PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Meeting Summary

Self-Advocates Workshop on IDD and Mental Health

Overview

On September 30, 2021, the Patient-Centered Outcomes Research Institute hosted a workshop for self-advocates and their health partners to discuss their experiences with mental health conditions and intellectual and/or developmental disabilities (IDD). There were eight participants from three organizations: the Autistic Self-Advocacy Network, the National Down Syndrome Society's Self-Advocate Advisory Board, and Self-Advocates Becoming Empowered. Participants represented the perspectives of self-advocates, family members, and allies.

The discussion was guided by questions about:

- Priorities when making decisions about getting help for mental health conditions
- Difficulties encountered when looking for and receiving treatment for mental health conditions
- Mental health conditions that PCORI should prioritize in future IDD-related funding initiatives
- Outcomes that matter most to patients receiving treatment for mental health conditions
- Remote care delivery during the COVID-19 pandemic

Key Themes

Throughout the discussion, several key themes emerged as participants discussed their experiences with mental health conditions and their intellectual and/or developmental disabilities:

There are many gaps in the research around people with IDD and mental health conditions

Participants talked about the difficulty families have recognizing signs of a mental health condition in a family member with an IDD. When asked about priority areas for future research into IDD and mental health conditions, one self-advocate flagged psychological trauma as a priority mental health area for people with IDD, and others identified priority populations, including patients with multiple IDDs, children who cannot advocate for themselves in the health system, and those least likely to be diagnosed with a mental health condition, such as those who rely on alternate communication methods.

Strong support systems are crucial

When navigating care for mental health conditions, individuals with IDD need a strong support system, including doctors, family, friends, and other social networks. This includes being in a supportive and comfortable environment.

People need to be seen as more than their diagnoses

Self-advocates emphasized their need to be seen as more than their combination of diagnoses by their support systems and care providers. One participant suggested that, instead of asking about medication compliance, friends and family should express interest in hobbies, goals, and achievements. An autistic participant shared that they avoid receiving treatment from doctors who specialize in autism because those doctors tend to see their patients through the lens of autism spectrum disorders rather than addressing the mental health concerns of their patients.

Treatment and treatment goals should be patient-centered

Participants highlighted that the current system of care for individuals with IDD and mental health conditions is fragmented and tends to focus on symptoms, such as behavioral problems, over the underlying health concerns. Self-advocates recommended that care providers work to understand their patients' goals for treatment and that the healthcare systems to treat mental and physical health should be more integrated.

There are many systemic barriers to care

Participants identified a wide range of barriers to accessing appropriate care for individuals with IDD and mental health conditions. They shared that it can be difficult to find providers who are willing to work with patients who have an IDD, which participants conjectured might be due to feeling ill-equipped or underqualified to work with those populations. Additionally, self-advocates said it can be challenging to find a provider that accepts their insurance. Self-advocates also flagged insufficient numbers of direct support professionals and therapists for one-on-one care to meet the needs of IDD communities. One participant highlighted that for those with more complicated needs, such as multiple diagnoses or different communication needs, these issues become more pronounced.

COVID has complicated receiving healthcare and other supports

Participants highlighted several ways in which regular healthcare and other supports for people with IDD were impacted by the COVID-19 pandemic, including disruption of physical or occupational therapy, ineffective remote learning, and increased difficulty traveling to access care at specialized clinics (such as Down syndrome clinics). Self-advocates also shared barriers to accessing telehealth services, such as not having a smartphone or computer, as well as potential "Zoom fatigue" for those who do. Where in-person care is possible, individuals with sensory issues may struggle with mask-wearing in healthcare settings that require it. Finally, one participant talked about difficulties knowing where and when they could receive the COVID-19 vaccine.

Next Steps

There will be a public workshop on October 21, 2021, where a panel of clinicians and researchers will discuss mental health treatment in individuals with intellectual and/or developmental disabilities. Workshop participants and attendees will be notified of future activities or funding announcements that may result from these conversations.