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

Survey Results and Recommendations from 2024 Regional Provider Forums

Executive Summary

Submitted by Georgetown University National Center for Cultural Competence

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Introduction

The New York State Office for People With Developmental Disabilities (OPWDD) contracted with Georgetown University National Center for Cultural Competence (NCCC) to help them identify how to promote policies and practices of cultural and linguistic competence, diversity, equity, and inclusion in their intellectual and developmental disability (IDD) service system. This project started in October 2022 and was named, Advancing Cultural and Linguistic Competence, Diversity, Equity, and Inclusion: OPWDD-Georgetown University NCCC Partnership for Systems Change. The project will be called the "Systems Change Project" in this report. This report provides results and recommendations for cultural and linguistic competence based on information collected from the 2024 Regional Provider Forums.

During the forums and in this report, there are important words that were used. Definitions are listed pages 1-3.

Culture

Culture includes beliefs about what is real, how people should be with each other, what they know about the world, and how they should respond to their social and material environments. Culture is seen in religion, spirituality, morals, customs, politics, technologies, and survival strategies of a given group. It affects how groups work, parent, love, marry, and understand health, mental health, wellness, illness, disability, and end of life. As humans, we are all 'cultural beings.' Culture is not limited to race and ethnicity.

Cultural competence

Cultural competence is a process that builds over time. Many of the systems that support persons with IDD and their staff are at various stages in this process.

Cultural competence requires organizations to have a clearly defined and aligned set of values and principles. Organizations must demonstrate behaviors, attitudes, policies, structures, and practices that enable them to work well across all cultures (adapted from Cross, Bazron, Dennis & Isaacs, 1989).

In organizations, this includes a process of:

- ***valuing diversity*** — including diversity of people, thought, and ways of being.
- ***conducting self-assessment***—which means reflecting on what is known and not known about the organization and its staff and the people, families, and communities supported;
- ***managing the dynamics of difference***—both as groups of people and individuals, we all have similarities and differences; it is our lack of understanding of cultural differences that cause us difficulties and conflicts;
- ***embedding cultural knowledge***—which means the many ways that cultural experiences and 'know how' of people with IDD, families, and staff are used to strengthen the work of the organization; and
- ***adapting to diversity***—involves the way the organization takes diversity into consideration in all it does (i.e., values, policies, structures, practices, supports, and services).

For **individuals** this process involves:

- being aware of cultural differences;
- understanding your own culture;
- being aware of what you know and do not know about yourself and others (who may be culturally the same or different;
- learning about culture (and what it looks like among people, communities, organizations, and systems) and developing skill sets to provide appropriate supports and services; and
- being able to view the behavior of people and organizations using culture as a lens.
- In order for **systems** that are designed to support people with IDD, their families, and the communities in which they live, cultural differences must be a part of all policymaking, administration, practices, and services.

Linguistic competence

Linguistic competence is the capacity of an organization and its staff to communicate information in a manner that is easily understood by diverse groups, including people who:

- may not be able to or are learning to speak English (limited English proficiency);
- are not able to read or write (or who have low reading and writing skills) in English or their first language;
- have disabilities; and
- are deaf or hard of hearing.

Linguistically competent supports and services often require other accommodations for persons with intellectual disabilities and their families. This includes but is not limited to:

- American Sign Language (ASL) and other sign languages,
- Information in plain language (oral, written, graphic, pictorial, & easy-to-read formats),
- Braille and low-vision technology; and
- Augmentative and Alternative Communication (AAC) – augmentative all the ways people can use to communicate besides talking. According to the American Speech, Language, and Hearing Association, AAC can be low-tech such as writing, drawing, and pointing to pictures, words, or letters. ACC can also be

high-tech which means using computer-assisted technology and apps to communicate that produce voice.

Diversity

Diversity is used to describe the broad array of differences ***and*** similarities among people, groups, and organizations. Characteristics of diversity include but are not limited to differences in ethnic or racial classification and how a person identifies, tribal or clan affiliation, nationality, language, age, gender, sexual orientation, gender identity or expression, social class (socioeconomic status), education, religion, spirituality, physical and intellectual abilities, personal appearance, and other factors that distinguish one group or person from another. Diversity also refers to "diversity of thought," values, beliefs, and behaviors among people, organizations, and systems.

Equity

Equity is about providing people with different types and amounts of support and assistance based on their needs, situations, and/or abilities. Achieving equity in IDD will require:

- ending unjust policies and practices that discriminate against people, groups, and communities;
- dedicating the right amount of resources to meet the individual interests and needs of persons, populations, and communities;
- complying with all disability and civil rights-related laws including the spirit or intent of such laws; and "recognizing and accepting that disability is a natural part of the human experience that does not diminish the rights of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society."

Inclusion

Inclusion means different things to different people, in different circumstances, and at different times in their lives. Inclusion is defined in legislation and reflects best practices for people with disabilities in general. As it pertains to disability supports and services, inclusion means and is not limited to:

- Getting fair treatment from others (nondiscrimination);
- Making products, communications, and the physical environment more usable by as many people as possible (universal design);
- Modifying items, procedures, or systems to enable persons with disabilities to use them to the maximum extent possible (reasonable accommodations); and
- Eliminating the belief that people with disabilities are unhealthy or less capable of doing things (stigma, stereotypes).

Data source: Retrieved on 5/1/19 from http://www.talentintelligence.com/blog/bid/377611/inclusion-and-the-benefits-of-diversity-in-the-workplace

Why we did this

One part of the Systems Change Project was to listen to the wealth of knowledge and experience of providers across New York State. These sessions were called "Regional Provider Forums." Representatives from provider organizations who participated were asked to:

- Define cultural competence, linguistic competence, diversity, equity, and inclusion and what they mean for the IDD system of supports and services in New York State.
- Assess to what degree each provider organization has existing policies, practices, and resources for cultural competence, linguistic competence, diversity, equity, and inclusion.
- Identify the success and challenge of putting into place policies and practices that support cultural competence, linguistic competence, diversity, equity, and inclusion within their organizations.
- Report results and recommendations to improve capacity for cultural and linguistic competence and equity among providers.

What we did

The NCCC held a total of 12 provider forums from May-August 2024. This included two in each region of New York state and two that included providers that serve multiple regions. All forums were held online.

The people invited to participate in these forums were the Chief Executive Officers (CEOs) or their assigned staff who had authority to speak on behalf of the organization. The NCCC invited people through email and the project website. The NCCC team used an online survey program called "Qualtrics" to register people who wanted to attend and obtain their permission to do so. Those who completed this process received a Zoom link to join the forums.

A total of 640 providers registered and 324 providers participated in the forums. Here is some information about the people who participated.

- Most were from Region 4 (a little over one-third or 35%). Region 3 had one-fifth (20%) of the participants, and a little over one-tenth (14%) were from Region 1.
- 10% of forum participants represented multi-regional provider organizations, twelve percent of participants represented Region 2, while nine percent of participants represented Region 5.
- **A total of 16% were** CEOs. Not quite half (43%) of the providers who participated were staff assigned by the CEOs and had authority to speak about their organizations. **Another 37% identified themselves as "other."**
- Nearly all (96%) of the participants indicated that they knew their organizations' policies and practices for cultural competence and linguistic competence, **diversity, equity, and inclusion.**
- The people who participated had been in their current jobs or positions for different amounts of time. About one-third (32%) had

been with their organizations for more than six years, about one-fifth (21%) between five and six years, and one-fifth (20%) between one and two years.

- Most of the participants (79%) work for organizations that have provided support to people with intellectual and developmental disabilities for more than six years.
- The organizations that participated in the forums provided community habilitation, structured day programs, and certified residential services.
- About half (49%) of the people who participated self-identified as White (non-Hispanic). Not quite one-third (28%) were Black or African American and under one-tenth (6%) were Asian. About three-fourths (77%) were non-Hispanic or Latino and just under one-fourth (23%) were Hispanic or Latino.

How we did it

The Forums described widely accepted definitions and frameworks for cultural competence, linguistic competence, diversity, equity, and inclusion.

During each forum, providers were asked to answer 14 questions. Of these questions, 13 were asked by using polls in the online system (called Zoom). One question was asked using a computer program called ThoughtExchange. This program allows people to share their responses to a question and rate the "thoughts" shared by others anonymously—that is without having to let anyone know who you are. All questions assessed an organization's commitment to cultural competence, linguistic competence, equity, diversity, and inclusion. The questions looked at whether organizations have:

- Definitions and frameworks for cultural competence and linguistic competence;
- Action plans to implement practices for cultural competence and linguistic competence;

- Policies and structures to support cultural and linguistic competence;
- A need for help from others (sometimes called technical assistance and consultation);
- The necessary resources to move cultural competence, linguistic competence, diversity, equity, and inclusion forward;
- Organizational capacity to lift up the impact of these efforts;
- Barriers in making progress on cultural and linguistic competence; and
- A definition and framework for advancing equity.

Participants were asked to complete an evaluation form. This report provides a summary of the results and recommendations based on the Regional Provider Forums data that was collected.

What we learned

Definitions and Framework Capacity

- The great majority of provider organizations that participated in the Forums shared a clear commitment to and understanding of the critical need for cultural competence, linguistic competence, diversity, equity, and inclusion within New York State's system of support and services for persons with IDD and their families.
- Data indicates that there are widely different ways that providers define and implement cultural competence, linguistic competence, and equity across Regions.
- Clear guidance from OPWDD is needed to define exactly what is meant by cultural competence, linguistic competence, and equity and how such policies and practices are demonstrated and measured. In the absence of this guidance, each provider organization will approach cultural competence, linguistic competence, and equity in its own way, which will likely make a coordinated and comprehensive approach to systems change very hard.
- Some provider organizations described themselves as "culturally competent" and "linguistically competent."
- When asked to elaborate on how their definition and framework for advancing equity guides their work, the participants indicated the following:
  - » goal setting,
  - » informing policy and training,
  - » communication,
  - » data collection,
  - » improve workplace culture, and
  - » decision-making.

- While a number of provider organizations indicated that they were culturally and linguistically competent, they also indicated they could benefit from technical assistance and resources. Participants cited the need for technical assistance and resources that will strengthen their capacity to serve people with IDD and their families in a manner that is responsive to their cultures, languages, and the communities in which they live.

Barriers

- Providers identified numerous barriers to implementing cultural competence, linguistic competence, and equity within their respective organizations. The following barriers are representative of those cited by providers.
  - » Not enough funding and resources,
  - » Need for staff and training,
  - » Lack of clear organizational structures and practices,
  - » Difficult to align organizational efforts and policies to systems-level change,
  - » Resistance
  - » Geographical barriers,
  - » Time and effort for implementation,
  - » What it takes to understand and navigate an organizational commitment to advancing

cultural and linguistic competence (e.g., staffing, resources, buy-in from both the people receiving supports and services including leadership and those providing them,

- » Lack of adequate interpretation services,
- » Need to prioritize cultural and linguistic competence,
- » Staffing challenges,
- » Language access,
- » Need for community engagement, and
- » Leadership buy-in.

Identified Approaches to Organizational Change

- None of the providers indicated that they drew upon individual and organizational theories of change, which are essential to advance cultural competence, linguistic competence, and equity within organizations and systems.
- Based on survey data, many provider organizations in New York State have knowledge and expertise in supporting people with IDD and their families across diverse racial, ethnic, cultural, linguistic, and other identity groups.
- Even though many provider organizations reported such capacity, it must be noted that these organizations did not identity: 1) conceptual frameworks based on evidence-based models of cultural competence and linguistic competence; and 2) supporting policies, structures, procedures, practices, and behaviors to maintain cultural competence and linguistic competence.
- Providers who indicated they have not yet started this work could benefit from ongoing technical assistance and resources as well as the knowledge and expertise of other providers.
- Delivering training was frequently described by provider organizations as one of the primary approaches they used to advance cultural and linguistic competence and equity. While training can be effective, it cannot be the sole approach and measure of achieving organizational change. Other approaches are necessary to facilitate and maintain organizational change for cultural and linguistic competence.

Change in the Context of New York State

Participants in the forums said that advancing cultural competence, linguistic competence, and equity can be difficult because of the demographic makeup (diverse populations that live in state), and the differences in the resources of geographic areas within New York State. The following are examples of the types of changes that would be necessary to advance cultural and linguistic competence and to strive for equity for people with IDD, their families, and the communities in which they live. Some centered on how people with IDD, across all racial, ethnic, and cultural groups are thought about and treated :

- There is a long history of inequitable treatment of people with IDD.
- People with IDD have in the past and continue to experience unfair treatment and marginalization which means:
  - » Excluding people socially or in other ways, not accepting people because of differences from what is considered “normal,”
  - » Minoritized describes when a social group

is devalued in society and given less access to its resources and a lower social status. Minority is the term often used for these social groups. Minoritized is now being used to explain 1) why and how these groups are given less access to society's resources; and 2) how society views these groups is not the same as the number of people in the population from these groups. People with IDD are a minoritized group.

- There is growing opposition to "all things DEI" (diversity, equity, and inclusion) in many areas of the U.S. including New York State. In this environment it may be very difficult to do this needed work to ensure all people with IDD and their families have supports and services that are equitable and culturally and linguistically competent.

Recommendations

1. OPWDD developed a vision statement for cultural competence, linguistic competence, diversity, equity, and inclusion for the IDD system in New York State. OPWDD also developed definitions and frameworks for cultural competence, linguistic competence, and equity for its internal functions as a state entity, which extends to the whole IDD system.
    a. It is recommended that OPWDD engage all providers in a process that:
        - Presents its vision statement and definitions and gets feedback from the perspectives of providers.
        - Strongly considers changes to the vision statement and definitions based on provider input.
        - Determines the funding and staffing implications of cultural and linguistic competence to providers.
        - Develops a multi-year action plan that responds to the interests and needs of provider organizations across all regions.
    b. It is recommended that OPWDD engage persons with IDD and their families across diverse racial, ethnic, linguistic, cultural, and other identity groups to review the OPWDD vision statement and definitions and get feedback from them based on their lived experience.
2. OPWDD, along with self-advocacy organizations and providers in New York State, should create a structure and fund the launch of and ability to maintain an "organizational learning and exchange community" dedicated to:
    a. Sharing best and emerging evidence-based practices for cultural and linguistic competence and equity.
    b. Offering mentoring and coaching to the leadership, boards, and other staff to increase capacity for cultural and linguistic competence and equity.

   c. Including persons with IDD and family members as "experts" based on their lived experience to guide the work of the organizational learning and exchange community.

3. OPWDD and provider organizations should consider:

   a. Applying organizational and individual change strategies and tools to guide the work of putting cultural and linguistic competence and equity in place within New York State. One example of a strategy to use is, Managing Complex Change, as originally developed by The Leadership Spectrum® Enterprise Management Limited 1994.

   b. Looking at all policies to determine the extent to which organizational values and policies align with efforts to move forward cultural and linguistic competence and equity.

4. Given recent changes in attitudes and policies in some states and nationally, provider organizations will need to develop reasons why cultural and linguistic competence are essential to the provision of supports and services to all persons with IDD and families that reside in New York State. This may involve:

   a. Providing data on disparities that affect persons with IDD and their families across all racial, ethnic, linguistic, cultural, and other identity groups.

   b. Describing all persons with IDD as an underserved population and bringing attention to the disproportionate impact on specific groups.

   c. Deciding if and when to use the term "DEI" when describing efforts to ensure equal access to supports and services as specified in federal and state laws and policies.

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