Addressing Mental Health Equity for People with Intellectual and Developmental Disabilities: Recommendations for National Goals

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Abstract

This paper informs scientific audiences of recommendations developed at the 2024 American Association on Intellectual and Developmental Disabilities (AAIDD) National Goals on Health Equity meeting convened to guide future practice, research, and policy. The *Mental Health in IDD Workgroup* was comprised of people with lived experience of intellectual and developmental disabilities and mental health conditions, along with representatives from five universities, clinicians, national policy and research organizations. While the need to address mental health in people with IDD has long been viewed as a major equity issue, movement has been largely sporadic and reactive. To promote effective changes toward improved mental health and emotional well-being in people with IDD, a multi-pronged, cross-systems, and proactive national strategy is needed.

Key words: mental health, standards, integrated approach, effectiveness, systems change

Acknowledgement

Introduction

Across the United States, an estimated 8.4 million people have IDD (Larson et al., 2024). People with IDD and mental health conditions have a high frequency of emergency room visits and protracted inpatient mental health stays when they occur (Kalb et al., 2019; Lunsky et al., 2012; Lunsky et al., 2014). While estimates of mental health conditions are high, the mental health service system is ineffective for people with IDD (Fletcher, Barnhill, & Cooper, 2017; Pinals et al., 2022; Pouls et al., 2022; Tasse et al., 2016). For mental health services to be effective they must be accessible (timely and available when needed), appropriate (match the needs of the service recipient) and accountable to the patient (including both treatment experiences and outcomes) (Beasley, 1997).

Access to mental health care for people with IDD

Access to services begins with service system design. Comprehensive mental health service systems provide a range of treatment options for people with mental health needs. As in all health care, a mental health continuum of care is essential as individual needs for services vary and can change over time. While estimates of mental health conditions for people with IDD remain high, barriers to access have continued over time (Pinals et al, 2022; Koks-Leensen et al, 2022; Tasse et al, 2016). Unfortunately, people with IDD have been excluded from mental health service system design and implementation. Therefore, in many locations across the United States, mental health services and options are not available to people with IDD.

Appropriate Treatment for People with IDD

One of the problems with inaccessible services is that they put people at risk of receiving inappropriate care based on what is available rather than what is needed. Inappropriate service outcomes include polypharmacy, high use of emergency departments, and restrictive management of challenges due to lack of capacity to provide appropriate care and polypharmacy (Witwer et al, 2022; Rich, DiGregorio, & Strassle, 2020).

In addition, unmet mental health needs are often correlated with a limited understanding of the population and lack of training for practitioners and caregivers (National Council on Disabilities, 2024; Pinals, et al., 2022). The capacity to provide appropriate treatment requires a trained and skilled workforce. Many clinicians feel ill-equipped to diagnose and treat mental health conditions for people with IDD. There have been few, if any, standards to improve formal clinician training and professional development to better treat people with IDD. As a result, old and debunked concepts regarding people with IDD continue and undermine inclusion (Pinals et al, 2022).

Accountability

Mental health services should be evidence-based with outcomes to benefit the person in treatment. Treatment engagement is a cornerstone of effective mental health care and promotes accountability for the treatment provider and the patient. However, for people with IDD, doctors and other professionals often make decisions about treatment with little direct input from patients (Camm-Crosbie, et al., 2019), thereby

undermining accountability. Dialogue and communication with the person in treatment is essential to ensure direct accountability.

In addition, there is a dearth of research to evaluate mental health treatment outcomes for people with IDD. Best practices rely upon anecdotal reports rather than peer reviewed research and evaluation. More research is needed to improve standards of practice thereby positively impacting the accountability of mental health providers to effectively treat people with IDD and mental health conditions.

AAIDD National Goals on Health Equity Meeting

The 2024 American Association on Intellectual and Developmental Disabilities (AAIDD) National Goals on Health Equity meeting convened a group of advocates, leaders, researchers, and clinicians across multiple focus areas. Each area of focus was addressed by a workgroup to provide recommendations pertaining to future practice, research, and policy. The *Mental Health in IDD Workgroup* was comprised of people with lived experience of intellectual and developmental disabilities and mental health conditions and representatives from five universities, clinicians, national policy and research organizations. Over a two-day period, the group met to discuss strategies to improve mental health services and supports for people with IDD.

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Recommendations and Resources

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The Mental Health and IDD Workgroup provided several recommendations toward the national goal to improve mental health service effectiveness for people with IDD. Recommendations address access to mental healthcare, appropriateness of mental health services, and service system accountability to people with IDD and

mental healthcare needs. We also identified some existing resources that have been developed in recent years.

Changing Attitudes to Improve Effectiveness

Shifting the language from "dual diagnosis" to "mental health conditions in people with intellectual and developmental disabilities" is an essential step in acknowledging the mental health needs of people with IDD and reducing diagnostic overshadowing. Diagnostic overshadowing occurs when a mental health issue is overlooked or misunderstood because it is assumed to be a direct result of a person's IDD (Reiss& Szysko, 1982). The focus, instead, should be on treating the person's mental health condition while considering their IDD (Beasley et. al. 2025, McLennan, 2018). By clearly articulating what is needed, we shift the narrative we increase the chances of offering effective mental health services.

An Integrated Approach to Ensure Appropriate Mental Healthcare

An integrated approach emphasizes the need to consider not only the mental health aspects of care but also the person's overall well-being, including their physical health, social and emotional well-being. A whole person approach considers all the factors that contribute to mental health in the context of developmental, medical and social determinants. Integration of approaches requires collaboration among all healthcare professionals with the person with IDD and their family. By working together, both mental health and physical health can be addressed and identified, making it possible to deliver care that is holistic, personalized, and more effective.

Professional Development

The provision of appropriate care is directly tied to professional development. In addition to the need for expanding curricula in higher education and medicine, dissemination of best practices through ongoing training and education allows clinicians to provide more treatment options and improve the diagnostic process (Hsieh, Scott, and Murphy, 2020). While some education and training are currently available, more is needed with standards of practice established. Two examples to improve standards of mental health care include guidelines for mental health prescribers working with people with IDD (Beasley, et al., 2021) and outpatient counseling guidelines for clinicians providing psychotherapy to adults with IDD (Witwer et al., 2024). These serve as examples of practical tools that can be utilized by mental health professionals to improve capacity and service effectiveness. Table 1 provides additional open access resources to address mental health in IDD.

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Mental Health in IDD Research is Needed

While federal grant funding is in some measure available, there is a dearth of research and engagement with people with IDD (Beasley et al, 2025). Research must address mental health conditions and the social determinants of health to improve mental health service effectiveness (Healthy People, 2030; Friedman, 2021; Friedman, 2024 Friedman & Rizzolo, 2018; Martinez, Smyth, & Carrick, 2024; Friedman, 2022). To ensure effective mental health services are delivered to people with IDD, research is needed to identify best practices in diagnosis and treatment formulation of mental health conditions. Epidemiological studies are also needed to determine prevalence of mental health conditions in people with IDD. This will help in service planning and resource

allocation. Currently, there are national datasets in place to better understand tobacco use, cancer and other health conditions for people with IDD. Yet, no dataset exists on mental health conditions of people with IDD. One common treatment issue is polypharmacy which may be directly tied to the lack of research to determine optimal prescribing practices.

The most effective and expedient way to ensure that new research & instruments are relevant, responsive, & accessible to people with IDD is to involve them as partners in all stages of research and development (Nicolaidis et. al., 2014). Participatory research yields meaningful engagement and useful feedback that can guide treatment decisions, future planning, policy, and governance. One project aimed at expanding participatory research capacity is the National Research Consortium on Mental Health in Intellectual and Developmental Disabilities (Institute on Disability, n.d.) which provides mentoring and innovation grants for new researchers.

Systems Change to Improve Effectiveness

There is a need for cross-systems policies and practices on both state and national levels to improve the effectiveness of support services and mental health treatment for people with IDD. Historically, systems have been siloed, undermining the development and implementation of effective approaches. In many states, administration of services for people with IDD is separate from the administration of mental health services, and few psychiatric services are designed to treat people with IDD (Pinals et al., 2022). A recent study of state agency employees across the United States found that systemic silos undermine the coordination between IDD and mental health departments except in response to crises (Stone et al., 2024).

Medicaid funding streams have done little to address the fact that people with IDD can have mental health conditions and require mental health treatment. Differences in waiver funding have resulted in barriers in access to mental health care for people with IDD. The establishment of a segregated mental health system for people with IDD under the IDD system would be costly and ineffective as it would be in the treatment of any other health condition. We need national and state policies to address the lack of mental health service equity for people with IDD.

Cross-systems accountability includes resources to provide mental health services, reasonable accommodation in integrated clinical settings, and proactive strategies to prevent and intervene in times of crisis. A notable effort toward cross-systems collaboration is the Link Center (Administration for Community Living, n.d.), focused on the development and dissemination of resources to enhance community capacity and service effectiveness across the U.S. In addition, the START (Systemic, Therapeutic, Assessment, Resources, and Treatment) Model is a well-researched and evidence-based cross-systems model for crisis prevention and intervention employed in many U.S. states (Beasley & Kroll, 2002; Kalb et al. 2019). These are just two examples of efforts toward improved cross systems collaboration. Clearly more targeted policies and resources are needed.

Conclusion

In considering national goals for health equity in the coming years, it is important to address disparities that impact mental healthcare for people with IDD. The absence of evidence-based and effective mental health care has resulted in restrictive, costly, and harmful interventions that have undermined mental health, emotional wellbeing,

primary health and quality of life in this population for many years. To be effective, three areas of focus must be addressed by policy makers. People with IDD require access to the care they need, services must be appropriate based on evidence-based standards provided by qualified professionals, and there needs to be greater accountability for outcomes to address both mental health needs and wishes of service users and their families. To meet our national goals to promote mental health equity for people with IDD, policies to address barriers and provide needed resources are required.

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