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

EXECUTIVE SUMMARY

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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.

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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