommend it."

"I don't think they asked me. If I did go to a meeting, I would say I'm saving money to go on vacation in August."

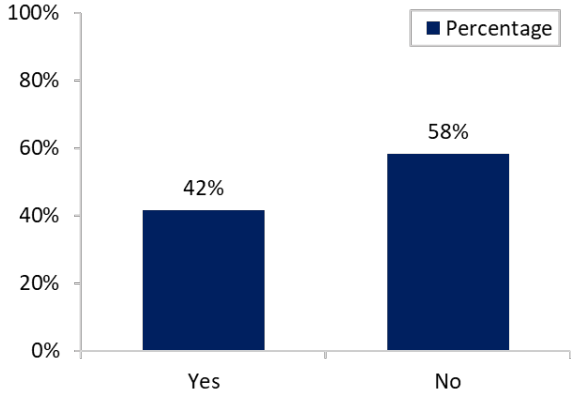
"I would come to the meeting. What day and time?"

Whether Providers Asked Respondents to Speak to Decision-Makers About What Is Important to Them

Respondents were asked, "Has your provider ever asked you to go with staff to meetings to tell people who make decisions about supports what is important to you?"

The percentage of respondents who indicated *No* (58%) was higher. See Figure 5 for the graphic representation of this item.

Figure 5.
Respondents' answers to whether their provider has ever asked them to go with staff to meetings to tell people who make decisions about what supports are important to them (n=24).



What Respondents Said and How They Felt About Speaking to Decision-Makers

Respondents were asked, "Has your provider ever asked you to go with staff to meetings to tell people who make decisions about supports what is important to you? If yes: what did you say? How did you feel?"

"Yes, I've done that. Early on, they asked me to tell them what self-direction was like. I shared the pros and cons and explained that people in self-direction have already been determined to manage it and should be allowed to help guide the process. It feels nice to be asked, but also frustrating that the same conversations keep happening years later. It can feel like being chosen as a token—part proud, part frustrated."

"Being able to share what's important to me feels very, very important."

"She tells me to join the meeting, but I forget to attend even when I put it on the calendar. If I did attend, I would say that I have trouble making decisions and that sometimes it doesn't work for me."

"I've done this many times across agencies. I'm on task forces and talk about what people who are aging want, like not being in day programs forever. Even when I'm speaking for others, I feel awesome about it."

Respondents' Interest in Speaking to Decision-Makers and What They Would Say

Respondents were asked, "Has your provider ever asked you to go with staff to meetings to tell people who make decisions about supports that are important to you? If no: would you like to do this? What would you say?"

"I've never been requested to do this. My wife used to be the point person and advocate for our child, but she passed away eight years ago. Every family is different, and I'd be happy to speak with others to help them find support and keep people home."

"No, they don't ask me to go to meetings to share my input. If meetings were local or online, I would do that, but they haven't been."

Family Members: Participant Demographics (n=330)

Interviews and listening sessions were conducted with n=330 family members of persons with IDD. As shown in Table 8, the majority of respondents, 85%, were family members of persons with IDD who were currently receiving supports and services (Group A). Three percent (3%) were family members of persons with IDD who previously received supports and services but were not currently receiving them (Group B). Twelve percent (12%) consisted of family members of persons with IDD who were never successful in accessing supports and services (Group C).

Respondents were represented across all OPWDD regions (Figure 6), with the largest proportion from Region 4 (Metro, Brooklyn, Staten Island & Bernard Fineson) at 43%; Region 3 (Capital District, Taconic & Hudson Valley) and Region 5 (Long Island), each at 18%. Respondents reflected a range of age groups (Figure 7), with the highest representation among persons aged 45–54 years (29%) and 55–64 years (28%), followed by those aged 35–44 years (24%). Ethnically, 82% were non-Hispanic or Latino (Table 9). Respondents reflected diverse racial backgrounds (Table 10), with 46% identifying as White, 24% identifying as Asian, followed by 13% identifying as Black or African American. Listening sessions and interviews with family members were conducted in five languages: English (81%), Chinese (12%), Spanish (4%), Korean (2%), and Russian (less than 1%) (Table 11).

Group C respondents are not included in the demographic data for types of supports and services because they reported not receiving supports and services. Respondents in Groups A and B (n=290) reported that types of supports and services most frequently received were Self-Direction (28%) and Community Habilitation or Personal Care (16%), followed closely by Respite Services (15%) (Figure 8). Length of time receiving supports and services varied across respondents (Figure 9), with the largest proportion reporting more than six years (47%), followed by three-four years (16%) and one-two years (14%). Tables 8-11 and Figures 6-9 present the frequencies for these demographic variables.

Group Type: Status of Supports and Services

Respondents were asked, "Has your family member ever received supports and services through OPWDD?"

Table 8.

Families' status on receiving supports and services through OPWDD (n=330).

Groupings	Status	Percentage*	Number of Participants*
Group A	Yes, currently receiving supports and services	85%	281
Group B	Yes, received supports and services in the past, but not currently	3%	9
Group C	No, not currently or did not receive supports and services in the past	12%	40

*Due to rounding, percentages and participant numbers may be higher or lower than expected

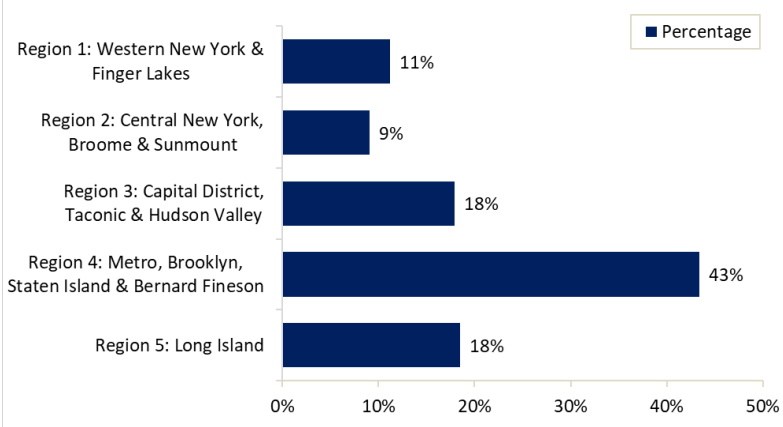
Questions differed by respondent group, reflecting their respective service experiences (refer to Appendices A-C for the full list of questions for each group).

Region

In which OPWDD region are you located?

Figure 6.

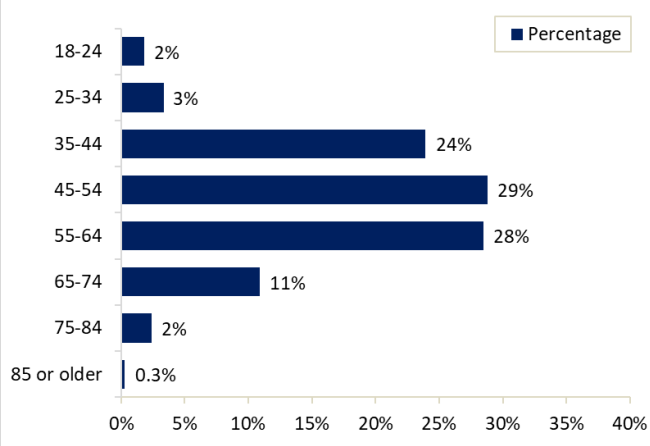
Distribution of participants by OPWDD region (n=330).



Age Range

Figure 7.

Distribution of respondents by age range (n=330).



Ethnicity

Table 9.

Ethnicity of Family Members of Persons with IDD (n=330).

Ethnicity	Percentage*	Number of Participants*
Hispanic or Latino	18%	61
non-Hispanic or Latino	82%	269

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

Racial Background

Table 10.
Racial Background of Family Members of Persons with IDD (n=330).

Racial background	Percentage*	Number of Participants*
White	46%	151
Black or African American	13%	44
Asian	24%	80
Native American or Alaska Native	1%	3
Two or more races	7%	22
Other	9%	30

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

For respondents who selected *Other (please specify)*, illustrative responses are provided below.

"Puerto Rican"

"Latino of African/European/Indigenous decent"

"Latino Indigenous (mestizo)"

"Jewish"

"Indigenous"

"I am Ashkenazi and my son is Native Central American."

"Guyanese East Indian"

"Bavarian"

"Ashkenazi"

Table 11.

Language Preferred for Participating in Listening Session by Family Members of Persons with IDD (n=330).

Language Preferred for Participating in Listening Session	Percentage*	Number of Participants*
English	81%	266
Chinese	12%	41
Spanish	4%	12
Korean	2%	8
Russian	0.3%	1
Other	1%	2

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

For respondents who selected *Other (please specify)*, illustrative responses are provided below.

"English or Spanish"

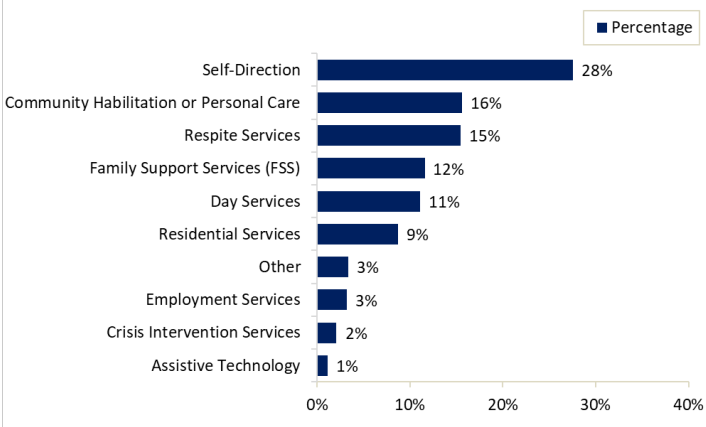
"English and ASL or closed-caption in English"

Types of Supports and Services

The types of supports and services reported by respondents in Groups A and B are shown, combining current and past service use. Percentages represent the total number of supports and services selected.

Figure 8.

Distribution of respondents by types of supports and services currently receiving or received in the past (n=290).

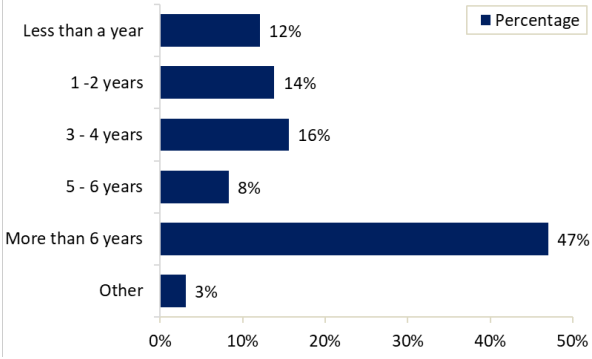


Length of Time Receiving Supports and Services

The figure below depicts the range of time respondents in Groups A and B reported receiving supports and services, including both current and previous service use. Percentages show the distribution of responses across time periods.

Figure 9.

Distribution of respondents by the length of time they have been receiving supports and services (n=290).



Findings for Family Members of Persons with IDD

Presentation of Findings by Framework Category

The sub-sections below present qualitative findings across the five framework categories—Availability, Accessibility, Acceptability, Quality, and Utilization. For **Group A (n=281)**, two themes are presented. Theme 1 represents the most frequently applied code, and Theme 2 represents the second most frequent. Due to the number of respondents in **Group B (n=9)** and **Group C (n=40)**, only one theme is presented. For Group C, the findings are organized across three of the five framework categories —*availability, accessibility, and utilization*. The other categories, *acceptability*, and *quality* were not presented to the respondents because they never received supports and services —and therefore could not evaluate these categories. For *utilization*, Group C respondents rated the ease of using the website for getting supports and services.

For all groups, illustrative comments were selected except in cases where a category included only one comment or no comments. The questions presented to respondents are included in the appendices. For ease of reference and to provide context for the data presented, each question is also provided within the findings section.

Summary of Findings for *Availability*

When discussing *availability*, the majority of respondents from Groups A and B indicated that the supports and services were available that met the needs of their family member with IDD and were responsive to their cultures. However, the percentages of respondents who reported either "yes or no" that supports and services were available when they needed them or in the amount that they needed were almost equal. Those who responded "yes" stated that they had positive experiences with providers that were supportive and timely. Respondents who said "no" indicated long wait times, complex processes to obtain supports and services, a lack of clear guidance, and feelings of frustration and lack of support in navigating the system. Group C respondents shared the reasons they thought supports and services were not available to them, including waiting lists, denials, and a lack of clarity about required documentation. Additionally, Group C indicated what they thought would make supports and services available to them and in ways that considered their cultural beliefs, practices, and preferred language. Suggestions included clearer guidance and culturally and linguistically competent staff. Illustrative responses are provided below.

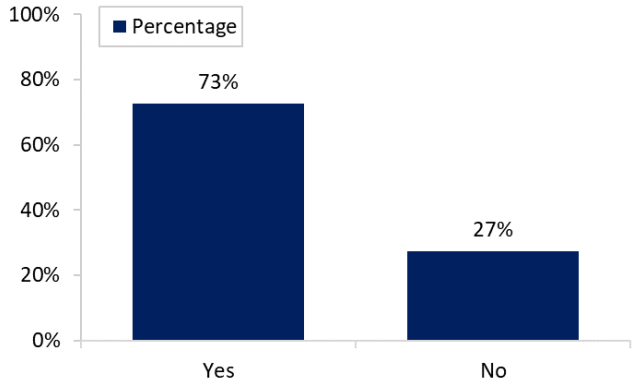
Group A – *Availability*

Whether Families Are Receiving the Supports and Services They Want and Need

Respondents were asked, "When you think about your family's cultural beliefs and practices, and preferred language: Would you say you are getting the supports and services you want and need for your family member who has an intellectual or other developmental disability?"

Figure 10.
Respondents' answers to whether they are getting the supports and services they want and need for their family member who has an intellectual or other developmental disability, when thinking about their family's cultural beliefs and practices, and preferred language (n=277).

The percentage of participants who indicated *Yes* (73%) was higher. Figure 10 presents the results for this item.



Supports and Services Families Are Receiving That Meet Their Needs

Respondents were asked, "If yes: Tell us more about the supports and services you are receiving that you want and need."

An analysis of the responses to the open-ended prompt above is presented below, categorized by emerging themes and their illustrative quotes.

Theme 1: Type of service

Respondents provided details about the types of supports and services they are receiving.

> *"My sons, who are autistic young men in their 20's, are receiving care management, and self-direction services. We are very happy with these supports though we have ideas regarding how they could be better."*
>
> *"We are receiving family support service, respite care, and assistive technology which is what we want and need."*
>
> *"Supported employment (SEMP) - not enough work hours but working. Job coach – helpful. Newly enrolled in self-direction. Psychiatry – adequate."*

Theme 2: Requesting more support

Respondents often requested more supports and services to complement what they were already receiving.

> *"We were recently approved for community habilitation (com hab) and respite. Through this, my son has begun inclusive fitness classes. We met with our care coordinator and applied for self-direction. As we are new to OPWDD, we are hoping to receive more supports and services as we learn more."*
>
> *"It would be good to expand job opportunities for people with disabilities. More vocational training and support would help."*
>
> *"Guidance is needed to help me understand the services available and how to access them."*

Reasons Families Are Not Receiving Needed Supports and Services

Respondents were asked, "If no: Tell us why you are not getting the supports and services you want and need."

An analysis of the responses to the open-ended prompt above is presented below, categorized by emerging themes and their illustrative quotes.

Theme 1: OPWDD system

Respondents described the OPWDD system as complex and difficult to navigate, with administrative barriers, limited guidance, and a significant burden placed on families to coordinate supports and services, often resulting in inadequate access.

> *"Far too many administrative barriers. The 'culture' of OPWDD is one of care-taking and compliance. A required service is not available unless it fits into one of a handful of narrowly defined categories."*

> *"There is an undue burden on families to manage everything to do with the IDD system. From FINDING services, to making them work, etc. It takes about 20 years for a family to figure out how it all works, and then getting the right people involved to help. That's from someone who speaks English, is highly educated, and has the resources to engage experts. If you AREN'T in those categories, then you are probably getting sub-optimal results for your family member. Housing, employment, and access to the community, are all still very siloed and hard to access."*

Theme 2: Type of service

Respondents described gaps in available supports and services, noting that supports were often insufficient, limited in scope, or difficult to access in a timely manner. As a result, families frequently had to fill in unmet needs themselves.

> *"We are grateful for the services we receive, but they are not enough to meet all of our needs. I often feel like I have to fill in the gaps myself because there are limited options available."*

> *"The supports we get help somewhat, but the day program hours are very short and do not provide enough structure or support throughout the day. This makes it hard for our family to manage everything."*

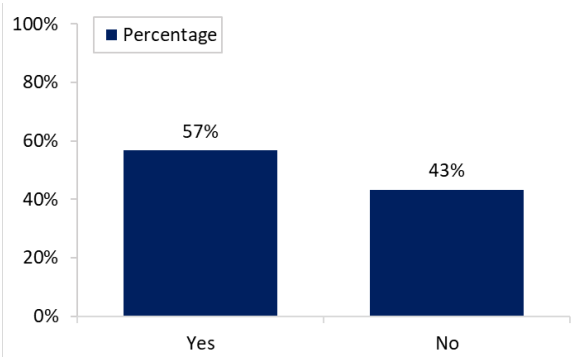
"It has been very difficult trying to access self-direction and other services. The process takes a long time, and while we wait, we are left without the supports we really need."

Whether Supports and Services Were Available When Needed

Respondents were asked, "Were the supports and services **available** when you and your family needed them?"

The percentage of participants who indicated *Yes* (57%) was higher. Figure 11 presents the results for this item.

Figure 11.
Respondents' answers to whether supports and services were available when the family needed them (n=277).



How Supports and Services Were Available When Needed

Respondents were asked, "If yes: Please describe how the supports and services were available when you and your family needed them."

An analysis of the responses to the open-ended prompt above is presented below, categorized by emerging themes and their illustrative quotes.

Theme 1: Type of service

Families reflected on how their access to supports and services had changed over time and emphasized the importance of specific service types—such as self-direction, school-based supports, and community programs—in meeting their family members' needs.

"When we started self-direction it was very difficult, but over time it has improved. The services we receive now are helpful, though it took a long time to get to this point."

"The supports were available in the school. She received what she needed while she was there, but once she aged out, those services were no longer available."

"The supports are available, but they do not always cover everything my family member needs, so we still have to fill in the gaps."

Theme 2: Positive experiences with providers

Many families shared positive experiences with providers, describing supports and services as timely, responsive, and aligned with their family member's needs. These comments emphasized feeling listened to, supported, and reassured by providers during moments when supports and services were most needed.

"Our providers were very supportive and helped us navigate what we needed during difficult times."

"We felt listened to, and the providers worked with us to make sure services were in place when our family needed them."

"The supports were available at the right time, and the providers made the process easier for our family."

How Supports and Services Were Not Available When Needed

Respondents were asked, "If no: Please describe how the supports and services were not available when you and your family needed them."

An analysis of the responses to the open-ended prompt above is presented below, categorized by emerging themes and their illustrative quotes.

Theme 1: OPWDD system

Families described challenges accessing supports and services through the OPWDD system when they were most needed, often citing long wait times, complex processes, and lack of clear guidance.

"The OPWDD process takes too long, and by the time services are approved, the need has already changed."

"It was very confusing trying to understand what OPWDD services we qualified for and how to access them."

Theme 2: Time Frame

Many families described challenges related to timing, explaining that supports and services were not available quickly enough or were delayed beyond when they were most needed. Comments pointed to long wait periods, slow approvals, and gaps during stressful times.

"We were told services were available, but it took months to actually receive any support."

"Supports were eventually offered, but not when our family actually needed them."

"There was a long gap between when we asked for help and when anything was put in place."

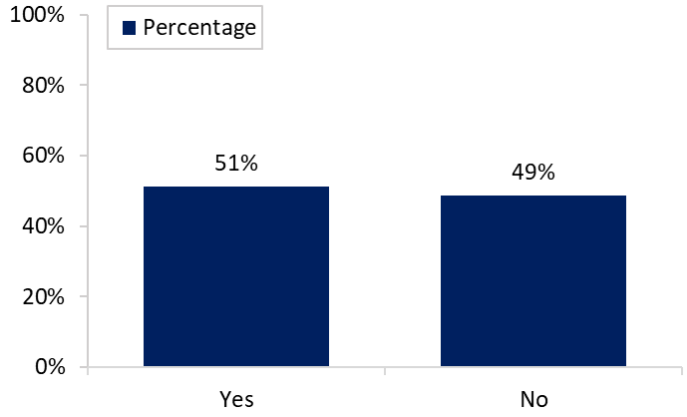
"There was no one to guide us through the system, and we felt left on our own during a very stressful time."

Whether Supports and Services Were Available in Needed Amount or Frequency

Respondents were asked, "Were the supports and services available in the amount or frequency that you needed?"

The percentage of participants who indicated *Yes* (51%) was higher but was followed closely by those who indicated *No* (49%). Figure 12 presents the results for this item.

Figure 12.
Respondents' answers to whether supports and services were available in the amount or frequency that they needed (n=277).



How Supports and Services Met Needed Amount or Frequency

Respondents were asked, "If yes: Please describe how the supports and services were available in the amount or frequency that you needed."

Theme 1: Amount of services
Families indicated that supports and services were available in the amount or frequency they needed, often describing consistent schedules, regular hours, or full-time supports that aligned with their family member's needs.

"They know how many days or hours to give us."

"Although my son moved into a community residence, the amount of services he receives has been appropriate for his needs."

"My daughter received the supports she needed in school and also for after-school programs."

"The support is available seven days a week."

"Five days a week of day habilitation and full-time residential services have met our needs."

Theme 2: Type of service

Families discussed whether the amount or frequency of supports and services met their needs, with many noting that although some supports were helpful, they were often insufficient in intensity, duration, or consistency.

"The services are helpful, but they are not frequent enough to fully meet our needs."

"We receive some support, but the number of hours is not enough."

"The type of services we get is good, but we need them more often."

"Supports are available, but the amount provided does not match what our family needs."

"We need more hours and more consistency with the services we receive."

How Supports and Services Did Not Meet Needed Amount or Frequency

Respondents were asked, "If no: Please describe how the supports and services were not available in the amount or frequency that you needed. In other words, please explain your answer."

Theme 1: OPWDD system

Respondents described challenges related to the OPWDD system that limited the amount or frequency of supports and services they received, including delays, administrative barriers such as difficulty navigating approval processes. These system-level issues often resulted in families receiving fewer supports than needed or waiting extended periods for supports and services to be put in place.

"The OPWDD process takes too long, and services are not approved in time to meet our needs."

"We were approved for services, but the amount provided was much less than what was needed."

"It is very difficult to navigate the OPWDD system, and that affects how much support we actually receive."

"Even after approval, it took a long time for services to start."

Theme 2: Staffing

Comments frequently pointed to long periods without assigned workers and structural barriers such as difficulty hiring and retaining staff, low pay, and limited hours.

"We waited a very long time, almost a year, for a com hab worker. There seems to be a worker shortage."

"Due to the low hourly rate, it is hard to find someone to do the job."

"Staff were rarely assigned, and even when they were, it was for a very short and disruptive amount of time."

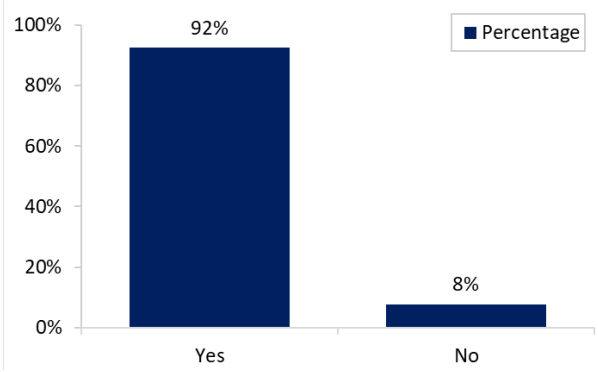
"After being without direct support assistance for a year, we advertised for six months and only one person responded."

Whether Supports and Services Were **Available** in Preferred Language

Respondents were asked, "Were the supports and services **available** in your preferred language?"

The percentage of participants who indicated *Yes* (92%) was higher. Figure 13 presents the results for this item.

Figure 13.
Respondents' answers to whether supports and services were available in their preferred language (n=277).



How Supports and Services Were Available in Preferred Language

Respondents were asked, "If yes: Please describe how the supports and services were available in your preferred language."

Theme 1: Linguistic needs met

Among families who reported that supports and services were available in their preferred language, overall comments indicated that this contributed to clear and effective communication. Respondents who referenced preferred languages other than English, commented on the presence of bilingual staff, interpreters, and providers who were able to communicate directly with them in their preferred language. It is important to note that the majority of respondents (81%) were English speakers, which likely contributed to the high rates reported for language access. Some families explicitly indicated that language-related questions did not apply to them, as they received supports and services in English.

"The services were always provided in Spanish when we needed them."

"Staff spoke our preferred language, which made communication much easier."

"Interpreters were available whenever we requested them."

"We were able to communicate clearly because the provider spoke our language."

"Language was never a barrier when receiving services."

Theme 2: Linguistic needs

Some families described mixed experiences with language access, including partial accommodations and neutral observations about language use. These comments reflected general experiences with communication rather than clearly positive or negative patterns.

"Some information was provided in our preferred language, but not everything."

"We usually communicated in English, even though another language is preferred at home."

"How language was handled seemed to change over time."

How Supports and Services Were Not Available in Preferred Language

Respondents were asked, "If no: Please describe how the supports and services were not available in your preferred language."

Theme 1: Linguistic needs not met

Respondents who reported that supports and services were not available in their preferred language described lack of translation or interpretation and difficulty locating language-specific supports and services.

"My main language is Spanish, and I had no translations."

"It's hard to find places that provide Korean language services."

"Classes were not in American Sign Language (ASL)."

Theme 2: Staffing

Families described staffing-related barriers, including a lack of bilingual staff and limited staff understanding of language needs.

> *"My brother speaks English, but he uses many Armenian words, such as for food, to say good morning and good night, sometimes to count to ten, and other miscellaneous words. It would be good for the staff to understand when he's using these words and what they mean, but it appears that doesn't happen."*
>
> *"[There is a] shortage of Chinese-speaking staff."*

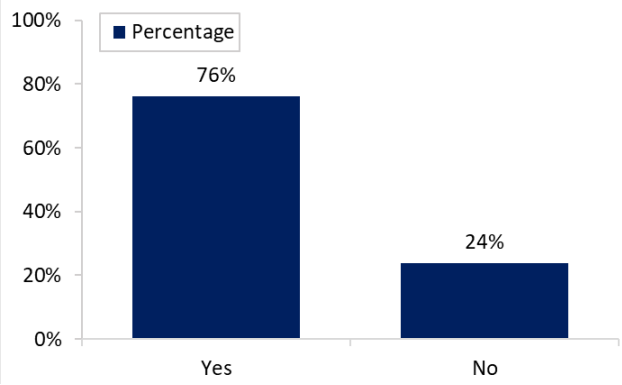
Whether Supports and Services Were **Available** in Ways That Considered Family Cultural Beliefs and Practices

Respondents were asked, "Were the supports and services **available** in ways that considered your family's cultural beliefs and practices?"

The percentage of respondents who indicated *Yes* (76%) was higher. Figure 14 presents the results for this item.

Figure 14.

Respondents' answers to whether supports and services were available in ways that considered their family's cultural beliefs and practices (n=277).



How Supports and Services Were Available in Ways That Considered Family Cultural Beliefs and Practices

Respondents were asked, "If yes: Please describe how the supports and services were available in ways that considered your family's cultural beliefs and practices."

Theme 1: Cultural needs met

Families described positive experiences in which supports and services aligned with and respected their family's cultural beliefs and practices. Respondents highlighted how providers incorporated cultural practices into service delivery, including participation in holidays and access to religious activities.

"My sons share in holidays and other observations reflecting their heritage and they benefit from sharing in those of their housemates."

"None of the services were in opposition to or disregarded our cultural beliefs and practices."

"My son's budget allowed him to take religious classes and join his temple."

Theme 2: Cultural needs

Within the broader category of cultural needs, some families described cultural needs as not applicable or not requiring special consideration. These comments reflected general or neutral perspectives rather than experiences of needs being met or not met.

"This doesn't really apply to us, as our cultural beliefs and practices are mostly in-line with typical American ones."

"We have no specific cultural beliefs that require special consideration."

How Supports and Services Were Not Available in Ways That Considered Family Cultural Beliefs and Practices

Respondents were asked, "If no: Please describe how the supports and services were not available in ways that considered your family's cultural beliefs and practices."

Theme 1: Cultural needs not met

Families described situations in which supports and services did not adequately consider their family's cultural beliefs and practices, including lack of cultural awareness, lack of recognition of cultural importance, and supports and services that did not align with culturally-specific needs.

"In the past, some program activities were scheduled without regard for our cultural holidays—for example, holding events on the Mid-Autumn Festival—which was not culturally appropriate. We hope this can be improved."

"When they are not acknowledged as important in our son's life."

"We are a mixed family. I have two culturally specific issues. 1. My daughter needs help with her hair and she's very sensitive because of her autism and getting help and getting this cost covered is not normally in the budget. 2. We are also survivors of domestic violence (DV) and there's no DV type supports that relate to OPWDD. I know that we are not the only ones. I think it's probably very common in special needs families."

"Dismissive and retaliatory actions towards recipient for family advocating and voicing concerns. Do not value or recognize family input and culture."

Theme 2: Cultural needs

Some respondents described lack of cultural understanding, lack of recognition of disability culture, and concerns about respect and alignment of supports and services with family interests and needs, without clearly framing their experiences as fully met or unmet.

"In planning conversations, I do not sense OPWDD understands (our) beliefs and practices."

"It is disrespectful at my age to be waiting for help and the staff not call to explain or warn they are not coming."

"They do not consider disability culture. More affirming and family-friendly supports are needed. For example, the non-approvable list includes "baby gates" - when you're applying for items for say a 10-year-old child, it's infantilizing to call it a baby gate. It's a "safety gate" or a support against elopement, for example. Also, this item should be allowed as one of the reasons for the program is to keep a child out of institutional care and the safety items that allow us to do that are almost always denied, as are adaptive items and sometimes clothes and mattresses. These are basic items, yet museum membership and craft supplies are covered? Families need much greater control over what their own family member with IDD needs most, within the context of their family budget. Recreation items are allowed but outdoor recreation is

not and it isn't explained why. Our family enjoys being outdoors. An outdoor playset isn't allowed, which often contain swings but outdoor swings were added as allowable. The whole list makes no sense and should be scrapped as well as the dual levels of approval that were added in 2022 (agency committee and then OPWDD regional office).”

Group B – *Availability*

Reasons Families Are Not Currently Receiving Supports and Services

Respondents were asked, “Tell us why you are not currently receiving supports and services.”

“I was told that my son was ineligible when he was eight years old. I engaged in extensive back-and-forth email communication with OPWDD, but nothing positive resulted.”

“In my case, I have a 15-year-old, and I was told that this represented a gap that made it difficult to apply. We have gone through the application process before, and the result was a denial.”

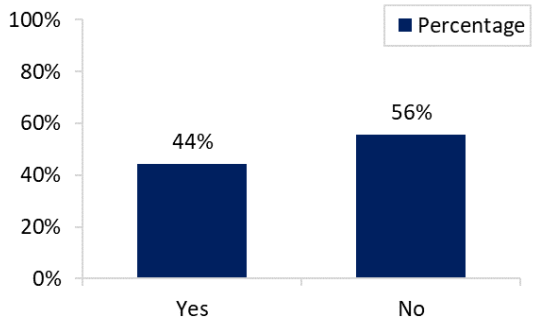
“Nothing was mentioned except that respite was not identified as a needed service.”

Whether Families Were Receiving the Supports and Services They Wanted and Needed in the Past

Respondents were asked, “When you think about your family’s cultural beliefs and practices, and preferred language: Would you say you were getting the supports and services you wanted and needed for your family member who has an intellectual or other developmental disability?”

The percentage of participants who indicated *No* (56%) was higher. Figure 15 presents the results for this item.

Figure 15.
Respondents' answers to whether they were getting the supports and services they wanted and needed for their family member who has an intellectual or other developmental disability, when thinking about their family's cultural beliefs and practices, and preferred language (n=9).



Supports and Services Families Were Receiving in the Past That Met Their Needs

Respondents were asked, "If yes: Tell us more about the supports and services you were receiving that you wanted and needed."

"The situation was complicated. We are not a very religious family (Jewish and Catholic), but we take our son home for Passover and Christmas and to temple for Yom Kippur. He enjoys doing these activities with us. However, we are 71 years old and would like to know whether the group home and day program will continue these activities when we are no longer able to do so."

"My child received counseling a few summers ago, which benefitted his well-being."

"The services we received included respite, family reimbursement, home health aide services, and community habilitation."

Reasons Families Were Not Receiving Needed Supports and Services in the Past

Respondents were asked, "If no: Tell us why you were not getting the supports and services you wanted and needed. In other words, please explain your answer."

"I have no idea."

"To obtain behavioral health services, we were denied help many times because our son came from a 'good' family, and services were limited to children within certain income levels. We were told that we were expected to be involved in the care of our

son, which makes little sense, as we are already his advocates and assist him in navigating services and needs."

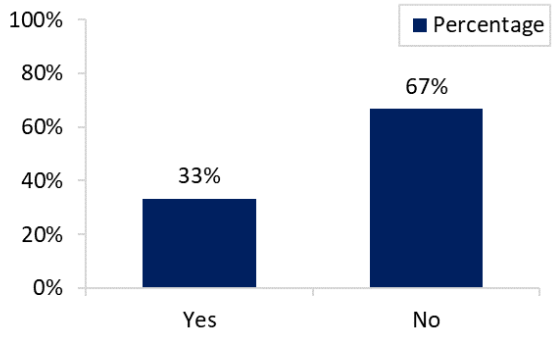
"There are not enough specialist doctors and therapists."

Whether Supports and Services Were **Available** When Needed

Respondents were asked, "Were the supports and services **available** when you and your family needed them?"

The percentage of respondents who indicated *No* (67%) was higher. Figure 16 presents the results for this item.

Figure 16.
Respondents' answers to whether supports and services were available when they and their family needed them (n=9).



How Supports and Services Were Available When Needed

Respondents were asked, "If yes: Please describe how the supports and services were available when you and your family needed them."

"The services were made available by the staff at the program."

"I called the facility, they accepted Medicaid, and my child was able to begin services the following week."

How Supports and Services Were Not Available When Needed

Respondents were asked, "If no: Please describe how the supports and services were not available when you and your family needed them. In other words, please explain your answer."

"Nothing was mentioned, except that respite was not identified as a needed service."

"I have needed these supports since moving back to New York City, and I still have not received them."

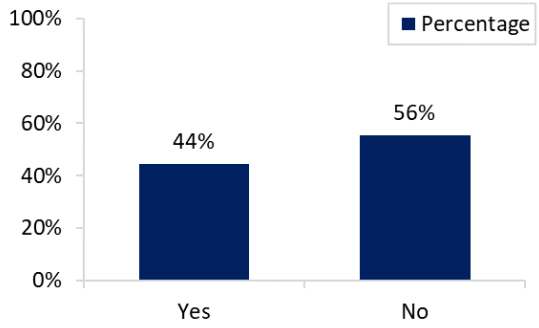
"The waiting list for the program was not staffed or available in Region 2."

Whether Supports and Services Were **Available** in Needed Amount or Frequency

Respondents were asked, "Were the supports and services **available** in the amount or frequency that you needed?"

The percentage of respondents who indicated *No* (56%) was higher. Figure 17 presents the results for this item.

Figure 17.
Respondents' answers to whether supports and services were available in the amount or frequency that they needed (n=9).



How Supports and Services Met Needed Amount or Frequency

Respondents were asked, "If yes: Please describe how the supports and services were available in the amount or frequency that you needed."

"The services were available six days per week."

"The facility was flexible with our schedule and with whether meetings took place on site or virtually."

How Supports and Services Did Not Meet Needed Amount or Frequency

Respondents were asked, "If no: Please describe how the supports and services were not available in the amount or frequency that you needed. In other words, please explain your answer."

"No services were ever provided over a three-year period."

"Only 12 hours were approved, and I have not yet received those hours."

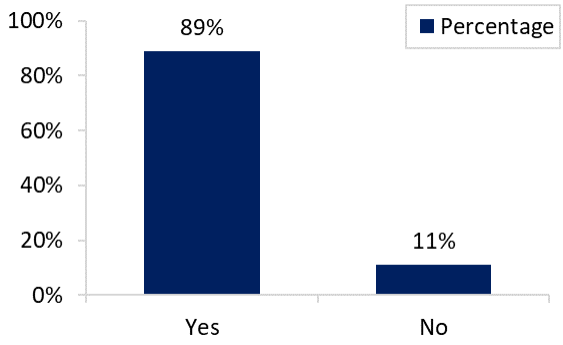
"There were limitations related to CSIDD services, emergency respite, community habilitation staff, respite staff, and approvals for behavioral specialists."

Whether Supports and Services Were **Available** in Preferred Language

Respondents were asked, "Were the supports and services **available** in your preferred language?"

The percentage of participants who indicated *Yes* (89%) was higher. Figure 18 presents the results for this item.

Figure 18.
Respondents' answers to whether supports and services were available in their preferred language (n=9).



How Supports and Services Were Available in Preferred Language

Respondents were asked, "If yes: Please describe how the supports and services were available in your preferred language."

"Services were available in Spanish."

"Services were available in English."

"I speak both English and Spanish."

"My son speaks and understands English, and the materials were available in English."

How Supports and Services Were Not Available in Preferred Language

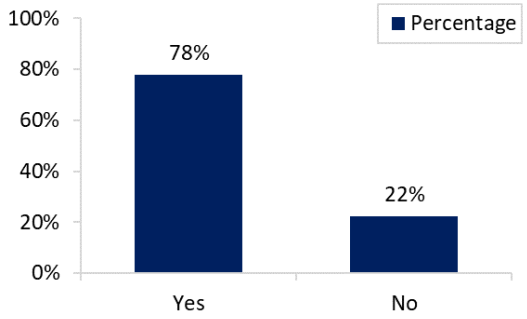
Respondents were asked, "If no: Please describe how the supports and services were not available in your preferred language."
There were no comments presented with this response.

Whether Supports and Services Were **Available** in Ways That Considered Family Cultural Beliefs and Practices

Respondents were asked, "Were the supports and services **available** in ways that considered your family's cultural beliefs and practices?"

The percentage of respondents who indicated *Yes* (78%) was higher. Figure 19 presents the results for this item.

Figure 19.
Respondents' answers to whether supports and services were available in ways that considered their family's cultural beliefs and practices (n=9).



How Supports and Services Were Available in Ways That Considered Family Cultural Beliefs and Practices

Respondents were asked, "If yes: Please describe how the supports and services were available in ways that considered your family's cultural beliefs and practices."

"Yes, the facility considered our beliefs."

"This was possible because, as a mother, I stayed actively involved."

"The worker respected our Christian values and did not speak against certain things we expressed in our home."

How Supports and Services Were Not Available in Ways That Considered Family Cultural Beliefs and Practices

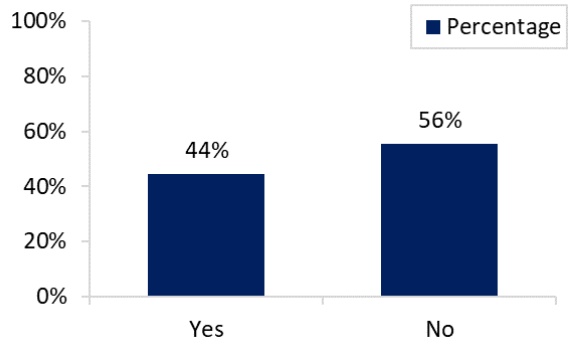
Respondents were asked, "If no: Please describe how the supports and services were not available in ways that considered your family's cultural beliefs and practices."
There was only one response coded to this question and the respondent said:
"*Providers were judgmental and placed greater emphasis on issues that were not relevant, such as gender, rather than focusing on my son's specific situation*."

Whether Supports and Services Were **Accessible** When Needed

Respondents were asked, "Were the supports and services **accessible** when you and your family needed them? (Accessible means easy to get to, find, or use.)"

The percentage of respondents who indicated *No* (56%) was higher. Figure 20 presents the results for this item.

Figure 20.
Respondents' answers to whether supports and services were accessible when they and their family needed them (n=9).



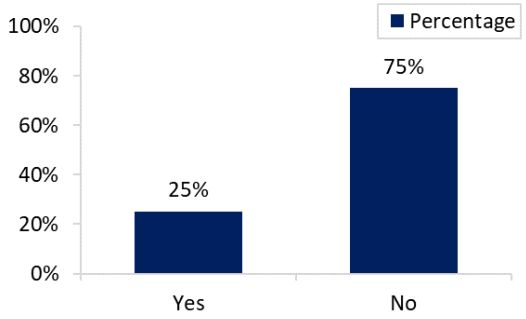
Group C – *Availability*

Whether Supports and Services Were Available to Families Who Have Never Received Supports and Services

Respondents were asked, "Were supports and services **available** to you?"

The percentage of respondents who indicated *No* (75%) was higher. Figure 21 presents the results for this item.

Figure 21.
Respondents' answers to whether supports and services were available to them (n=40).

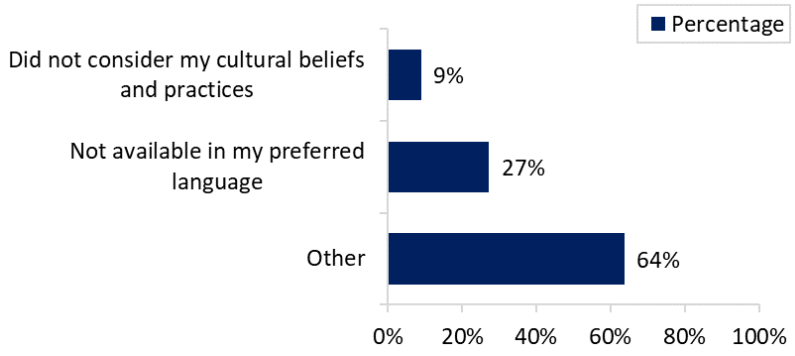


Reasons Families Did Not Use Available Supports and Services

Respondents were asked, "If supports and services were available, why didn't you use them? Was it because they: Did not consider your cultural beliefs and practices, Were not available in your preferred language, Other (please specify)."

The percentage of respondents who indicated *Other* (64%) was the highest. Figure 22 presents the results for this item.

Figure 22.
Respondents' answers to why they did not use supports and services if they were available (n=11).



For respondents who selected *Other (please specify)*, illustrative responses are provided below.

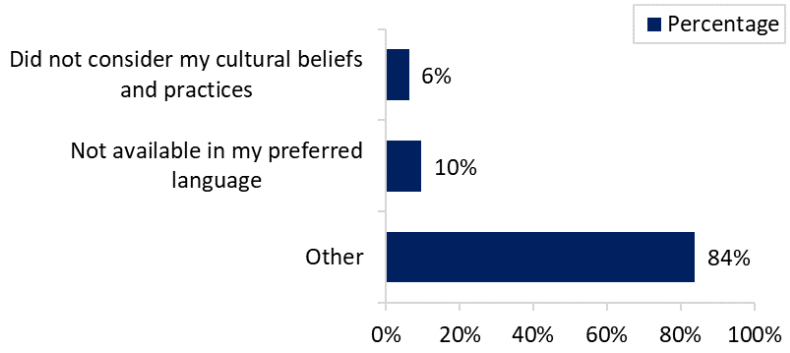
> *"Processing entities incorrectly denied or processed applications for support."*
>
> *"I've just been on a waiting list."*
>
> *"Process of getting papers together"*

Reasons Supports and Services Were Not Available to Families

Respondents were asked, "What are the reasons that supports and services were not available to you? Was it because they: Did not consider your cultural beliefs and practices, Were not available in your preferred language, Other (please specify)."

The percentage of respondents who indicated *Other* (84%) was the highest. Figure 23 presents the results for this item.

Figure 23.
Respondents' answers to the reasons that supports and services were not available to them (n=31).



For respondents who selected *Other (please specify)*, illustrative responses are provided below.

"When first diagnosed, I was told cognitively by his pediatrician he wouldn't get services. I wish I never listened and (had) applied when he was 10. It would have made a big difference in his development."

"Not enough CCOs in the state. Not enough employees at the CCOs."

"Specific diagnosis not recognized by OPWDD."

What Families Identified as Needed to Make Supports and Services **Available**

Respondents were asked, "When you think of your family's cultural beliefs and practices or preferred language, what could OPWDD do to make supports and services **available** to you and your family member with an intellectual or other developmental disabilities (IDD)?"

"I wanted to know exactly what documents were needed in my language. The process was too complicated."

"Make sure that workers really understand Spanish. Take siblings into account, and please do not send us to an agency that will deny us. This is very frustrating, especially with long waiting lists."

Summary of Findings for *Accessibility*

When discussing *accessibility*, family members from Groups A and B described multiple challenges when attempting to access supports and services, including difficulty navigating application processes, limited awareness of available programs, and difficulty communicating with service providers and systems. Some respondents noted that supports and services were difficult to access due to administrative requirements, lack of clear guidance, uncertainty about eligibility requirements and next steps, and significant delays between applying for supports and services and actually receiving them. The OPWDD website was described by many as being inaccessible and very difficult to navigate and understand. Group C respondents indicated what they thought could make supports and services accessible, including follow-up from social workers, improved attitudinal and professional staff behavior during interactions, and clarification of service options for their family members.

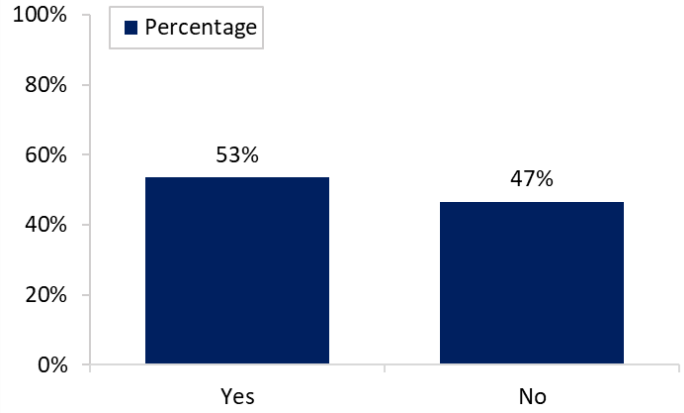
Group A – *Accessibility*

Whether Supports and Services Were **Accessible** When Needed

Respondents were asked, "Were the supports and services **accessible** when you and your family needed them? (Accessible means easy to get to, find, or use.)"

The percentage of respondents who indicated *Yes* (53%) was higher than those who indicated *No* (47%). Figure 24 presents the results for this item.

Figure 24.
Respondents' answers to whether supports and services were accessible when they and their family needed them (n=277).



How Supports and Services Were Accessible

Respondents were asked, "If yes: Please describe how the supports and services were accessible when you and your family needed them."

Theme 1: Positive experiences with providers

Respondents who reported positive experiences emphasized the approachability and responsiveness of providers, singling out case managers who served as navigators. Families described being able to reach providers when needed and receiving timely and accurate information.

"Things are much better now. We can reach the case manager by phone or email directly, instead of having to call the agency's main line and get transferred through extensions, which used to make it very difficult to find the right person. Now we can contact his work cell phone directly."

"Agencies and organizations do a good job of informing participants of pertinent directions."

"We get prompt and true answers to our questions. We are informed when our son needs urgent care."

Theme 2: Mode of services

Respondents described supports and services as accessible because they were delivered in practical, flexible, and family-centered ways, often tied to location (e.g., in-home or nearby) and mode of access (e.g., transportation and virtual options).

"A stable is nearby with a trainer willing to work with our child. We got lucky."

"My son is driven to the program and takes the van home or to his after day program."

"The services were either in my home or within our community environment."

"The case manager comes to our home or meets with us over the phone or Zoom, so that works and the services my son receives are accessible by subway or bicycle."

How Supports and Services Were Not Accessible

Respondents were asked, "If no: Please describe how the supports and services were not accessible when you and your family needed them."

Theme 1: OPWDD system

Respondents who described supports and services that were not accessible pointed to structural barriers within the OPWDD system, including extensive paperwork requirements, limited provider availability, administrative complexity, difficulty contacting OPWDD, and limited communication about available supports and services.

"There are too many required documents."

"This is a difficult process. Every time we think we're all set, there's another hurdle to apply for, more paperwork to send, another person to speak to to prove our son has a developmental disability. In that way, supports and services were not accessible."

"It is very difficult to contact OPWDD."

"OPWDD does not do an acceptable level of communicating all services that are available."

Theme 2: Time frame

Families describing accessibility challenges related to time frame emphasized prolonged delays at multiple stages of the process. They reported extended waitlists, slow approval timelines, and long periods without communication or follow-up. These delays affected access to providers, fiscal intermediaries, and counseling services, with respondents characterizing the overall process as time-intensive and difficult to move through in a timely manner.

"No available service providers, long wait lists, and months and years of waiting."

"Phone calls and messages were not answered and there was no follow through on the life plan."

"I submitted forms on March 29, 2024, for OTPS: Other Goods and Services Related to Health and Safety, including Care.com, Nest Camera, and AngelSense. AngelSense was approved on May 1, Care.com on May 7, but Nest Camera was never submitted to OPWDD. When I realized this, I resubmitted on August 6 and only received

approval on October 15, missing out on reimbursement during the reasonable approval period between May and August."

"Before self-direction, my child was on a list for assisted housing for a year. No one told me that there was a miniscule chance she would ever get off the list. She never got off the list. There were also issues finding com hab workers."

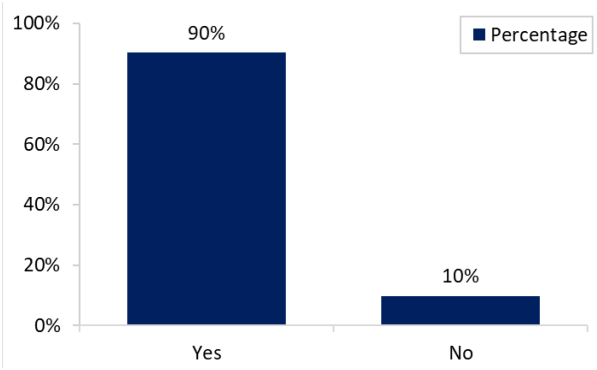
"We wait for a long time to get back in counseling and speech services."

Whether Supports and Services Were Accessible in Preferred Language

Respondents were asked, "Were the supports and services **accessible** in your preferred language?"

The percentage of respondents who indicated *Yes* (90%) was higher. Figure 25 presents the results for this item.

Figure 25.
Participants' answers to whether supports and services were accessible in their preferred language (n=277).



How Supports and Services Were Accessible in Preferred Language

Respondents were asked, "If yes: Please describe how the supports and services were accessible in your preferred language."

Theme 1: Linguistic needs met

The majority of responders (81%) spoke English. Respondents who spoke other languages indicated that supports and services were accessible in their preferred language, including access to interpreters. Some respondents also noted issues with translation supports being available when needed, both in-person and by phone. Several respondents emphasized that interpreters helped them understand meetings, supports and services, and communications, making interactions more accessible.

"The case manager and broker speak Cantonese and can interpret for me."

"We are able to communicate in English but do know many families have no access because of language or cultural barriers."

"Language is never the problem. It's the other parts (of the system that are a problem)."

"Our preferred language is English, so there is no problem with that."

"OPWDD provided my language, but the translation is not in good quality. It is very confusion sometimes."

Theme 2: Linguistic needs

Many respondents framed linguistic accessibility as a function of alignment between English being the respondents' preferred language and the dominant language of service delivery.

"All of his staff speak English."

"I am bilingual no problem."

"Based on English alone, I can access supports and services. I have personally been in the field for 37 years and know more on accessing services than (staff) today."

How Supports and Services Were Not Accessible in Preferred Language

Respondents were asked, "If no: Please describe how the supports and services were not accessible in your preferred language."

Theme 1: Linguistic needs not met

Respondents described lack of translated materials, limited availability of bilingual staff, and inaccurate interpretation, which made it difficult to understand information and access supports and services. Comments also highlighted communication barriers due to staff not fully understanding and delays in supports and services related to language barriers.

"Important documents and written materials were not available in my preferred language, which made it difficult to fully understand the information I was being given."

"Even though the case manager is bilingual, he is extremely busy and handles too many cases. As a result, we sometimes have to communicate directly with other providers ourselves, and language barriers often lead to long waits and service delays."

"Sometimes the Chinese interpretation is inaccurate."

"Very few agencies have bilingual services and staff."

"People assisting me did not fully understand."

Theme 2: OPWDD system

Respondents described long approval timelines, limited program options, and confusing and difficult application processes within the OPWDD system. Comments also highlighted lack of culturally responsive and strengths-based approaches and the emotional burden on families navigating the system.

"I've been receiving self-direction service for two months now, but it took too long from application to approval. It took over a year and a half for me to get approved, and many parents of disabled children around us are still waiting for approval."

"It is better than before, with more suitable classes and activities, but OPWDD allows only limited program options, which restricts his opportunities for progress."

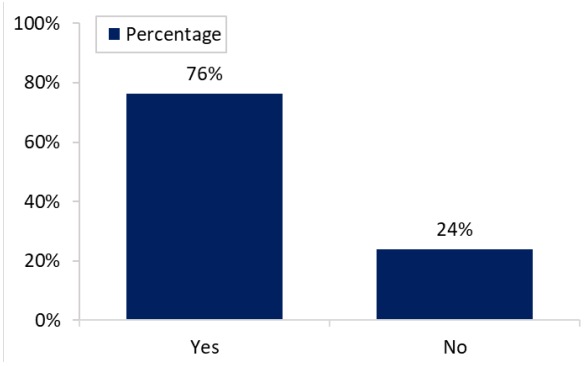
"The process is confusing and gathering all of the needed info is really, really hard. We were lucky that the case coordinator from early intervention helped us. Our child had a genetic diagnosis and for the provisional, the questions are not culturally responsive and are very, very ableist. It was very trying emotionally as a parent, and it did not consider my child as a whole person, and was not strengths-based."

Whether Supports And Services Were **Accessible** in Ways That Considered Family Cultural Beliefs and Practices

Respondents were asked, "Were the supports and services **accessible** in ways that considered your family's cultural beliefs and practices?"

The percentage of participants who indicated *Yes* (76%) was higher. Figure 26 presents the results for this item.

Figure 26.
Respondents' answers to whether supports and services were accessible in ways that considered their family's cultural beliefs and practices (n=277).



How Supports and Services Were Accessible in Ways That Considered Family Cultural Beliefs and Practices

Respondents were asked, "If yes: Please describe how the supports and services were accessible in ways that considered your family's cultural beliefs and practices."

Theme 1: Cultural needs met

Comments described supports and services as accessible when providers respected and incorporated families' cultural and religious beliefs into planning and daily practices, including support for participation in faith practices; alignment with family beliefs, traditions, and norms; and connections to culturally relevant programs and communities.

"My brother expressed an interest in going to church a few years ago, and the direct support professionals at his IRA took him and a few other members of the IRA to a local church. It's been a very nice experience for him."

"CM and broker helped locate programs with good reputations among Chinese families."

"The support aligned with our beliefs and practices."

"Church members offer acceptance and understanding. They offer an inclusive atmosphere."

Theme 2: Positive experiences with providers

Many families described positive experiences with providers, highlighting supportive staff and care managers who helped them navigate supports and services and offered programs aligned with their family member's interests and needs. Respondents also noted access to culturally aligned supports and services, and described feeling supported.

"My son found classes and programs that accommodate what he likes."

"Orthodox Jewish agencies are very available in our county."

"We were able to navigate our family's unique situation with much assistance from caring staff and care managers."

How Supports and Services Were Not Accessible in Ways That Considered Family Cultural Beliefs and Practices

Respondents were asked, "If no: Please describe how the supports and services were not accessible in ways that considered your family's cultural beliefs and practices."

Theme 1: Cultural needs not met

Respondents attributed supports and services that were not accessible to limited staff knowledge and a lack of accommodation for diverse cultural, religious, and identity-based interests and needs. Families also described a lack of culturally-specific supports and services, and feeling left on their own to navigate supports.

"Potential staff who had never met a Jewish person did not understand why my son did the things he did or ate the way he ate."

"Our society does not support non-conforming gender identity."

"There are no classes or programs that cater to Chinese families. I feel I am mostly on my own to navigate and do research."

"No—my daughter is African, and dealing with her hair is a huge issue. This is something that should be easily covered (hair maintenance, training, etc.) in the self-direction budget."

"Not given the opportunity to attend church."

Theme 2: Negative satisfaction

Some families reported challenges related to cultural understanding and difficulty accessing supports and services.

"Because there is saturation of one group in the landscape, it presents barriers."

"Lack of understanding."

"So far, it's not easy to access."

Group B - *Accessibility*

How Supports and Services Were Accessible

Respondents were asked, "If yes: Please describe how the supports and services were accessible when you and your family needed them."

"Supports were available either on site or virtually and were located close to the nearest train station."

"When my son was a child, I was able to navigate the system and obtain the supports he needed."

How Supports and Services Were Not Accessible

Respondents were asked, "If no: Please describe how the supports and services were not accessible when you and your family needed them. In other words, please explain your answer."

"No one informed us that there were programs within agencies that my son could have accessed. I had to locate them myself, make the calls, and repeatedly ask providers to see him. OPWDD Article 16 felt like a waste of resources in my region.

Providers did not listen, offered no crisis support, and did not help with medication issues when problems arose."

"The services were not accessible for one of my children."

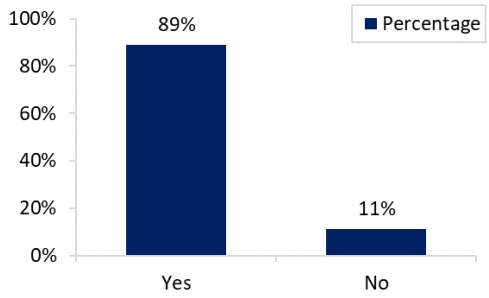
"We needed assistance from our service coordinator during hours that were convenient for our family."

Whether Supports and Services Were **Accessible** in Preferred Language

Respondents were asked, "Were the supports and services **accessible** in your preferred language?"

The percentage of participants who indicated *Yes* (89%) was higher. Figure 27 presents the results for this item.

Figure 27.
Respondents' answers to whether supports and services were accessible in their preferred language (n=9).



How Supports and Services Were Accessible in Preferred Language

Respondents were asked, "If yes: Please describe how the supports and services were accessible in your preferred language."

"Staff consistently provided assistance in Spanish during activities."

"I am bilingual."

How Supports and Services Were Not Accessible in Preferred Language

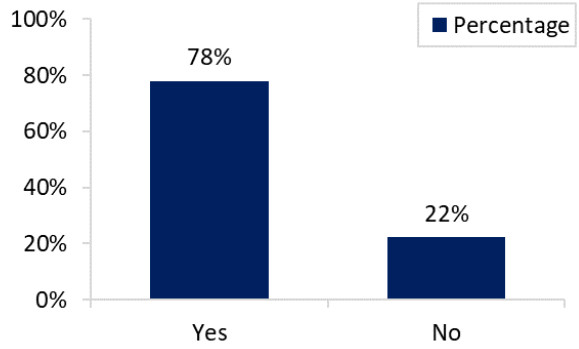
Respondents were asked, "If no: Please describe how the supports and services were not accessible in your preferred language."
There was only one response coded to this question and the respondent said:
"*No services were provided over a three-year period*."

Whether Supports and Services Were **Accessible** in Ways That Considered Family Cultural Beliefs and Practices

Respondents were asked, "Were the supports and services **accessible** in ways that considered your family's cultural beliefs and practices?"

The percentage of participants who indicated *Yes* (78%) was higher. Figure 28 presents the results for this item.

Figure 28.
Participants' answers to whether supports and services were accessible in ways that considered their family's cultural beliefs and practices (n=9).



How Supports and Services Were Accessible in Ways That Considered Family Cultural Beliefs and Practice

Respondents were asked, "If yes: Please describe how the supports and services were accessible in ways that considered your family's cultural beliefs and practices."

> *"The activities provided were designed with our beliefs in mind and consistently respected my wishes and cultural beliefs."*
>
> *"They prepared our son in ways that aligned with our family's practices."*
>
> *"We only accessed services that were aligned with our beliefs."*

How Supports and Services Were Not Accessible in Ways That Considered Family Cultural Beliefs and Practices

Respondents were asked, "If no: Please describe how the supports and services were not accessible in ways that considered your family's cultural beliefs and practices."
There was only one response coded to this question and the respondent said:
"*Providers placed greater emphasis on gender and sexuality questions than on the help my son needed. He did not require gender-related care, and when this topic was raised, it caused him distress because the focus shifted away from obtaining the services he needed*."

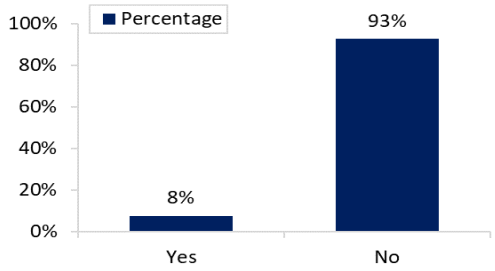
Group C - *Accessibility*

Whether Supports and Services Were **Accessible** to Families Who Have Never Received Supports and Services

Respondents were asked, "Were supports and services **accessible** to you?"

The percentage of respondents who indicated *No* (93%) was higher. Figure 29 presents the results for this item.

Figure 29.
Respondents' answers to whether supports and services were accessible to them (n=40).



Reasons Families Did Not Use Accessible Supports and Services

Respondents were asked, "If supports and services were accessible, why didn't you use them? Was it because they: Did not consider your cultural beliefs and practices, Were not available in your preferred language, Other (please specify)."

Of the three (3) respondents who selected *Yes,* supports and services were accessible, when asked "why didn't you use them?," all three (3) selected *Other (please specify)*. Illustrative responses are provided below.

"I think they would be easy to get to once we receive them."

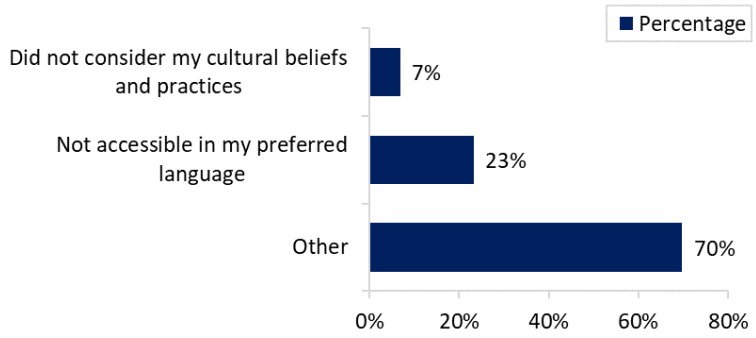
"Applications spuriously denied."

Reasons Supports and Services Were Not Accessible to Families

Respondents were asked, "What are the reasons that supports and services were not accessible to you? Was it because they: Did not consider your cultural beliefs and practices, Were not available in your preferred language, Other (please specify)."

The percentage of respondents who indicated *Other* (70%) was the highest. Figure 30 presents the results for this item.

Figure 30.
Respondents' answers to the reasons that supports and services were not accessible to them (n=43).



For respondents who selected *Other (please specify)*, illustrative responses are provided below.

"I was told by every service provider on the list given to me by OPWDD that they either don't serve my area or they just didn't respond to my inquiries at all."

"No response or follow up to address the issue. Inappropriate behavior and communication - lack of"

"Because I didn't know these services existed before."

What Families Identified as Needed to Make Supports and Services **Accessible**

Respondents were asked, "When you think of your family's cultural beliefs and practices or preferred language, what could OPWDD do to make supports and services **accessible** to you and your family member with IDD?"

"More follow-up from social workers."

"Increase communication and clarification—if we ask questions, don't make us feel like we're stupid and then send us to someone's voicemail when you know that person is never going to call us back."

"More training and returning calls. It took me eight months to get in contact with OPWDD."

"Be clear on how the services are offered, because recommending something that is not going to work is like making fun of me. I look for agencies on the web and I hear that they don't accept my insurance because I am not an expert—but how can a care manager do that? Shouldn't they investigate that first?"

Summary of Findings for *Acceptability* and *Quality*

When discussing the *acceptability* and *quality* of supports and services, respondents in Groups A and B emphasized the importance of staff who demonstrate cultural understanding, communicate respectfully (in English and other languages), take the time to listen to understand persons with IDD and families, and offer the types and quantity of supports and services needed and preferred. The majority of family respondents, once they were able to secure supports and services, rated them relatively highly. A small minority of family respondents indicated inconsistent and insufficient supports and services overall, and OPWDD's or system providers' lack of capacity to respond to their cultural and linguistic needs. Group C was not presented with items on acceptability and quality.

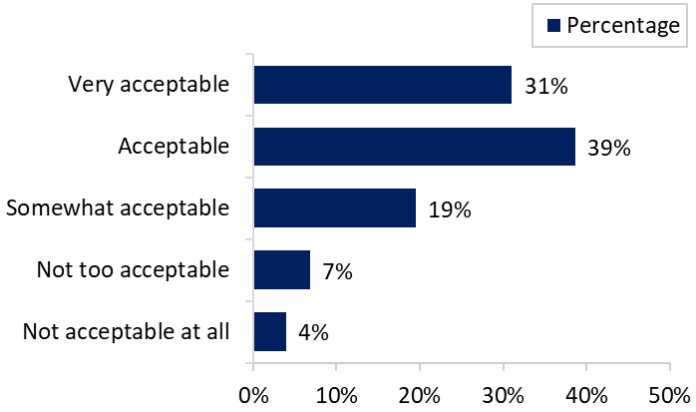
Group A – *Acceptability*

Whether Supports and Services Were Acceptable in Ways That Considered Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "When you think about your family's cultural beliefs and practices, and preferred language: How **acceptable** are the supports and services you are currently receiving?"

The percentage of participants who indicated *Acceptable* (39%) was the highest. Figure 31 presents the results for this item.

Figure 31.
Respondents' ratings of the acceptability of the supports and services they are currently receiving when thinking about their family's cultural beliefs and practices, and preferred language (n=277).



Why Supports and Services Were Rated **Very Acceptable** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **very acceptable**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Very acceptable

Respondents rated supports and services as very acceptable when staff demonstrated sensitivity toward families' cultural beliefs and practices, supported cultural identity, and when cultural needs were not a barrier to accessing supports and services.

"The com hab and respite care support have been excellent and very sensitive to our family's cultural needs."

"My son can feel supported and proud of his heritage."

"Our cultural beliefs and practices are pretty mainstream, so it has not been a problem. Although, in recent times, political divisions in our country have created some tensions."

Why Supports and Services Were Rated **Acceptable** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **acceptable**. When you think

about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Acceptable

Respondents who rated supports and services as acceptable described them as meeting their interests and needs adequately. Respondents noted limitations in scope and control and, in some cases, the need for active system navigation to access supports and services.

"They paid attention to our needs."

"(Supports and services) are in our language, which is good. But it is far too limited—controlled by the state rather than the individual, which is not good. I can navigate the system and push boundaries, which helps. But most people cannot. On balance, it is barely acceptable."

"I haven't had a real problem so far."

Why Supports and Services Were Rated **Somewhat Acceptable** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **somewhat acceptable**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Somewhat acceptable

Respondents who rated supports and services as somewhat acceptable described mixed experiences, with staffing shortages, restrictive rules, and complex processes limiting effectiveness. Comments also highlighted lack of cultural understanding and concerns about staff competency.

"People do not generally seem interested in learning about our different practices. Some are, however, and we appreciate that."

"The respite workers provided through OPWDD are not very competent or caring."

"There are low wages for respite and com hab workers. We have a hard time finding workers when we need help."

"With self-direction, it is better but extremely complicated. I can hire my sister and my oldest daughter, who do not live in the home, although they both have full-time jobs. Ideally, my oldest son, who lives at home, would be the best person to work with my son, but OPWDD does not allow this because he lives in the home. This is a ridiculous rule. Who made this rule, and what can be changed about it?"

Why Supports and Services Were Rated **Not Too Acceptable** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **not too acceptable**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Not too acceptable

Family respondents who rated supports and services as not too acceptable described minimal recognition of cultural practices, limited choice, and insufficient accommodation when cultural needs differed from those of others.

"Limited options and availability hinder our family member from selecting supports that align with his cultural and family background."

"There is almost no accommodation of my brother's cultural practices when they differ from those of his housemates."

Why Supports and Services Were Rated **Not Acceptable At All** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **not acceptable at all**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Not acceptable at all

Respondents described severe systemic failures, including lack of staff availability, poor training, and administrative breakdowns, which left families responsible for navigating complex processes and prevented access to essential supports and services. These challenges added significant stress for families.

"I have been eligible since last summer for my daughter to receive com hab and respite services, and the agency has provided no help in securing a worker. Everything is left to the parents, and even when we are resourceful and knowledgeable, it is still impossible. She has been eligible since June 2024, and to date we have received nothing. I am repeatedly told that no one is available, that I need to find my own worker, and then, when I do, I am required to complete yet another intake."

"Staff are not properly trained. We have to reach out multiple times and access resources on our own, only to be rejected again and again."

"Our case manager, broker, and family all fulfill our responsibilities diligently. We rely on our fiscal intermediary to process reimbursements accurately and on time. The delays and errors over the past year have deprived my daughter of essential services, including com hab, respite services, travel reimbursement, and physical training. These mistakes have real-life consequences that negatively impact my daughter. This program is meant to enrich her life and support our family, not add stress."

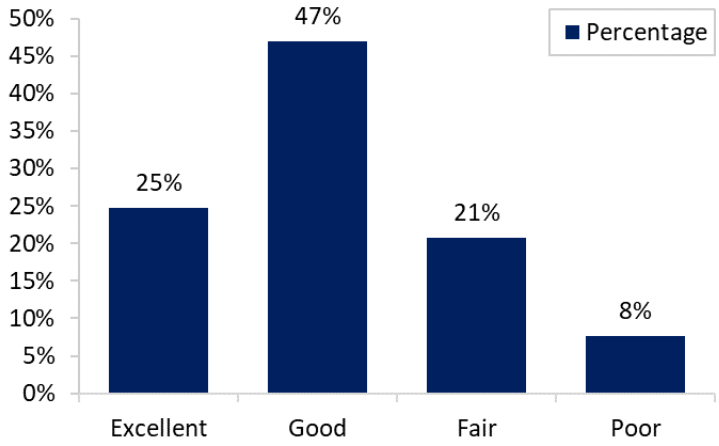
Group A – *Quality*

Rating of **Quality** of Supports and Services Based on Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "When you think about your family's cultural beliefs and practices, and preferred language: How would you rate the **quality** of the supports and services you are currently receiving?"

The percentage of respondents who indicated *Good* (47%) was the highest. Figure 32 presents the results for this item.

Figure 32.
Respondents' ratings of the quality of the supports and services they are currently receiving when thinking about their family's cultural beliefs and practices, and preferred language (n=275).



Why Supports and Services Were Rated **Excellent** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **excellent**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Excellent

Respondents who rated supports and services as excellent emphasized consistent, long-term relationships with staff, the capacity to meet individual needs, and alignment with family cultural beliefs and practices. Some respondents also described services exceeding expectations, while noting occasional challenges in accessing certain types of supports and services.

"I say excellent because my son's needs are being met, and his programs are in English."

"We have had the same care manager for about 15 years. She has really gotten to know my sons and understands their needs and our family's cultural beliefs and practices."

"Satisfied with massage therapy services. We are just beginning in-home occupational therapy (OT) after much difficulty."

"The support we received was more than we expected."

Why Supports and Services Were Rated **Good** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **good**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Good

Respondents who rated supports and services as good described functional and helpful supports and services that met core interests and needs, particularly in employment and self-direction. However, many noted that accessing and coordinating supports and services required significant effort, with system complexity and policy constraints reducing overall satisfaction.

"Com hab has been excellent, though employment services could be improved."

"The supports my child receives through self-direction are good, but it is a lot of work. Applying for a housing subsidy will be complicated because she wants to live in NYC, which is a different Medicaid region than Westchester. She will need to move to NYC before we can apply for a Manhattan housing subsidy."

"Help with employment and community habilitation has been very helpful."

Why Supports and Services Were Rated **Fair** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **fair**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Fair

Respondents who rated quality as fair described inconsistent and insufficient supports and services, with unmet requests, staffing challenges, communication barriers, and complex system requirements. Comments also reflected restrictive rules and difficulty navigating supports and services.

"There is so much more that is needed, but there are too many excuses for why needs are not being met. I was even told that they couldn't hire anyone because the pay didn't match the workload."

"We are told during meetings that our requests will be met; however, they rarely are."

"Accents are very thick and, unfortunately, difficult for a person with Down syndrome and advanced dementia to understand."

"There is insufficient support to help address my child's behavior issues."

"Fair because I cannot hire my son who lives in our home, even though he has a great relationship with his brother with autism and would be a good fit. Self-direction is better, but it is far too complicated."

Why Supports and Services Were Rated **Poor** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **poor**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Poor

Respondents who rated supports and services as poor described lack of access to needed supports, limited service options, and unmet expectations.

"I am not receiving any of the support that I have been asking for since my son was 2 he is now 7 1/2."

"More family involvement in residential would be nice but I'd really just like to see her have something to do during the day and get out of the house and off the technology."

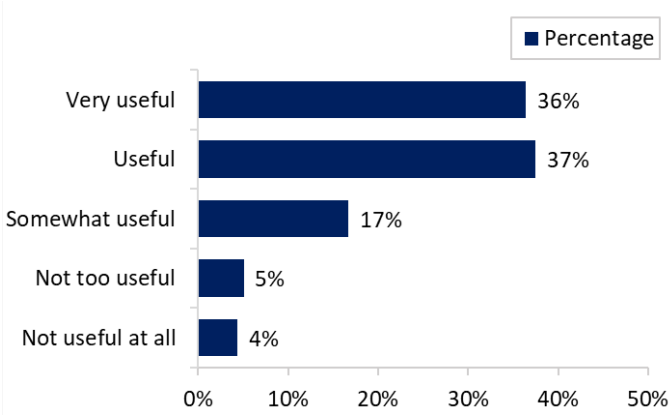
"Culturally I expect a lot more for him. It is so hard as a parent to watch your child suffer and be in pain."

Usefulness of Supports and Services Based on Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "When you think about your family's cultural beliefs and practices, and preferred language: How **useful** are the supports and services you are currently receiving?"

The percentage of participants who indicated *Useful* (37%) was the highest, followed closely behind by those that selected *Very Useful*, (36%). Figure 33 presents the results for this item.

Figure 33.
Respondents' ratings of the usefulness of the supports and services they are currently receiving when thinking about their family's cultural beliefs and practices, and preferred language (n=275).



Why Supports and Services Were Rated **Very Useful** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **very useful**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Very useful

Respondents who rated supports and services as very useful described them as aligning with their family's cultural beliefs and met daily needs. Comments emphasized improvements in quality of life, health outcomes, and prevention of crisis situations.

"They have found useful staff quickly to meet the needs of my son during times of crisis."

"The services are provided in a way that closely matches our cultural beliefs and practices, which makes them very useful. Our family member would have a very difficult time maintaining a good quality of life without these services. They are supporting my daughter in living a fulfilling life."

"My family member has not been in the emergency room for months, with minimal self-injury."

"My daughter receives what she needs, and it is delivered in a timely manner. The supports and services help her maintain a quality of life that is appropriate."

Why Supports and Services Were Rated **Useful** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **useful**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Useful

Respondents who rated supports and services as useful described them as meeting day-to-day needs and generally aligned with cultural beliefs. Some respondents noted limitations in scope, staff shortages, and gaps in staff skill levels.

"Community habilitation has been excellent. Employment services could be improved."

"We appreciate that self-direction helps allow someone with IDD to live independently in the community."

"Aside from our religious holidays, most services are useful in terms of our cultural beliefs and practices; however, there is not enough support due to staff shortages."

"Help with employment and community habilitation has been very helpful."

"Staff are aware of what is needed to support my son, but they do not yet have the skill level needed to support his growth."

Why Supports and Services Were Rated **Somewhat Useful** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **somewhat useful**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Somewhat useful

Respondents who rated supports and services as somewhat useful described mixed experiences, with inconsistent or incomplete supports and services, gaps in service options, ineffective care coordination, and limitations within self-direction reducing overall usefulness.

"Care coordinators are not helpful today with agencies. Taking away the not-for-profits was a big loss of support to us."

"Supports are somewhat useful overall."

"The residential services are very useful. Our daughter cannot live at home; however, that is only one piece of the supports and services she needs. I feel that for this population, we lack appropriate options for day services, and unfortunately self-direction is not helpful due to the time and monetary restrictions placed on it."

Why Supports and Services Were Rated **Not Too Useful** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **not too useful**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Not too useful

Respondents who rated supports and services as not too useful described barriers that limited access, including language access challenges requiring family members to serve as interpreters, and insufficient financial reimbursement that did not offset the cost of care.

"When visiting OPWDD, I must always have a family member who speaks English present in order to proceed with services."

"We should have received $3,000 in reimbursement after submitting over $4,000 in items, but we only received $700. This does not begin to defray the cost of caring for my daughter at home. We likely spend $700 per month, not per year."

Why Supports and Services Were Rated **Not Useful At All** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **not useful at all**. When you

think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Not useful at all

Respondents who rated supports and services as not useful at all described not receiving the supports and services they needed and reported that available supports and services were insufficient in both quantity and quality.

"We do not have the support we need, either in quantity or quality."

"Our family member does not receive the services he needs."

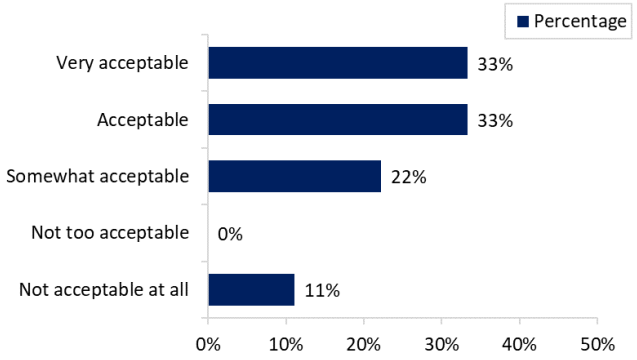
Group B - *Acceptability*

Whether Supports and Services Were **Acceptable** in Ways That Considered Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "When you think about your family's cultural beliefs and practices, and preferred language: How **acceptable** were the supports and services you received in the past?"

The percentage of respondents who indicated *Very Acceptable* (33%) and *Acceptable* (33%) were the highest. Figure 34 presents the results for this item.

Figure 34.
Respondents' ratings of the acceptability of the supports and services they received in the past when thinking about their family's cultural beliefs and practices, and preferred language (n=9).



Why Supports and Services Were Rated **Very Acceptable** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **very acceptable**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Very acceptable

"They always respected my beliefs and culture by allowing me to speak my language."

"This was very acceptable because I ensured that my beliefs were respected and that I managed the services that were requested."

Why Supports and Services Were Rated **Acceptable** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **acceptable**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Acceptable

"There was a provider book with some good programs listed, but we did not know how to go about using them."

"The services were acceptable because they had counselors from a variety of backgrounds."

Why Supports and Services Were Rated **Somewhat Acceptable** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **somewhat acceptable**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Somewhat acceptable

"The services were somewhat acceptable because we were able to receive some care."

"Services are not available to everyone, and there are not enough mental health services within OPWDD."

Why Supports and Services Were Rated **Not Too Acceptable** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **not too acceptable**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Not too acceptable

There were no comments presented with this response.

Why Supports and Services Were Rated **Not Acceptable At All** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **not acceptable at all**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Not acceptable at all

There were no comments presented with this response.

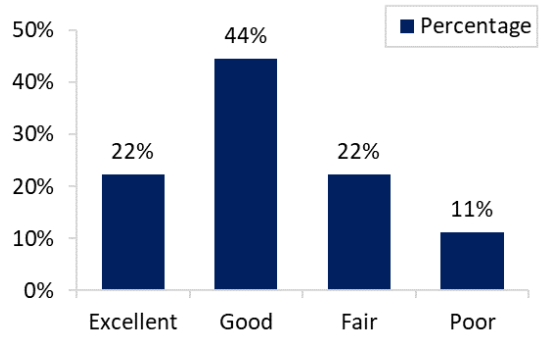
Group B - *Quality*

Rating of **Quality** of Supports and Services Based on Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "When you think about your family's cultural beliefs and practices, and preferred language: How would you rate the **quality** of the supports and services you received in the past?"

The percentage of respondents who indicated *Good* (44%) was the highest. Figure 35 presents the results for this item.

Figure 35.
Respondents' ratings of the quality of the supports and services they received in the past when thinking about their family's cultural beliefs and practices, and preferred language (n=9).



Why Supports and Services Were Rated **Excellent** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **excellent**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Excellent

There was only one response coded to this question and the respondent said:

"*The services are excellent because I make them work for me and my son.*"

Why Supports and Services Were Rated **Good** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **good**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Good

> *"When he was finally given the care he needed, providers were able to work with him in ways he understood and that supported his success."*
>
> *"The service coordinator worked hard on our behalf."*

Why Supports and Services Were Rated **Fair** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **fair**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Fair

There were no comments presented with this response.

Why Supports and Services Were Rated **Poor** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **poor**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Poor

There was only one response coded to this question and the respondent said:

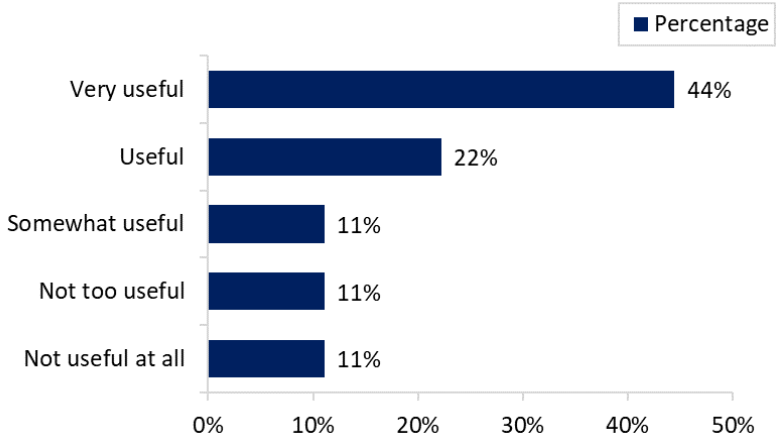
"*No services were provided over a three-year period*."

Usefulness of Supports and Services Based on Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "When you think about your family's cultural beliefs and practices, and preferred language: How **useful** were the supports and services you received in the past?"

The percentage of respondents who indicated *Very Useful* (44%) was the highest. Figure 36 presents the results for this item.

Figure 36.
Respondents' ratings of the usefulness of the supports and services they received in the past when thinking about their family's cultural beliefs and practices, and preferred language (n=9).



Why Supports and Services Were Rated **Very Useful** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **very useful**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Very useful

> *"It was very useful to have people who understood differences in culture and language."*
>
> *"The supports were very useful because they helped my child learn about themselves and their feelings."*

Why Supports and Services Were Rated **Useful** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **useful**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Useful

"Once he was connected with a provider, he received the help he needed."

"We only continued services that we found to be useful."

Why Supports and Services Were Rated **Somewhat Useful** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **somewhat useful**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Somewhat useful

There were no comments presented with this response.

Why Supports and Services Were Rated **Not Too Useful** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **not too useful**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Not too useful

There was only one response coded to this question and the respondent said:

"*I am not able to use the services*."

Why Supports and Services Were Rated **Not Useful At All** When Considering Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "You said that supports and services are **not useful at all**. When you think about your family's cultural beliefs and practices, and preferred language. Please tell us why."

Rating: Not useful at all

There were no comments presented with this response.

Summary of Findings for *Utilization*

The majority of responses from families regarding *utilization* revealed that the process to use supports and services ranged from difficult to very difficult. Families indicated frustration with excessive paperwork and forms, long wait times, repeated and lost document requests, inconsistent responsiveness, and a website that was difficult to navigate. While some families reported that the approval process itself could be bureaucratic, time-consuming, or overwhelming, once supports and services were approved, they were easy to use.

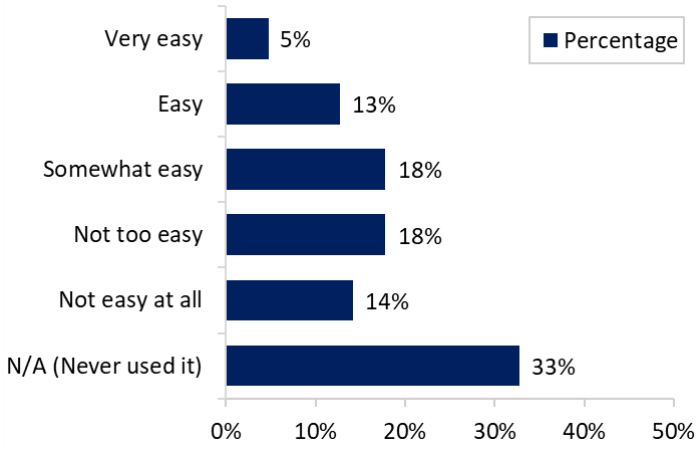
Group A - *Utilization*

Ease of Using the OPWDD Website When Applying for Supports and Services

When you applied for supports and services, how easy was it for you to use the OPWDD website?

The percentage of participants who indicated *Not Applicable (Never Used It)* (33%) was the highest. Figure 37 presents the results for this item.

Figure 37.
Respondents' ratings of how easy it was for them to use the OPWDD website when applying for supports and services (n=275).

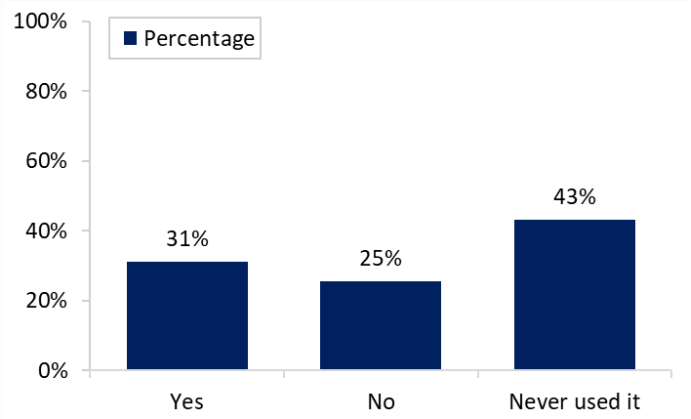


Whether the OPWDD Website Was Helpful in Ways That Considered Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "Keeping in mind your family's cultural beliefs and practices or preferred language: Would you say that OPWDD's website was helpful to you as you tried to get supports and services for your family member with IDD?"

The percentage of participants who indicated *Never Used It* (43%) was the highest. Figure 38 presents the results for this item.

Figure 38.
Respondents' answers to whether OPWDD's website was helpful to them as they tried to get supports and services for their family member with IDD, when keeping in mind their family's cultural beliefs and practices or preferred language (n=275).



How the OPWDD Website Was Helpful in Getting Supports and Services

Respondents were asked, "If yes: Please tell us how the website was helpful to you as you tried to get supports and services."

Theme 1: OPWDD system

Respondents who indicated that the website was helpful described it primarily as a tool for accessing information, understanding the application process, and identifying next steps and sources of assistance. Some respondents also noted that additional support was needed to navigate the process effectively.

"The ease of the website helped me get answers to what I needed."

"I was able to find information on how the OPWDD application process works and where to obtain assistance."

"It was easier because I received support; doing it on my own would have been difficult."

"It is fairly user-friendly."

"The pertinent information is on the website."

Theme 2: Positive satisfaction

Respondents who indicated positive satisfaction highlighted availability of information, helpfulness in completing the application process, and access to resources in multiple languages, while noting some difficulty reaching staff by phone.

"We can look up the information we need."

"It was helpful for getting my application approved."

"They are doing a great job providing resources in different languages, although reaching a contact person by phone at the regional office was not as easy."

How the OPWDD Website Was Not Helpful in Getting Supports and Services

Respondents were asked, "If no: Please tell us how the website was not helpful to you as you tried to get supports and services."

Theme 1: OPWDD system

Respondents who indicated that the website was not helpful described challenges navigating the OPWDD system online, including unclear pathways, outdated and overly technical information, and difficulty identifying next steps and contact information. Comments also highlighted limited contact access and difficulty reaching staff by phone.

"Much of the guidance is not up to date, and public-facing information is compliance-oriented."

"The website is information- and data-heavy. It is hard to figure out where to start."

"The website is very technical, and providers do not have well-developed websites either."

"It is circular, unclear, and not user-friendly."

"The website does not have enough contact information, and most departments do not answer their phones."

Theme 2: Negative satisfaction

Respondents who reported negative experiences described the OPWDD website as difficult to navigate and overly dense, with challenges finding information and identifying next steps. Comments also reflected reliance on self-navigation and difficulty obtaining needed assistance.

"OPWDD has not helped us get any services. We have always had to find appropriate services on our own."

"My sons have had OPWDD services for about 20 years. The website was not very sophisticated back then, and I still find it difficult to navigate today."

"We do not get the assistance we need, despite what the website states."

"The website is not user-friendly. It is hard to find information. It would be helpful if it listed all programs available in each county, their requirements, and whether they have the capacity to accept new consumers."

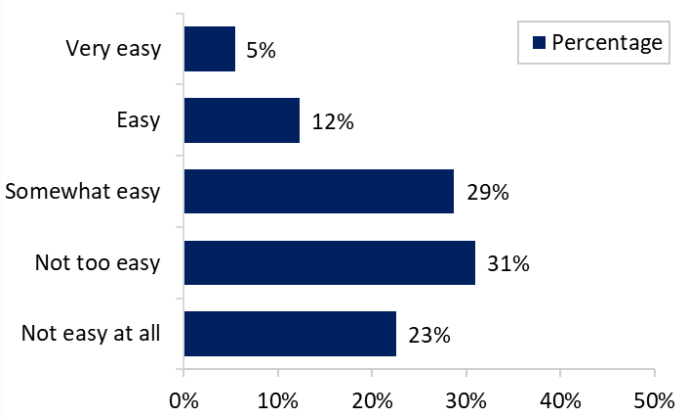
"The information is extremely dense and overwhelming."

Ease of the Process for Getting Supports and Services Through OPWDD

Respondents were asked, "How easy was the process for getting supports and services through OPWDD?"

The percentage of participants who indicated *Not Too Easy* (31%) was the highest, followed closely by *Somewhat Easy* (29%). Figure 39 presents the results for this item.

Figure 39.
Participants' ratings of how easy the process was for getting supports and services through OPWDD (n=275).



Why the Process for Getting Supports and Services Through OPWDD Was Rated **Very Easy**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **very easy**. Please tell us why."

Rating: Very easy

Respondents who described the process as very easy attributed this to early guidance from professionals, support from care managers or brokers, and familiarity with whom to contact. These supports helped make the process intuitive and manageable, with training and assistance navigating the system, further simplifying the experience.

"Someone (the social worker) in my son's preschool suggested we get involved with OPWDD when my son transitioned to preschool services. My son's care manager suggested I look into brokering, so I generated an information sheet for families I work with that answers all the information that I was not provided by my broker. Going through broker training while my son was entering services educated me much more thoroughly than my care manager."

"I was able to maneuver the site, and with the help of her broker, we were able to get the supports and services she needs."

"When my girls were diagnosed, it was easy to get OPWDD eligibility."

"Once you know who to speak to, they will get back to you."

"It is mostly intuitive."

Why the Process for Getting Supports and Services Through OPWDD Was Rated **Easy**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **easy**. Please tell us why."

Rating: Easy

Respondents who described the OPWDD process as easy attributed this to support from brokers, care managers, and other professionals who guided them through the process, noting that the system itself could be complex and difficult to navigate without assistance.

"We speak English, but the process itself can be somewhat complex and bureaucratic. We were fortunate to work with our support staff—mainly our broker, but also our care manager and fiscal intermediary—who helped guide us through the process. Without them, the process would have been much harder, and possibly impossible, to navigate."

"I started over 15 years ago, and it was a learning experience. There was more human interaction then, rather than automation."

"My daughter was approved easily when she was younger. I know that now, younger people are being denied in cases where they would have been accepted in the past, because OPWDD does not have sufficient funding to serve everyone who needs services."

Why the Process for Getting Supports and Services Through OPWDD Was Rated **Somewhat Easy**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **somewhat easy**. Please tell us why."

Rating: Somewhat easy

Respondents who described the OPWDD process as somewhat easy stated that it was time-consuming, lengthy, and bureaucratic, with stressful waiting periods, redundant steps, and delays, but noted that accessing supports and services became easier once approval was obtained.

"Getting services was somewhat easy but extremely time-consuming and lengthy."

"Somewhat easy to obtain services, but the waiting process is stressful."

"There are way too many forms and redundant interviews required for some services."

"It was difficult to apply and get approved for OPWDD, but after we were accepted everything was much easier."

"Somewhat easy because we have had services for over 25 years; it is more complicated now with long waitlists and delays."

Why the Process for Getting Supports and Services Through OPWDD Was Rated **Not Too Easy**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **not too easy**. Please tell us why."

Rating: Not too easy

Respondents who selected not too easy described the process as complex with unclear guidance, cumbersome paperwork, and delays both before and after approval that made it difficult to navigate.

"SO many steps. The process is complicated. It felt like no one could say, 'This is step one, this is the next step.'"

"The document submission was cumbersome. All the required paperwork was not clear in the beginning."

"It seemed like we had to jump through hoops to get services."

"There were long wait times to get approved and then even longer waits to actually receive services after approval."

Why the Process for Getting Supports and Services Through OPWDD Was Rated **Not Easy At All**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **not easy at all**. Please tell us why."

Rating: Not easy at all

Respondents who described the OPWDD process as not easy at all indicated that it was highly bureaucratic, time-consuming, and difficult to navigate, with long wait times, limited access to guidance, language barriers, and the need for persistent advocacy to obtain supports and services.

"Had to constantly fight for anything we got. Had to see legislators and OPWDD managers."

"It's a long and difficult process. It took us years. Also, once you are approved, that's just part one… It's been 4 years since our front door session and we are just now utilizing services. It shouldn't be this difficult."

"It's an incredibly difficult task… it becomes a full-time job for us as family members just to get services… the language is very hard to understand, even for an educated person like me."

"There are many barriers to access, very little opportunity to speak directly to OPWDD, many delays, and overburdened care managers."

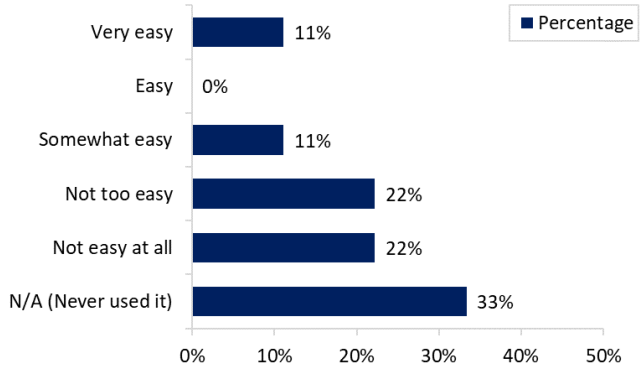
Group B - *Utilization*

Ease of Using the OPWDD Website When Applying for Supports and Services

Respondents were asked, "When you applied for supports and services, how easy was it for you to use the OPWDD website?"

The percentage of respondents who indicated *Not Applicable (Never Used It)* (33%) was the highest. Figure 40 presents the results for this item.

Figure 40.
Respondents' ratings of how easy it was for them to use the OPWDD website when applying for supports and services (n=9).

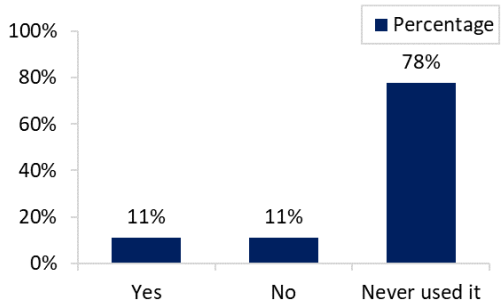


Whether the OPWDD Website Was Helpful in Ways That Considered Family Cultural Beliefs, Practices, and Preferred Language

Respondents were asked, "Keeping in mind your family's cultural beliefs and practices or preferred language: Would you say that OPWDD's website was helpful to you as you tried to get supports and services for your family member with IDD?"

The percentage of respondents who indicated *Never Used It* (78%) was highest. Figure 41 presents the results for this item.

Figure 41.
Respondents' ratings of whether the OPWDD website was helpful to them as they tried to get supports and services for their family member with IDD, when keeping in mind their family's cultural beliefs and practices or preferred language (n=9).



How the OPWDD Website Was Helpful in Getting Supports and Services

Respondents were asked, "If yes: Please tell us how the website was helpful to you as you tried to get supports and services."
There was only one response coded to this question and the respondent said:
"*The website was easy to navigate*."

How the OPWDD Website Was Not Helpful in Getting Supports and Services

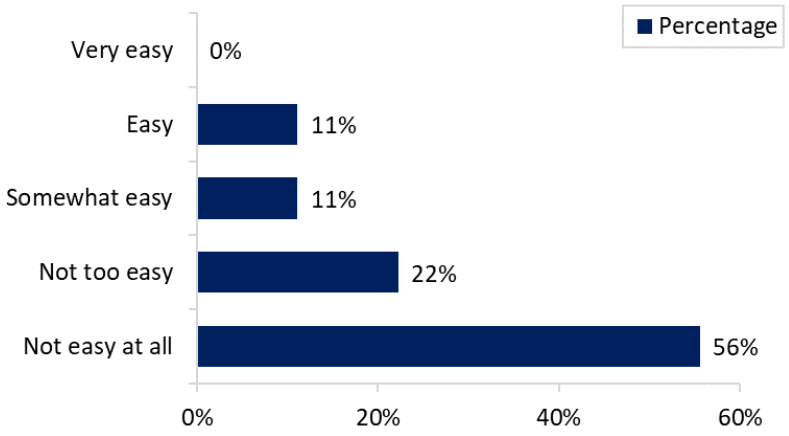
Respondents were asked, "If no: Please tell us how the website was not helpful to you as you tried to get supports and services. In other words, please explain your answer."
There was only one response coded to this question and the respondent said:
"*It has too much information and I couldn't get to what I needed*."

Ease of the Process for Getting Supports and Services Through OPWDD

Respondents were asked, "How easy was the process for getting supports and services through OPWDD?"

The percentage of respondents who indicated *Not Easy At All* (56%) was the highest. Figure 42 presents the results for this item.

Figure 42.
Respondents' ratings of how easy the process was for getting supports and services through OPWDD (n=9).



Why the Process for Getting Supports and Services Through OPWDD Was Rated **Very Easy**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **very easy**. Please tell us why."

Rating: Very easy

There were no comments presented with this response.

Why the Process for Getting Supports and Services Through OPWDD Was Rated **Easy**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **easy**. Please tell us why."

Rating: Easy

There were no comments presented with this response.

Why the Process for Getting Supports and Services Through OPWDD Was Rated **Somewhat Easy**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **somewhat easy**. Please tell us why."

Rating: Somewhat easy

There were no comments presented with this response.

Why the Process for Getting Supports and Services Through OPWDD Was Rated **Not Too Easy**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **not too easy**. Please tell us why."

Rating: Not too easy

"The process took several years."

"I have been trying to connect to services."

Why the Process for Getting Supports and Services Through OPWDD Was Rated **Not Easy At All**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **not easy at all**. Please tell us why."

Rating: Not easy at all

"From my perspective, OPWDD was ineffective in providing services and felt overly bureaucratic rather than responsive to the needs of people with disabilities."

"The process was very tedious and exhausting. Deadlines did not align with my child's annual checkups and evaluations, it took a long time, and it required time away from work."

"There was excessive waiting, and paperwork was frequently lost."

"Coordinating services through OPWDD was difficult. The paperwork and overall process were long and frustrating, and staff were often unresponsive unless multiple people were copied on emails."

"I am currently seeking services I had in the past; the process has not been easy at all"

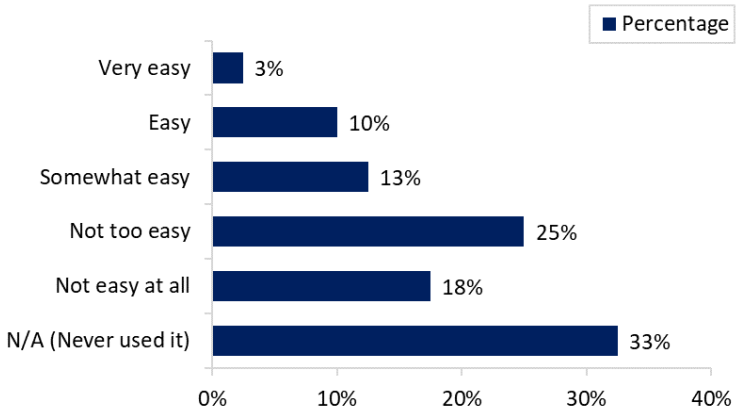
Group C - *Utilization*

Ease of Using the OPWDD Website When Applying for Supports and Services

Respondents were asked, "When you applied for supports and services, how easy was it for you to use OPWDD's website?"

The percentage of respondents who indicated *Not Applicable (Never Used It)* (33%) was the highest. Figure 43 presents the results for this item.

Figure 43.
Respondents' answers to how easy it was for them to use OPWDD's website when they tried to apply for supports and services (n=40).

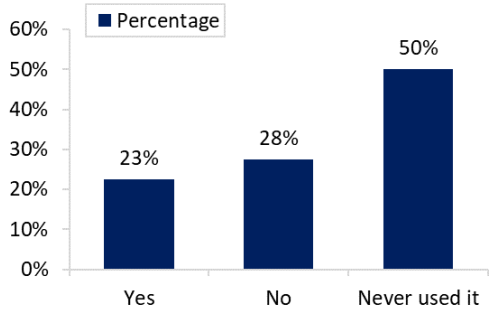


Whether the OPWDD Website Was Helpful When Attempting to Access Supports and Services

Respondents were asked, "Keeping in mind your family's cultural beliefs and practices or preferred language, Would you say that OPWDD's website was helpful to you as you tried to get supports and services for your family member with IDD?"

The percentage of respondents who indicated *Never Used It* (50%) was the highest. Figure 44 presents the results for this item.

Figure 44.
Respondents' answers to whether OPWDD's website was helpful to them as they tried to get supports and services for their family member with IDD, keeping in mind their family's cultural beliefs and practices or preferred language (n=40).



How the OPWDD Website Was Helpful When Attempting to Access Supports and Services

Respondents were asked, "Please tell us how the website was helpful to you as you tried to get supports and services."

"It helped a lot with getting other contact information."

"There is some useful information on it."

"It pointed me toward the starting point (front door), which led to a mostly telephone-driven and paperwork-based process. There was not much online access to the process."

How the OPWDD Website Was Not Helpful When Attempting to Access Supports and Services

Respondents were asked, "Please tell us how the website was not helpful to you as you tried to get supports and services."

"It was confusing."

"I referred to documents sent by our OPWDD contact. I looked at the website during the application process, and it was fine for that, but it was not helpful for accessing services. I didn't use it for that purpose."

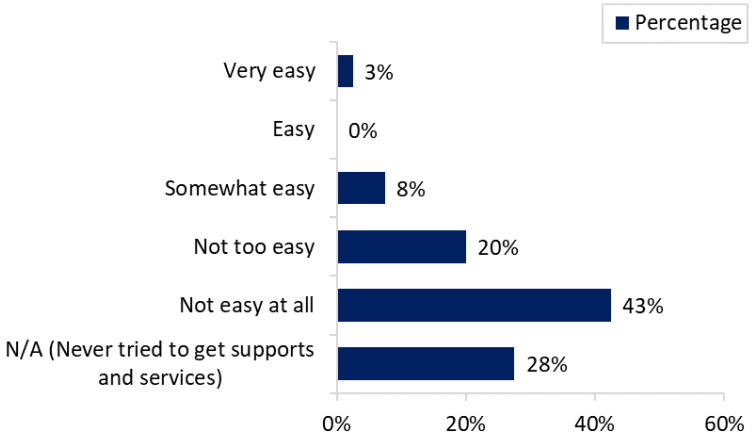
"We couldn't understand or find our way through anything. We called for help and were repeatedly turned away."

Ease of the Process for Getting Supports and Services Through OPWDD

Respondents were asked, "How **easy** was the process for getting supports and services through OPWDD?"

The percentage of respondents who indicated *Not Easy At All* (43%) was the highest. Figure 45 presents the results for this item.

Figure 45.
Respondents' answers to how easy the process was for getting supports and services through OPWDD (n=40).



Why the Process for Getting Supports and Services Through OPWDD Was Rated **Very Easy**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **very easy**. Please tell us why. "

Rating: Very easy

There was only one response coded to this question and the respondent said:

"*The process is easy. My caseworker takes care of it*."

Why the Process for Getting Supports and Services Through OPWDD Was Rated **Easy**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **easy**. Please tell us why."

Rating: Easy

There were no comments presented with this response.

Why the Process for Getting Supports and Services Through OPWDD Was Rated **Somewhat Easy**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **somewhat easy**. Please tell us why."

Rating: Somewhat easy

There was only one response coded to this question and the respondent said:

"*The process was somewhat easy because I went to the office with all the required information and supporting documents. The staff were very kind, and the school also helped me*."

Why the Process for Getting Supports and Services Through OPWDD Was Rated **Not Too Easy**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **not too easy**. Please tell us why."

Rating: Not too easy

"There were things I did not understand."

"There was a lot of waiting, and additional documents and evaluations were required."

"The process is complicated and long."

Why the Process for Getting Supports and Services Through OPWDD Was Rated **Not Easy At All**

Respondents were asked, "You said that the process for getting supports and services through OPWDD was **not easy at all**. Please tell us why."

Rating: Not easy at all

"I completed the application on my son's behalf—a very long and grueling process—and received an award letter, but I was unable to get any supports or services because no providers were available."

"I started applying three years ago, and there has been no progress at all."

"We completed all applications and appeals but never received services for our son. We do receive services for our daughter, but that process was also long, with constant additional steps and new people involved."

Limitations

The NCCC solicited voluntary statewide participation in the listening sessions initiative. A total of **354** people, persons with IDD and family members, participated. Although the respondent group included all OPWDD Regions, the total number of respondents is not a representative sample of the population of people residing in New York who are eligible for, receive, or want to receive supports and services. This does not, however, invalidate the experiences and recommendations of these respondents and the implications for supports and services.

It is important to note that some respondents may not have understood the meaning of culture as used in the questions posed to them. For example, a number of these responses stated that culture was not relevant, culture did not apply to them, or that they identified as "typical American." As a result, cultural influences on how disability is understood and preferences for culturally-informed supports and services are present but may be underrecognized or underreported in the data gathered in this report.

Recommendations from Persons with IDD

Persons with IDD provided recommendations during the interviews. Respondents were asked:

> *"Thinking about your culture and language, is there anything you want to tell us that can make the supports and services you receive better?"*

Recommendations related to respondents' racial, ethnic, or cultural community

Respondents' recommendations related to racial, ethnic, or cultural community emphasized the importance of person-centered supports and services, cultural competence, and recognizing that people within the same cultural or language group may still have different interests, needs, and preferences. Some respondents also recommended hiring staff from diverse cultural backgrounds and continuing to remain open-minded about diverse cultures. Illustrative quotes are provided below.

"It has… everything has to be taken from a person-centered point of view... I think it's very important that we don't try to cookie-cutter every person who seems to check off boxes as all being the same. Because they're not."

"I'd like them to hire staff with a different culture."

"I want them to know to continue to have an open mind about all the different cultures... and to not go backwards at least."

Recommendations related to communication

Respondents' recommendations related to communication emphasized the importance of clear, timely, and consistent communication from providers and systems. Participants highlighted the need for information to be shared in ways that are easy to understand, with advance notice about changes, and with multiple options for staying informed. Respondents also described the importance of ongoing communication, follow-through, and ensuring that individuals are kept informed about their supports and services, plans, and next steps. Illustrative quotes are provided below.

"If they would communicate certain criteria about what's going on with a certain case or give you a heads up as to what's going on. I know with the budget cuts, it's

always a challenge, but I would say just information to let the person know one thing they could do... They don't allow for text messaging. Maybe if they did something like that. And maybe if they had an updated website with some valuable information the person can look at, some videos."

"To be able to... keep a constant schedule for me... I sometimes don't like it when things are sprung up on me at the last minute... give us some heads up or notification about a schedule change. Just keep in contact with me."

"To make sure that... individuals with disabilities... have their assessments that they have to have... and make sure they have it in time..."

Recommendations related to every age of a person's life

Respondents emphasized clearer communication, more individualized planning, stronger follow-through, and more supports and services that reflects the person's actual goals and daily life. Respondents highlighted the importance of being listened to, having stable schedules and advance notice of changes, and receiving supports and services that support community participation, relationship building, and long-term planning. Illustrative quotes are provided below.

"More lobbying in DC and other states and countries - for more programs and opportunities."

"Finding out what the person needs."

"I think we should have a choice in how we want our plans written, because personally for me, I cannot remove my disability from my identity, and I don't choose to. So, for me, being a person with a disability is like being a person with red hair, I guess. It feels like I can dye it, and it would change. You know, like, I could dye it black, and I'd be a person with black hair. It feels removable. Like, if something could change. Which, I guess, technically, your disability could change, but that's semantics, I suppose. But being a disabled person for me, it informs every part of the decisions I make. It informs every part of my interactions, whether I know it or not, because I have to consider, is this accessible? Is this safe for me to do? I think we need disabled people at the top of OPWDD. Not just being sort of consulted."

Family Members' Recommendations

Family members provided recommendations during the reflection portion of the listening sessions and interviews. Respondents were asked:

> "What recommendations would you make to OPWDD to improve supports and services for persons with IDD :
>
> - For your own racial, ethnic, or cultural community?
> - For your preferred language and communities that speak languages other than English?
> - Across the life course (every age of a person's life)?"

Recommendations related to respondents' racial, ethnic, or cultural community

Respondents offered a range of suggestions in response to this prompt. Recommendations included simplified process of accessing supports and services, clearer guidance and communication from OPWDD, staff training, and additional resources. Illustrative quotes are provided below.

"Educating more people about what services OPWDD offers. Many, many families have no clue that OPWDD services are available to them outside of school services. Some don't even know what OPWDD is."

"Our child can self-promote [self-direct]. But it's difficult for us to find community rehab. What I wanted to say is that I wanted to increase the staff's salary in order to ensure that our child has received good services. For example, the previous community rehab person, that person found a better paying job. As a result, we lost this valuable individual. So that is what I think."

"Make things simple and easy to understand when accessing services, so we know the process."

"I think the culture of disability is a culture in itself. I am a school psychologist, and I often have to refer to my son's care manager for support, and she doesn't always know how to respond. The information requested cannot be provided by the family and has to go through the care manager all the time."

"For self-direction, it would help if there were videos to help families understand how it works and all the vocabulary. Starting up with self-direction is very confusing. There are so many new words, entities, etc."

Recommendations related to respondents' preferred language and communities that speak languages other than English

Family members' responses to this prompt emphasized the ways to improve navigation of supports and services for all families, including families who speak languages other than English. Their recommendations included recruiting bilingual staff, interpretation and translation services, and enhancing focused outreach and community engagement.

"It was difficult to prepare documents and not only the personnel in the agency, almost no one speaks Korean...the care manager as well. There is no Korean care manager. First, in order to communicate, I need to have someone who knows how to speak Korean, and there's no Korean care manager whatsoever. So it is difficult. So in terms of your policy, I think, it must be set up in the way that we can communicate. We can have, Korean speaking, care manager in the case. If that happens, I think it's going to be more comfortable, more convenient for us to support our children."

"Have outreach events at school districts that have a significant student population that speaks a language other than English. Many families are not aware of the services that are offered and could make a huge difference in their lives."

"There are far too few seminars on disability services hosted by OPWDD in the Chinese community, and media outreach is also severely lacking."

"The key is the day-to-day support! And you hear about people having language issues in the day hab, in the com hab, with their care manager (CM) and the interactions with a lot of different people. So you're talking to a group of people who have older kids. For the younger kids, when they interact with their therapist or with their teacher, it's a day-to-day struggle…And, OPWDD should consider a way to support community-based organizations like us, because we're doing boots on the ground work. They should consider how to support us. And then we can provide a very adequate and a very easy, accessible support to our families and to our people with disabilities.

"The caseloads are impossible for care managers who speak other languages and it is hard for them to service all their clients properly."

Recommendations related to every age of a person's life:

Respondents often requested information about supports and services available at every stage, improving transition-related supports and services, and involving families and persons with IDD in the planning processes. Families emphasized the importance of having supports and services across ages, with some participants requesting early intervention for children, while others wanted supports and services for adults as they age out of the school system. Illustrative quotes are provided below.

"Autism...the future for an autistic child is uncertain. So the parents are very proactive because they want to provide intervention early. Because kids with autism, the behavior may be changed forever, so families are very proactive in terms of education and participation. So I would like OPWDD to provide good services for kids who are younger, to provide more support. So that way we'll give the children a brighter future. And also, provide more peace and assurance for the parents. Otherwise, if there are no extracurricular activities, it makes us, the parents, feel more anxious."

"My daughter is now in her late twenties and has a boyfriend, and her siblings are also adults and have moved out. And she wants to have that kind of life and understanding of what her housing options are and about supported housing. And there's very little information once students, clients, age out of that high school program at 22 years old, and the next steps. You get day hab or some programming. Well, I'm down in New York City, so it's much easier, I guess, than maybe other parts of New York State. But for them to become more independent, what are their options? Where do we find them? What are the supports? Who can provide them? I think that is a very big deal."

"Where do I start...more consistency with staffing, pre-planning. I would have benefited from a list of things to come, i.e., guardianship, housing. I learn about things from peers, not staff or care managers. If I weren't in the field I'm in, I would be clueless. We are on our 10+ care manager and just got self-direction after 6 years of trying."

Family Members' Thoughts on Equity

All family respondents were asked the following open-ended question in listening sessions and interviews: "There is a lot of talk about equity. In a few words, what does this mean to you and your family in the New York State developmental disabilities system?"

Illustrative quotes are provided below:

"I hope that my children will have a fair opportunity to get employed in order that my children can support themselves, in order to live a dignified life, especially by the time their parents are no longer here."

"I feel, sometimes it makes me feel uncomfortable when people look at us differently. My husband minds it more. So my husband takes my child out less. But I'm okay. I feel that I need to let my child integrate in the society. So I would take my child to take public transportation. And because I don't drive, I use alternative transportation. Sometimes, the bus drivers do not let us in. I can't always fold my child's stroller, because if I fold the stroller, my older child will become rambunctious and run around on the bus. So as a result, I have to do special rides. But my child prefers public transportation instead of specialty transportation. So for kids who have developmental delays or families, this aspect is quite important."

"I feel like a lot of our contributions have already sort of delved into this equitable concept, but because it's not equitable if, from whatever your financial stream is in terms of having extra funds or not having extra funds. It's not equitable in terms of service and programming, we can't take advantage of things because my son can't manage himself in certain situations. Even if I was the one supporting him, even if my husband was the one supporting him. Some situations have to be avoided. And so in terms of equity he's being disparaged for what he can't do and told those are the only things that we're going to allow you to do, where he should be given more opportunity and more control over his choices, and what his family sees as appropriate and safe, and what makes him happy. And all of those choices, all the families should be able to make their own choices. There's only like 2 psychiatrists on all of Staten Island. How is that equitable?"

"Equity is for people to receive what they need. Everybody's equity is not the same, right?"

”Our son is, 21, and he has partial brain damage and epilepsy from birth. And for us, I think equity would just mean him being treated the same as his sister, who is in a wheelchair. Him being treated the same, and being able to have access to the same services that she is able to have. Because even though she's in a wheelchair, there's nothing wrong with her mentally, and it would be just because he does have some of those disabilities mentally, still being able to be treated and offered the same exact services as her.”

“It's important that my family member is be able to access education and leisure, community, and cultural activities, job training and opportunities in a way that is meaningful to him. That helps him to get further along in life. That the same pathways that work for people who are typical neurologically and typical developmentally are not going to work for my child, or others like him, but that he can work towards those goals, he just needs something different than the typical pathway.”

Conclusion

The respondent group of persons with IDD described varied experiences regarding the *accessibility*, *acceptability*, *quality*, and *utilization* of supports and services. Respondents emphasized the importance of respectful communication, helpfulness, and the overall quality of supports and services. While perspectives on the necessity of staff sharing their racial, ethnic, or cultural identities were mixed, the ability of staff to speak their preferred language was viewed as essential for effective communication. High-quality supports and services were characterized by staff who listen to understand, tailor supports and services to unique interests and lived experiences, and take the time to learn about their cultural backgrounds. Regarding utilization, experiences ranged from positive engagements in shared decision-making to challenges involving communication barriers, power dynamics, minimal involvement with decision makers, and limited opportunities for meaningful participation.

Family members across Groups A and B generally indicated a high level of *availability* of supports and services that met the needs of their family member with IDD and were responsive to their cultures. However, experiences regarding the timeliness and adequate amount of these supports and services were divided. Positive experiences highlighted supportive and timely providers, whereas challenges included long wait times, complex processes, and a lack of clear guidance that led to frustration in navigating the system. Group C respondents similarly noted barriers to availability, such as waiting lists, denials, and unclear documentation requirements.

Regarding *accessibility*, family members across Groups A and B described multiple challenges when attempting to access supports and services, including difficult application processes, limited program awareness, and communication difficulties with providers and systems. The OPWDD website was described by many as inaccessible and very difficult to navigate and understand. Group C respondents indicated that clearer guidance, more culturally and linguistically competent staff, and follow-up from staff could make supports and services more accessible.

When discussing *acceptability* and *quality*, family respondents in Groups A and B emphasized the critical need for staff to demonstrate cultural understanding, communicate respectfully in their preferred languages, and actively listen to understand persons with IDD and their families. Once secured, supports and services were generally rated highly, though a small minority noted inconsistent supports and services and a lack of systemic capacity to respond to their cultural and linguistic needs.

The majority of responses from families regarding *utilization* revealed that the process to use supports and services ranged from difficult to very difficult. They described it as being marked by excessive paperwork, long wait times, repeated document requests, and inconsistent responsiveness. Despite these bureaucratic, time-consuming, and overwhelming approval processes, families reported that once supports and services were finally approved, they were easy to use.

Recommendations

A total of **354** people participated in Listening Sessions conducted by the Georgetown University National Center for Cultural Competence (NCCC) from February 18 and December 16, 2025. This data collection initiative was designed to better understand the experiences of persons with intellectual and developmental disabilities (IDD) and their family members when seeking or receiving supports and services through OPWDD. The initiative explored in depth the sociocultural contexts and the lived experiences of people with IDD and their families – an approach that had not previously been attempted on a statewide basis.

The recommendations put forth by the NCCC are based on a comprehensive analysis of: 1) the demographic makeup of the respondent groups; 2) themes of individual respondent comments; and 3) the implications for system level change to advance cultural and linguistic competence in New York State's developmental disabilities system.

Recommendation 1. Convene statewide public forums to discuss the findings from this report.

As stated previously, a total of **354** people, persons with IDD and family members, participated in the listening sessions. Although the respondent group included all OPWDD Regions, the total number of respondents is not a representative sample of the population of people residing in New York who are eligible for, actually receive, or want to receive IDD supports and services. This, however, does not invalidate the experiences and recommendations of these respondents or the implications for supports and services. Therefore, it is recommended that OPWDD collaborate with self-advocacy and family organizations, the network of voluntary service providers, and other constituents and organizations concerned with IDD supports and services to discuss the implications of the findings of this report statewide, including the following respondent demographics.

Table 12.

Ethnicity of respondents with IDD (n=24).

Ethnicity	Percentage*	Number of Participants*
Hispanic or Latino	8%	2
non-Hispanic or Latino	92%	22

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

Table 13.
Racial background of respondents with IDD (n=24).

Racial background	Percentage*	Number of Participants*
White	67%	16
Black or African American	25%	6
Other (please specify)	8%	2

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

For respondents who selected *Other (please specify)*, only one response indicated "Hispano."

Table 14.
Ethnicity of family members of persons with IDD (n=330).

Ethnicity	Percentage*	Number of Participants*
Hispanic or Latino	18%	61
non-Hispanic or Latino	82%	269

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

Table 15.
Racial background of family members of persons with IDD (n=330).

Racial background	Percentage*	Number of Participants*
White	46%	151
Black or African American	13%	44
Asian	24%	80
Native American or Alaska Native	1%	3
Two or more races	7%	22
Other	9%	30

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

For respondents who selected *Other (please specify)*, illustrative responses included: "Puerto Rican," "Latino of African/European/Indigenous decent," "Latino Indigenous (mestizo)," "Jewish," "Indigenous," "I am Ashkenazi and my son is Native Central American," "Guyanese East Indian," "Bavarian," "Ashkenazi."

Table 16.

Language preferred for participating in listening session by family members of persons with IDD (n=330).

Language Preferred for Participating in Listening Session	Percentage*	Number of Participants*
English	81%	266
Chinese	12%	41
Spanish	4%	12
Korean	2%	8
Russian	0.3%	1
Other	1%	2

*Due to rounding, percentages and respondent numbers may be higher or lower than expected

For respondents who selected *Other (please specify),* two responses indicated "English or Spanish" and "English and ASL or closed-caption in English."

Recommendation 2. Consider the sociocultural and political contexts that affect data collection across New York State's diverse communities.

As stated previously, participation in the listening sessions initiative was voluntary and conducted during a highly sensitive time for immigrant families and communities in New York and across the United States. This sociocultural and political environment may have impacted the willingness of some persons with IDD and families to participate. Future data collection will need to take these factors into consideration in efforts to engage New York's diverse immigrant communities.

Recommendation 3. Establish a statewide structure and process to evaluate supports and services delivered directly by OPWDD and by its network of voluntary IDD providers.

Given OPWDD's priority of working to advance cultural competence, linguistic competence, and equity within New York State's system, it is recommended that OPWDD:

- Improve the overall experience of persons with IDD and family members when applying for supports and services. This includes having: a) an accessible website; b) easy to understand eligibility criteria, application forms, and diagnostic protocols and processes; c) professional and courteous interactions with OPWDD staff; and d) effective communications.
- Offer additional opportunities to engage in data collection across all demographic groups in the state and continue to gather data, such as those captured in this report.
- Make a concerted effort to elicit the experiences of persons with IDD and family members who speak languages other than English (including ASL or other sign languages). It is important to note that this recommendation is made because the number of listening session respondents (i.e., persons with IDD and families) is not

representative of the languages spoken in the state or those mandated by the New York State Language Access Law.

- Invest in a statewide structure and processes to evaluate supports and services from the user perspective – people with IDD across the life course and their families from the diverse cultural and linguistic groups residing in the state.
- Partner with people with IDD, their families, other key constituency groups, and organizations to inform data analysis and dissemination strategies of the findings.
- Create a solutions-oriented statewide action coalition to address disparities in availability, accessibility, acceptability, quality, and utilization of supports and services as identified for future data collection efforts.

Appendices

Appendix A

Interview Questions for Persons with IDD

Question #1

Prompts

People with developmental disabilities who live in New York:

- Are from many different racial, ethnic, and cultural groups.
- Speak many different languages.
- Belong to many different religious or faith groups
- May live in cities or small towns or on farms or close to beaches.

Question. What can providers of supports and services do that show they understand that people with developmental disabilities come from many backgrounds?

Question #2

Prompt. Think about staff who provide supports and services to you.

Question. How important is it to you that staff are from the same racial, ethnic, or cultural group as you? [*Very important, important, somewhat important, not too important, not important at all]*

- You said staff being from the same racial, ethnic, or cultural group as you is [*participant's rating*]. Please tell us why.

Question. How important is it to you that staff speak the same language as you? [*Very important, important, somewhat important, not too important, not important at all]*

- You said staff speaking the same language as you is [*participant's rating*]. Please tell us why.

Question #3

Now, I want you to think about your culture and your family's culture.

Question. What can the staff who support you do that shows they understand what is important to you about your culture?

Question #4

Prompt. I am now going to ask you about ways that providers of supports and services can include persons with developmental disabilities in how they provide supports. One way is for providers to listen to persons with developmental disabilities about the kinds of supports and services they want and need.

Question 4a. Have you been able to tell staff who support you about what you want and need? [**yes/no**].

- If yes: tell me how this happened.

- If no: what would you tell staff that you want and need? How would you want to do this?

Prompt. I am now going to ask you another question about ways persons with developmental disabilities can be included in how supports and services are provided. One of those ways is for providers to advocate with persons with developmental disabilities for things that are important to their lives. Things like:

- choosing where you live or who lives with you
- who is the person that provides your supports
- having a job
- choosing how to spend your money
- where to go to have fun or take a vacation
- going to a school or college program

Question 4b. Has your provider ever asked you to come to a meeting to tell staff what is important to how you want to live? **[yes/no]**

- If yes: what did you say?
- If no: what would you say?

Question 4c. Has your provider ever asked you to go with staff to meetings to tell people who make decisions about supports what is important to you? [**yes/no**]

- If yes: what did you say? How did you feel?
- If no: would you like to do this? What would you say?

Question #5

Thinking about your culture and language, is there anything you want to tell us that can make the services and supports you receive better?

Appendix B

Interview Questions for Group A

Family members of persons with IDD who are currently receiving services

Estimated Session Run Time: 60-90min

Introductory statement

We understand that you are currently receiving supports and services for your family member with intellectual or other developmental disabilities (IDD) from OPWDD.

Just to confirm, do you and your family member receive supports and services in [their region]? *If participant is unsure of their region, ask them which county they receive supports and services in, and inform them of their region based on the OPWDD region map.*

1. When you think about your family's cultural beliefs and practices and preferred language, would you say you are getting the supports and services you want and need for your family member who has an intellectual or other developmental disability? **<Yes/No>**
    a. **<Yes>** Tell us more about the supports and services you are receiving that you want and need.
    b. **<No>** Tell us why you are not getting the supports and services you want and need.

Thank you for your response. For the next questions, we are going to ask you to think about the services you are receiving. The next few questions are on availability.

If elaboration/definition is requested: Availability means that the different types and amount of supports and services are provided when needed. For example, you do not have to be on a wait list.

2. Were the supports and services **available** when you and your family needed them? **<Yes/No>**
    a. **<Yes>** Please describe how the supports and services were **available** when you and your family needed them.
    b. **<No>** Please describe how the supports and services were **not available** when you and your family needed them. In other words, please explain your answer.

3. Were the supports and services **available** in the amount or frequency that you needed? **<Yes/No>**
    a. **<Yes>** Please describe how the supports and services were **available** in the amount

or frequency that you needed.

b. **<No>** Please describe how the supports and services were **not available** in the amount or frequency that you needed. In other words, please explain your answer.

4. Were the supports and services **available** in your preferred language? **<Yes/No>**
   a. **<Yes>** Please describe how the supports and services were **available** in your preferred language.
   b. **<No>** Please describe how the supports and services were **not available** in your preferred language. In other words, please explain your answer.

5. Were the supports and services **available** in ways that considered your family's cultural beliefs and practices? **<Yes/No>**
   a. **<Yes>** Please describe how the supports and services were **available** in ways that considered your family's cultural beliefs and practices.
   b. **<No>** Please describe how the supports and services were **not available** in ways that considered your family's cultural beliefs and practices. In other words, please explain your answer.

Thank you for your response. The next few questions are on accessibility.

If elaboration/definition is requested: Accessibility relates to the supports and services being easy to get to. For example, times offered are convenient, and appropriate.

6. Were the supports and services **accessible** when you and your family needed them? **<Yes/No>**
   a. **<Yes>** Please describe how the supports and services were **accessible** when you and your family needed them.
   b. **<No>** Please describe how the supports and services were **not accessible** when you and your family needed them. In other words, please explain your answer.

7. Were the supports and services **accessible** in your preferred language? **<Yes/No>**
   a. **<Yes>** Please describe how the supports and services were **accessible** in your preferred language.
   b. **<No>** Please describe how the supports and services were **not accessible** in your preferred language. In other words, please explain your answer.

8. Were the supports and services **accessible** in ways that considered your family's cultural beliefs and practices? **<Yes/No>**
   a. **<Yes>** Please describe how the supports and services were **accessible** in ways that

considered your family's cultural beliefs and practices.

b. **<No>** Please describe how the supports and services were **not accessible** in ways that considered your family's cultural beliefs and practices. In other words, please explain your answer.

We are halfway through the questions. Thank you for sharing. The next question is on acceptability.

If elaboration/definition is requested: Acceptability means that supports and services are provided in a way that is responsive to the person with IDD's language, culture, needs, and interests.

9. When you think about your family's cultural beliefs and practices, and preferred language, how **acceptable** are the supports and services you are currently receiving? Would you say that they are:
    - Very acceptable
    - Acceptable
    - Somewhat acceptable
    - Not acceptable at all

a. You said that supports and services are ***[participant's rating]*** when you think about your family's cultural beliefs and practices, and preferred language. Please tell us why.

Thank you for your response. The next question is on quality.

If elaboration/definition is requested: Quality refers to whether supports and services follow best practices and are provided according to high standards.

10. When you think about your family's cultural beliefs and practices and preferred language, how would you rate the **quality** of the supports and services you are currently receiving? Would you say that they are:
    - Excellent
    - Good
    - Fair
    - Poor

a. You said that supports and services are ***[participant's rating]*** when you think about your family's cultural beliefs and practices, and preferred language. Please tell us why.

Thank you for your response. The next question is...

11. When you think about your family's cultural beliefs and practices and preferred language, how **useful** are the supports and services you are currently receiving? Would you say that they are:
    - Very useful
    - Useful
    - Somewhat useful
    - Not too useful
    - Not useful at all

    a. You said that supports and services are ***[participant's rating]*** when you think about your family's cultural beliefs and practices, and preferred language. Please tell us why.

Thank you for your response. The next question is...

12. When you applied for supports and services, how easy was it for you to use the OPWDD website? Would you say that it was:
    - Very easy
    - Easy
    - Somewhat easy
    - Not too easy
    - Not easy at all
    - N/A (Never used it)

13. Keeping in mind your family's cultural beliefs and practices, or preferred language, would you say that OPWDD's website was helpful to you as you tried to get supports and services for your family member with an intellectual or other developmental disabilities (IDD)? **<Yes/No/Never used it>**

    a. **<Yes>** Please tell us how the website was helpful to you as you tried to get supports and services.
    b. **<No>** Please tell us how the website was not helpful to you as you tried to get supports and services.

14. How easy was the process for getting supports and services through OPWDD? Would you say that it was:
    - Very easy
    - Easy
    - Somewhat easy

- Not too easy
- Not easy at all

a. You said that the process for getting supports and services through OPWDD was ***[participant's rating]***. Please tell us why.

15. What recommendations would you make to OPWDD to improve supports and services for persons with intellectual or other developmental disabilities:
    - For your own racial, ethnic, or cultural community?

16. What recommendations would you make to OPWDD to improve supports and services for persons with intellectual or other developmental disabilities:
    - For your preferred language and communities that speak languages other than English?

17. What recommendations would you make to OPWDD to improve supports and services for persons with intellectual or other developmental disabilities:
    - Across the life course (every age of a person's life)?

Ok, it's time for our final question. Thank you so much for your thoughtful responses. We truly value them. The last question is...

18. There is a lot of talk about equity. In a few words, what does this mean to you and your family in the New York State developmental disabilities system?

If elaboration/additional definition is requested: When we think of equity...there are many definitions of equity. Equity means being treated fairly. This is different from equality, which means being treated the same. Thinking of it broadly, we can see equity as everyone getting what they need – understanding the barriers, circumstances, and conditions.

We have completed the questions. Thank you for your responses. Would you like to share any final thoughts?"

Appendix C

Interview Questions for Group B

Family members of persons with IDD who have received in the past but are not currently

Estimated Session Run Time: 60-90min

Introductory statement

We understand that you are currently not receiving supports and services that are needed for your family member with intellectual or other developmental disabilities (IDD) from OPWDD though you did in the past.

Just to confirm, do you and your family member receive supports and services in [their region]? *If participant is unsure of their region, ask them which county they receive supports and services in, and inform them of their region based on the OPWDD region map.*

1. Tell us why you are not currently receiving supports and services.

Thank you for your response. For the next questions, we are going to ask you to think about when you received services in the past. The next question is...

2. When you think about your family's cultural beliefs and practices, and preferred language, would you say you were getting the supports and services you wanted and needed for your family member who has an intellectual or other developmental disability? **<Yes/No>**
    a. **<Yes>** Tell us more about the supports and services you were receiving that you wanted and needed.
    b. **<No>** Tell us why you were not getting the supports and services you wanted and needed. In other words, please explain your answer.

Thank you for your response. The next question is...

Thank you for your response. For the next questions, we are going to ask you to think about the services you are receiving. The next few questions are on availability.

If elaboration/definition is requested: Availability means that the different types and amount of supports and services are provided when needed. For example, you do not have to be on a wait list.

3. Were the supports and services **available** when you and your family needed them? **<Yes/No>**
    a. **<Yes>** Please describe how the supports and services were **available** when you and your family needed them.
    b. **<No>** Please describe how the supports and services were **not available** when you and your family needed them. In other words, please explain your answer.

4. Were the supports and services **available** in the amount or frequency that you needed? **<Yes/No>**
    a. **<Yes>** Please describe how the supports and services were **available** in the amount or frequency that you needed.
    b. **<No>** Please describe how the supports and services were **not available** in the amount or frequency that you needed. In other words, please explain your answer.

5. Were the supports and services **available** in your preferred language? **<Yes/No>**
    a. **<Yes>** Please describe how the supports and services were **available** in your preferred language.
    b. **<No>** Please describe how the supports and services were **not available** in your preferred language. In other words, please explain your answer.

6. Were the supports and services **available** in ways that considered your family's cultural beliefs and practices? **<Yes/No>**
    a. **<Yes>** Please describe how the supports and services were **available** in ways that considered your family's cultural beliefs and practices.
    b. **<No>** Please describe how the supports and services were **not available** in ways that considered your family's cultural beliefs and practices. In other words, please explain your answer.

Thank you for your response. The next few questions are on accessibility.

If elaboration/definition is requested: Accessibility relates to the supports and services being easy to get to. For example, times offered are convenient, and appropriate.

7. Were the supports and services **accessible** when you and your family needed them? (Accessible means easy to get to, find, or use.) **<Yes/No>**
    a. **<Yes>** Please describe how the supports and services were **accessible** when you and your family needed them.
    b. **<No>** Please describe how the supports and services were **not accessible** when you

and your family needed them. In other words, please explain your answer.

8. Were the supports and services **accessible** in your preferred language? **<Yes/No>**
   a. **<Yes>** Please describe how the supports and services were **accessible** in your preferred language.
   b. **<No>** Please describe how the supports and services were **not accessible** in your preferred language. In other words, please explain your answer.

9. Were the supports and services **accessible** in ways that considered your family's cultural beliefs and practices? **<Yes/No>**
   a. **<Yes>** Please describe how the supports and services were **accessible** in ways that considered your family's cultural beliefs and practices.
   b. **<No>** Please describe how the supports and services were **not accessible** in ways that considered your family's cultural beliefs and practices. In other words, please explain your answer.

We are halfway through the questions. Thank you for sharing. The next question is on acceptability.

If elaboration/definition is requested: Acceptability means that supports and services are provided in a way that is responsive to the person with IDD's language, culture, needs, and interests.

10. When you think about your family's cultural beliefs and practices, and preferred language, how **acceptable** were the supports and services you received in the past? Would you say that they were:
    - Very acceptable
    - Acceptable
    - Somewhat acceptable
    - Not acceptable at all

   a. You said that supports and services were ***[participant's rating]*** when you think about your family's cultural beliefs and practices, and preferred language. Please tell us why.

Thank you for your response. The next question is on quality.

If elaboration/definition is requested: Quality refers to whether supports and services follow best practices and are provided according to high standards.

11. When you think about your family's cultural beliefs and practices and preferred language, how would you rate the **quality** of the supports and services you received in the past? Would you say that they were:

- Excellent
- Good
- Fair
- Poor

a. You said that supports and services were ***[participant's rating]*** when you think about your family's cultural beliefs and practices, and preferred language. Please tell us why.

We are halfway through the questions. Thank you for sharing. The next question is...

12. When you think about your family's cultural beliefs and practices and preferred language, how **useful** were the supports and services you received in the past? Would you say that they were:

- Very useful
- Useful
- Somewhat useful
- Not too useful
- Not useful at all

a. You said that supports and services were ***[participant's rating]*** when you think about your family's cultural beliefs and practices, and preferred language. Please tell us why.

Thank you for your response. The next question is...

13. When you applied for supports and services, how easy was it for you to use the OPWDD website? Would you say that it was:

- Very easy
- Easy
- Somewhat easy
- Not too easy
- Not easy at all
- N/A (Never used it)

14. Keeping in mind your family's cultural beliefs and practices, or preferred language, would you say that OPWDD's website was helpful to you as you tried to get supports and services for your family member with an intellectual or other developmental disabilities

(IDD)? **<Yes/No/Never used it>**

a. **<Yes>** Please tell us how the website was helpful to you as you tried to get supports and services.
b. **<No>** Please tell us how the website was not helpful to you as you tried to get supports and services. In other words, please explain your answer.

Thank you for your response. The next question is...

15. How easy was the process for getting supports and services through OPWDD? Would you say that it was:
    - Very easy
    - Easy
    - Somewhat easy
    - Not too easy
    - Not easy at all

    a. You said that the process for getting supports and services through OPWDD was ***[participant's rating]***. Please tell us why.

16. What recommendations would you make to OPWDD to improve supports and services for persons with intellectual or other developmental disabilities:
    - For your own racial, ethnic, or cultural community?

17. What recommendations would you make to OPWDD to improve supports and services for persons with intellectual or other developmental disabilities:
    - For your preferred language and communities that speak languages other than English?

18. What recommendations would you make to OPWDD to improve supports and services for persons with intellectual or other developmental disabilities:
    - Across the life course (every age of a person's life)?

Ok, it's time for our final question. Thank you so much for your thoughtful responses. We truly value them. The last question is...

19. There is a lot of talk about equity. In a few words, what does this mean to you and your family in the New York State developmental disabilities system?

If elaboration/additional definition is requested: When we think of equity...there are many definitions of equity. Equity means being treated fairly. This is different from equality, which means being treated the same. Thinking of it broadly, we can see equity as everyone getting

what they need – understanding the barriers, circumstances, and conditions.
We have completed the questions. Thank you for your responses. Would you like to share any final thoughts?

Appendix D

Interview Questions for Group C

Family members of persons with intellectual or other developmental disabilities who have not received services, attempted to receive services, or want to receive services

Estimated Session Run Time: 60-90 mins

Introductory statement

We understand that you're not receiving and have never received supports and services from OPWDD that are needed for your family member with intellectual or other developmental disabilities (IDD).

Just to confirm, are you and your family member located in [their region]? *If participant is unsure of their region, ask them which county they reside in, and inform them of their region based on the OPWDD region map.*

For the next questions, we are going to ask you about the availability of services.

If elaboration/definition is requested: Availability means that the different types and amount of supports and services are provided when needed. For example, you do not have to be on a wait list.

1. Were supports and services **available** to you? **<Yes/No>**
   a. **<Yes>** If supports and services were available, why didn't you use them? Was it because they:
      - Did not consider your cultural beliefs and practices **<Yes/No>**
      - Were not available in your preferred language **<Yes/No>**
      - Other (please specify)
        i. *If response to any of the previous questions is "no", ask:* Please tell us more about how supports and services were **not available** in ways that considered *[participant's response].* In other words, please explain your answer.

   b. **<No>** What are the reasons that supports and services were not available to you? Was it because they:
      - Did not consider your cultural beliefs and practices **<Yes/No>**
      - Were not available in your preferred language **<Yes/No>**
      - Other (please specify)
        i. Please tell us more about how supports and services were **not available** in ways that considered *[participant's response]*. In other words, please explain

your answer.

2. When you think of your family's cultural beliefs and practices or preferred language, what could OPWDD do to make supports and services **available** to you and your family member with an intellectual or other developmental disabilities (IDD)?

Thank you for your response. The next few questions are on accessibility.

If elaboration/definition is requested: Accessibility relates to the supports and services being easy to get to. For example, times offered are convenient, and appropriate.

3. Were supports and services **accessible** to you? **<Yes/No>**
   a. **<Yes>** If supports and services were accessible, why didn't you use them? Was it because they:
      - Did not consider your cultural beliefs and practices **<Yes/No>**
      - Were not available in your preferred language **<Yes/No>**
      - Other (please specify)
        i. *If response to any of the previous questions is "no", ask:* Please tell us more about how supports and services were **not accessible** in ways that considered *[participant's response]*. In other words, please explain your answer.
   b. **<No>** What are the reasons that supports and services were not accessible to you? Was it because they:
      - Did not consider your cultural beliefs and practices **<Yes/No>**
      - Were not available in your preferred language **<Yes/No>**
      - Other (please specify)
        i. Please tell us more about how supports and services were **not accessible** in ways that considered *[participant's response]*. In other words, please explain your answer.

4. When you think of your family's cultural beliefs and practices or preferred language, what could OPWDD do to make supports and services **accessible** to you and your family member with IDD?

We are halfway through the questions. Thank you for sharing. The next question is on acceptability.

If elaboration/definition is requested: Acceptability means that supports and services are provided in a way that is responsive to the person with IDD's language, culture, needs, and

interests.

5. Were supports and services **acceptable** to you? **<Yes/No>**
    a. **<Yes>** If supports and services were acceptable, why didn't you use them? Was it because they:
        - Did not consider your cultural beliefs and practices **<Yes/No>**
        - Were not available in your preferred language **<Yes/No>**
        - Other (please specify)
            i. *If response to any of the previous questions is "no", ask:* Please tell us more about how supports and services were **not acceptable** in ways that considered *[participant's response]*. In other words, please explain your answer.
    b. **<No>** What are the reasons that supports and services were not acceptable to you? Was it because they:
        - Did not consider your cultural beliefs and practices **<Yes/No>**
        - Were not available in your preferred language **<Yes/No>**
        - Other (please specify)
            i. Please tell us more about how supports and services were **not acceptable** in ways that considered *[participant's response]*. In other words, please explain your answer.

6. When you think of your family's cultural beliefs and practices or preferred language, what could OPWDD do to make supports and services **acceptable** to you and your family member with IDD?

Thank you for your response. The next question is...

7. When you tried to apply for supports and services, how easy was it for you to use OPWDD's website? Would you say that it was:
    - Very easy
    - Easy
    - Somewhat easy
    - Not too easy
    - Not easy to all
    - N/A (Never used it)

Just a few more questions. Thank you so much for all your thoughtful responses.

8. Keeping in mind your family's cultural beliefs and practices or preferred language, would

you say that OPWDD's website was helpful to you as you tried to get supports and services for your family member with IDD? **<Yes/No/Never used it>**

a. **<Yes>** Please tell us how the website was helpful to you as you tried to get supports and services.
b. **<No>** Please tell us how the website was not helpful to you as you tried to get supports and services.

9. How easy was the process for getting supports and services through OPWDD? Would you say that it was:
    - Very easy
    - Easy
    - Somewhat easy
    - Not too easy
    - Not easy at all
    - N/A (Never tried to get supports and services)

a. You said that the process for getting supports and services through OPWDD was ***[participant's rating].*** Please tell us why.

Ok, it's time for our final question. Thank you so much for your thoughtful responses. We truly value them. The last question is...

10. There is a lot of talk about equity. In a few words, what does this mean to you and your family in the New York State developmental disabilities system?

If elaboration/additional definition is requested: When we think of equity...there are many definitions of equity. Equity means being treated fairly. This is different from equality, which means being treated the same. Thinking of it broadly, we can see equity as everyone getting what they need – understanding the barriers, circumstances, and conditions.

We have completed the questions. Thank you for your responses. Would you like to share any final thoughts?

References

Goode, T. D. (2017). *Disparities in intellectual and developmental disabilities: A framework for understanding and action*. National Center for Cultural Competence, Georgetown University Center for Child and Human Development. https://nccc.georgetown.edu/resources/disparities-in-idd.php

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