



Cultural Responsiveness in Assessment and Decision Support for People with Intellectual and Developmental Challenges. Transformational Collaborative Outcomes Management

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Abstract

We have made major strides in healthcare access and supportive resources for those with IDD (intellectual and developmental disabilities); however, their care and well-being remain a major issue both within the United States and worldwide. The Centers for Disease Control and Prevention (CDC) and the World Health Organization report that those with IDC struggle to get the services they need [1,2]. In addition, there also remains a large gap in accessing services for those with IDD who also identify as belonging to a racial minority group. In the U.S., data from 2019 to 2021 show that Black and Latino communities are identified with IDD more often, but they are less likely to get timely and adequate support.

Keywords: Disease Control and Prevention; intellectual and developmental disabilities; National Core Indicators; Transformational Collaborative; Crisis Assessment Tool

Abbreviations: IDD: Intellectual and developmental disabilities; NCI: National Core Indicators; CDC: Centers for Disease Control and Prevention; TCOM: Transformational Collaborative Outcomes Management; CANS: Child & Adolescent Needs & Strengths; ANSA: Adult Needs & Strength Assessment; FAST: Family Advocacy & Support Tool; CAT: Crisis Assessment Tool

Opinion Article

We have made major strides in healthcare access and supportive resources for those with IDD (intellectual and developmental disabilities); however, their care and well-being remain a major issue both within the United States and worldwide. The Centers for Disease Control and Prevention (CDC) and the World Health Organization report that those with IDC struggle to get the services they need [1,2]. In addition, there also remains a large gap in accessing services for those with IDD who also identify as belonging to a racial minority group. In the U.S., data from 2019 to 2021 show that Black and Latino communities are identified with IDD more often, but they are less likely to get timely and adequate support.

Although the prevalence of ASD has been found not to differ across racial and ethnic groups, studies have found that White children and those of higher socioeconomic status are more likely to be both identified and diagnosed with ASD earlier compared with Black, Latino/a, and Asian children [3]. The National Core

Indicators (NCI-IDD) and the National Survey on Health and Disability (2021-2024) indicate substantial gaps in access to community-based and Medicaid-supported services for racial and ethnic minorities, people with low incomes, and those living in rural areas [4]. For these groups, language differences, a lack of cultural understanding among providers, and other barriers make it even harder to get needed services. To address this fundamental challenge, we propose specific mechanisms to support culturally responsive care that can strengthen culturally appropriate services for the IDD population by identifying these barriers.

People without cognitive difficulties can face challenges understanding the unique needs of those with intellectual and developmental disabilities (IDD). However, working with the IDD population enhances human dignity and advances social justice with integrity, improving things for everyone [5]. Ensuring effective service for the IDD population does not end with providing adequate treatment but should be an all-encompassing task,

including enhancing their self-efficacy and ensuring inclusivity. While there have been dramatic improvements in how intellectual and developmental disabilities (IDD) are identified and addressed [6], there remains substantial room for improvement.

People with IDD have inadequate housing and work opportunities and lack the overall opportunity to live their best lives. We believe that the core of our challenges to providing the types of support people require is grounded in a lack of understanding of the cultural experiences of those with IDD. That is why we propose a change to how helping systems are structured and financed to better serve and include those with IDD in their own care [7]. As has already been found, those with IDD are not usually included in the decisions made about their care. What creates further difficulties for minorities who identify as IDD is that, in general, those from diverse ethnic groups are infrequently included in the systems that impact IDD care.

The prime factor is a lack of understanding of cultural variation in communication patterns and language. Frequently, natural communication and behavioral patterns are mistakenly considered a “problem.” The rules and tools of an assessment should be formed by thinking about a specific cultural context; for this, people of other cultures with IDD do not get the equitable services in an accessible way. Too often assessments focus on ‘objective’ criteria that count behaviors or describe activities without any cultural context. Families with IDD from different cultures lack the opportunity to share their cultural perspectives and values, as their voices are not included. Poverty, language difficulties, and societal discrimination instigate this issue. To ensure that people from all cultures receive equitable services in the IDD system, we need to propose a framework that works in a culture-specific manner at similar levels, with meaningful context.

We pay professionals to spend time with people, even though the actual enterprise is intended to help people change their lives in fundamental ways [8]. In 2001, the Institute of Medicine (now the Academy) recognized many of these shortcomings and proposed person-centered care-making people full partners in their health care-as a partial solution to these problems. Building off these ideas, we propose a comprehensive framework to address this major limitation in how we work together on behalf of people seeking help, including people with IDD: An important component of this framework is embedding cultural responsiveness as a routine component to this system. There remains evidence that social and cultural determinants have just as great an impact within the IDD community as within other health and helping sectors [9].

Transformational Collaborative Outcomes Management (TCOM) is a conceptual framework to implement person-centered care at all levels of the system simultaneously. Components of the TCOM framework have been widely used to encourage a range of system improvements [10]. These tools have been used in mental health, child welfare, justice, health and IDD systems across the

United States and around the world. TCOM primary assessments including the CANS (Child & Adolescent Needs & Strengths), ANSA (Adult Needs & Strength Assessment), FAST (Family Advocacy & Support Tool), and CAT (Crisis Assessment Tool) include action priorities for specific, relevant needs and strengths. Together these indicators guide the development of person-centered action plans to support the management of complex helping service systems. For example, the specific needs of children and adults with IDD can be identified either with a specific version or as a component of a more comprehensive version. This allows customizations across applications without threatening the validity of the tools.

Focusing on the culturally responsive IDD system, the fundamental premise of TCOM increases the effectiveness by encouraging that all decisions from planning care to supervising to program and system management could be based on the best interests of the people seeking help [11]. Simple enough idea, but the only way that can happen is if there is a robust representation of different cultural people showcasing the best interests at all levels of the system simultaneously-the person, the provider, the program, the agency, and the system. This is not a simple task.

As questioning across all levels of the system, emphasizing culturally appropriate IDD services might be challenging due to the variability of systemic inequalities and power imbalances. However, by starting with the individual’s story, particularly for people with IDD, and aggregating up levels of the system, TCOM offers the possibility to inform all decisions and integrate these with stories of various cultural needs and strengths, including the people with IDD. To achieve this conceptual aspiration of representing people with IDD seeking help within a system, a measurement approach that serves as a common language while remaining culturally responsive is required. TCOM provides the tools necessary to do this within four components.

The first step in TCOM’s approach involves creating culturally responsive assessments. To achieve this goal, we must rethink measurement. Rather than using psychometric or behavioral counts, we use a communication-based theory of measurement called communimetrics [10]. As the term implies, this is a theory of measurement that reconceptualizes measurement as a form of communication. When you use a community’s tool such as the CANS, you are measuring a person’s story. Starting with a simple example, domains indicate the general concerns and strengths of each member of the family, and based on the identified concerns & strengths, it assists the providers to find common ground across teams and with individuals and their families in term of the concerns and strengths, which are used to create action priorities moving forward. Unlike traditional measures, you are not claiming to reveal an objective ‘truth’. You are describing what people believe to be the truth at the time of the assessment. This difference is fundamental to our ability to be culturally responsive while still speaking a common language necessary for working in potentially complex environments, particularly for populations with IDD.

It can be challenging to rely on person-centric measures for the intellectually and developmentally disabled population to assess needs and strengths [12], due to inherent differences in how they communicate, express, and think about concepts compared to the wider population. The flexibility with a communimetric approach allows whatever level of participation is possible in whatever format that participation can occur. Rather than specifying how information is collected as most traditional measures do, this approach allows any manner of discovery and focuses instead on how the information is compiled and used moving forward.

That is how a communimetric tool can play a major role in establishing a strong association between the unique needs population’s requirements while remaining culturally responsive in the creation of an action plan. Cultural responsiveness for the IDD population has been somewhat overlooked, as people assume it is neurotypical and shaped by dominant cultural norms [13]. Based on this, a person with IDD’s behavioral, communication, language, caregiving, and emotional intelligence criteria have been addressed without assessing these needs within their cultural context.

Without a focus on the cultural variation within the IDD population, it might be challenging to empower the people with IDD’s voices about their unique needs, challenges and strengths. Frequently, family-based “cultural beliefs” are perceived as barriers rather than as strengths and assets. This perception

creates misconceptions for the providers and families who are involved in these services and results in increasing mistrust and social insulation among people with IDD and their families/caregivers. In the absence of awareness and understanding, stigma can be created, and systematic bias becomes prominent in any cultural appraisal. Ensuring a culturally responsive service plan for the IDD population is required to make it strength-based, inclusive, welcoming, and person-centered.

Table 1 presents the characteristics that define a communimetric tool. Of these, the one that is most salient to creating a culturally sensitive measurement is the fifth, Cultural and Development decontextualized. This principle is the operationalization of cultural humility. This means it is incumbent on the assessment process to discuss, understand, and reach consensus on how cultural factors may or may not impact the expression of needs and strengths. In other words, culture can be factored in, but that is not required. What is required is understanding what needs to be done. The message we try to give, focusing on cultural responsiveness, is to explore more how people with IDC express their needs across cultural variations and how the compilation of their own unique traditions might affect their daily living experiences. This will help providers gather more information on how to support people with different cultural and developmental needs by linking the evaluation process to culturally responsive communication metrics and person-centered service plans.

Table 1: Key Principles of a Communimetric Measure.

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| Principle 1: Relevance. Indicators re selected based on their relevance to decision-making. Once named an indicator is the same across versions; however, only relevant indicators are included in any single version. |
| Principle 2: Action-orientation. Levels of all indicators translate immediately into action priorities. Needs are often prioritized as 0=no evidence, 1=watchful waiting/prevention, 2=action, and 3=immediate/intensive action, for example. |
| Principle 3: Descriptive. Indicators are used to describe without attempting to embed theories of causes or effects |
| Principle 4: Interventions decontextualized. Indicators describe the person, not the person when they have received services/interventions. |
| Principle 5: Cultural and Development decontextualized. Action levels incorporate both a cultural and developmental understanding before action priority is determined. |
| Principle 6: Current focus. Indicators prioritized based on the person’s current status rather than historical factors that may no longer be relevant. |

Applying evidence-based practices through the integration of person-centered service plans for people with IDD can make current and future services more feasible, facilitating decision-making processes. When cultural background is not taken into consideration, several aspects of care are impacted including diagnosis, treatment, and medical care. In the US, we have commonly had difficulties with a subset of European American clinicians interpreting that a Native American youth who talks to their ancestors has a major mental illness, when it is, in fact, a common cultural belief regarding parallels between the living and the spiritual worlds. In this example, it is incumbent on the assessment process to understand this cultural belief and ensure that it doesn’t result in inappropriate intervention.

As a counterpoint, there are some cultures that condone corporal punishment of children. This type of corporal punishment might be viewed as a “natural environmental teaching” for children, as per one culture, although in the United States, it is generally illegal and can result in children being removed. It does not matter what a parent believes about the use of physical punishment; they must understand and follow the law or risk child welfare involvement. Again, often the parents lack understanding of how to apply the rules or principles, leading to adjustments in cultural beliefs about how to manage children’s challenging behavior. This happens only when individuals from different cultures lack the understanding of how to shift cultural beliefs to reflect required new norms for their behavior.

The second approach in TCOM to address cultural responsiveness requires the identification of specific cultural needs and strengths. Sometimes cultural characteristics can themselves be strengths (e.g. identify, access to traditions) or needs (e.g. cultural stress). We often focus on fulfilling the health needs of people with intellectual and developmental disabilities while ignoring their ability or inability to access their own cultural experiences and traditions. Culture plays an essential role in recognizing a person's lived experience because family, spirituality, and the types of communication patterns vary from one culture to another (Raghavan & Small, 2004). If service providers overlook the differential meaning of living experiences for the population with IDD, they might miss the opportunity to explore adequate service plans for them.

Communimetrics approaches culture from a cultural humility lens [10]. Anyone not in your skin is in at least a somewhat different culture. That means establishing cultural norms etc., can become stereotyping. Rather, effective cultural responsiveness requires an individualized understanding of a person's cultural beliefs and practices. Simply, understanding a person's cultural beliefs and practices is not possible through prediction and labeling. It might only be possible if we actively listen to individuals' cultural perspectives and real-life experiences rather than explain [14]. Cultural humility involves acknowledging our limitations in our perceived knowledge and accepting others' perceptions and views. This process gives us the opportunity to value the shared perspectives of the assessor and the assessed person.

Also, it is important to know that cultural practices are not static and may vary according to individuals' stories based on their daily experiences. Many versions of TCOM tools include a specific assessment of cultural needs and strengths to aid our understanding of how these factors influence our approach to helping. It is common to use Cultural Identity as a Strength. People who have a strong sense of themselves as a part of a larger group generally have greater resilience and well-being. The majority population may not understand the sense of cultural identity that people with IDC have, and it can be difficult for those with IDC to develop that identity [15].

TCOM tools emphasize identifying the domains, such as cultural strengths, language, and caregiving strengths that are essential for people with IDD who struggle to identify those. There are myriad barriers for people with IDD to develop a natural pathway in creating relational strengths. Cultural needs and strength identification can include such things as a need for language accommodation, stress related to cultural differences within a community, and stress related to cultural differences within a household or family. If we can identify cultural needs and help resolve them, each family with a person with IDD can increase their faith and reliance on the services that are provided.

The third way in which TCOM embeds cultural responsiveness

in its approach is, perhaps, ironic. TCOM never includes static personal characteristics such as race or cultural background because these factors institutionalize decision-making. Institutionalizing decisions create the systemic racism and other 'baked-in' biases that we see in our systems. Instead of focusing on these static demographics, TCOM prioritizes only those indicators and domains that are changeable and assist in understanding people's decisions. People who need services will easily explain their needs and focusing on those needs will no longer be challenging for them. Deciding is not only justified by this process, but also, it becomes a more sensitive and responsible process for them.

By excluding the static personal characteristics, TCOM makes the process very easy for individuals, including people with IDD, not to focus only on systemic racism and bias. This results in a more unique look through a more respectful manner into intellectually disabled people's decisions regarding their needs from service providers. Thus, this process makes services more equitable and accessible to everyone. Some statisticians may argue that these factors include race, gender and other demographic controls for these factors by removing associated variation and create a culture free of color-blind decisions. But That is quite simply not the case. There are two problems with this common myth; First, most predictive analytic models are built off the General Linear Model (GLM) [16], and therefore remove the linear relationship (i.e., only additive effects) and thus, Interactions are ignored.

We know that interactions with cultural factors are commonplace and therefore should always be acknowledged. Second, removing statistical variation does not eliminate bias. It assumes all people of a given race or cultural group are replicated, which is also simply false. Identity, culture and social status are not static, and these variables are changeable according to time [17]. Resulting "culture free of color blind" might influence the service providers to accept the systemic racism, overlooking the cultural responsiveness and humility. Person-centric TCOM assessment might expand the opportunity to understand IDD people's real experiences in a meaningful manner. This aspect does not limit the "decision" by predictive analytics, but rather makes it more equitable, justifiable, and human-centric.

Fourth, we recommend frequent disaggregation by important cultural groups to understand differences and potential disparities. This is achieved by frequently using and reviewing person-centered data, which is A major emphasis of TCOM [8]. Whenever possible, these analyses are studied separately for different cultural groups which creates a "group-wise" approach and helps identify hidden structural inequality. TCOM transforms power, voice and experiences into a research hub by utilizing person-centered information. The results of "group-wise" evaluation and analysis ensure that the service providers become more accountable and establish effective guidance to enhance the service quality for that culture.

This assures the ethical and systematic utilization of person-centered information and bridges the gap between research and practice. That said, TCOM tools can help create sustainable services that focus on improving quality of life rather than “controlling” the disability. The domains of TCOM achieve this goal by integrating individuals’ daily activities, social relationships, and available resources. through the lens of changing time, which makes the assessment more realistic. In addition, the TCOM tools are flexible, and there is always an opportunity to reassess them to determine when and which intervention to implement for the person with IDD. This idea of ‘mass customization is fundamental to our approach and will advance flexible, person-centered plans for people with IDD. The effectiveness of systems to serve people with IDD has been limited by structural, cultural, and ethical concerns [19-21].

Although there have been some improvements in these systems over the past several decades, people with low income and ethnic minority groups are still struggling to get the help and support they need. Ongoing research on IDD demonstrates that current systems focus on strong neurotypical and dominant cultural indicators, limiting opportunities to empower the unheard voices across all people. In this regard, TCOM offers promise as a strategy and moral compass that might help lessen the limitations of current system. By focusing on an inclusive, shared understanding of how we depict people, we are better positioned to create systems that are more responsive to the people they are intended to serve. This process can ensure that people from all cultures can be viewed with a common framework while humbly recognizing their differences. We believe this is the path envisioned originally by person-centered care and it starts by making sure people are full partners in their care, beginning with the assessment process.

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