The Link Center: A Federally Funded Technical Assistance and Resource Center Aimed at Improving Mental Health Treatment and Access for People with I/DD, Brain Injury, and other Cognitive and Communication Differences.

Stacy L. Nonnemacher  
*National Association of State Directors of Developmental Disabilities Services*

Jeanne Farr  
*NADD*

Wendy Morris  
*National Association of State Mental Health Program Directors*

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**Recommended Citation**
Nonnemacher, Stacy L.; Farr, Jeanne; and Morris, Wendy (2024) "The Link Center: A Federally Funded Technical Assistance and Resource Center Aimed at Improving Mental Health Treatment and Access for People with I/DD, Brain Injury, and other Cognitive and Communication Differences.," *Developmental Disabilities Network Journal*. Vol. 4: Iss. 1, Article 7.  
DOI: 10.59620/2694-1104.1094  
Available at: [https://digitalcommons.usu.edu/ddnj/vol4/iss1/7](https://digitalcommons.usu.edu/ddnj/vol4/iss1/7)

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The Link Center: A Federally Funded Technical Assistance and Resource Center Aimed at Improving Mental Health Treatment and Access for People with I/DD, Brain Injury, and other Cognitive and Communication Differences

Stacy L. Nonnemacher, Jeanne Farr, and Wendy Morris

1National Association of State Directors of Developmental Disabilities Services, Alexandria, VA
2The National Association for the Dually Diagnosed, Kingston, NY
3National Association of State Mental Health Program Directors, Alexandria, VA

Plain Language Summary

We know that people with intellectual and developmental disabilities (I/DD) can also have a mental health (MH) condition. Yet, it is hard for people with I/DD to get good mental health care and supports that help them stay well. Because of this, a growing number of people with I/DD have MH crises and suffer bad results. This can mean people have poor health outcomes, that they do not get well, or get sicker. Other bad results might be staying in an emergency room or psychiatric hospital for a long time or getting involved with the police. These are very serious issues and show that there is a need for a national resource center that can help everyone do better for people who have both I/DD and a MH condition and their families.

This paper talks about The Link Center project and how it started. It is funded with a grant from the Administration for Community Living (ACL) and led by experts and leaders who know about I/DD-MH conditions. Three organizations are part of the grant. One is the National Association of State Directors of Developmental Disabilities Services (NASDDDS). Another is the National Association for the Dually Diagnosed (NADD), an Association for Persons with I/DD and MH Conditions. The third is the National Association of State Mental Health Program Directors (NASMHPD). The Link Center has several major goals to help people do a better job of supporting individuals with I/DD who also have MH needs. The first goal is to change the system of care. The second goal is to improve the skills of direct service workers and other professionals. The third goal is to make it easier to get services. There is a steering committee made up of people who have disabilities, and it serves as an important guide for The Link Center. Other activities include shared learning groups, finding published resources, and developing new resources. The Link Center also partners with the Substance Abuse and Mental Health Services Administration (SAMHSA).

This work was supported by the Administration for Community Living under Grant 90DDMH0001-02-01.

Correspondence concerning this article should be addressed to Stacy L. Nonnemacher, National Association of State Directors of Developmental Disabilities Services, PO Box 26128, Alexandria, VA 22313. Email: snonnemacher@nasddds.org.
Abstract

Although we do not have robust prevalence studies in the U.S., a recent meta-analysis estimated that 33.6% of individuals with intellectual and developmental disabilities (I/DD) have a mental health (MH) condition. We know that this prevalence may be an underrepresentation because of factors like diagnostic overshadowing. We also know that people with I/DD experience inequitable access to quality MH and preventive care. This highlights the chronic lack of and access to holistic, integrated care for individuals with I/DD, especially those who also have MH conditions. Consequently, an increasing number of individuals with I/DD experience MH crises and suffer adverse consequences. These consequences range from negative health outcomes and difficulties accessing community-based services, to prolonged boarding in hospital emergency departments, placement at psychiatric settings without proper accommodations for communication or disability-related needs, and engagement with law enforcement when behaviors are perceived as problematic for the public at large. These critical issues highlight the need for a comprehensive, national center that pulls together resources focusing on the dual diagnosis of I/DD and MH to support states and all their system partners, most importantly individuals with disabilities and their families. The need for a national resource center focused on increasing capacity and guided by principles of diversity, equity, and inclusion is significant. This paper outlines the establishment of The Link Center funded by the Administration for Community Living (ACL) and led by the collective experience and expertise of the following organizations with unparalleled I/DD-MH dual diagnosis leadership: the National Association of State Directors of Developmental Disabilities Services (NASDDDS); the National Association for the Dually Diagnosed (NADD), an Association for Persons with Intellectual Disabilities and Mental Health Conditions; and the National Association of State Mental Health Program Directors (NASMHPD). The Link Center is guided by three overarching goals to increase the capacity in the U.S. to support individuals equitably and more effectively with co-occurring cognitive, communication and MH conditions: (1) systems change, (2) direct service workforce and clinical capacity development, and (3) improved service access. The grant’s steering committee, comprised entirely of people with lived experience, serves as an essential rudder for The Link Center. Other efforts incorporated into the grant include shared learning groups, resource identification and development, and other efforts in collaboration with the Substance Abuse and Mental Health Services Administration (SAMHSA).

Introduction

Although we do not have robust prevalence studies in the U.S., a recent meta-analysis estimated that 33.6% of individuals with intellectual and developmental disabilities (I/DD) have a mental health (MH) condition (Mazza et al., 2020). We know that this prevalence may be an underrepresentation because of factors like diagnostic overshadowing. We also know that people with I/DD experience inequitable access to quality MH and preventive care. This highlights the chronic lack of and access to holistic, integrated care for individuals with I/DD, especially those who also have MH conditions. Consequently, an increasing number of individuals with I/DD experience MH crises and suffer adverse consequences. The consequences range from negative
health outcomes and difficulties accessing community-based services, to prolonged boarding in hospital emergency departments, placement at psychiatric settings without proper accommodations for communication or disability-related needs, and engagement with law enforcement when behaviors are perceived as problematic for the public at large. These critical issues highlight the need for a comprehensive, national center that pulls together resources focusing on the dual diagnosis of I/DD and MH to support states and all their system partners, most importantly individuals with disabilities and their families. The need for a national resource center focused on increasing capacity and guided by principles of diversity, equity, and inclusion is significant.

**Systems Change for Effective and Equitable Support**

A multifaceted approach is crucial to ensure effective and equitable support for individuals with I/DD and co-occurring MH conditions. This approach must incorporate the voices of those impacted by the system change and clear pathways to support positive outcomes. Strategies to promote equitable implementation of evidence-based interventions are vital in supporting individuals with co-occurring MH and substance use disorders (Gaba et al., 2023).

Understanding the impact of changes in accommodation and support arrangements on the well-being of individuals with I/DD and enduring MH problems is of paramount importance (McConkey et al., 2017). Quality-of-life assessments have revealed that individuals with I/DD and MH problems often lack a well-articulated support system to lead fulfilling lives comparable to those of the general population (Córdova et al., 2022). Effective collaboration among generalists, mental health professionals, families, and support persons is necessary to address the mental health needs of individuals with I/DD (Weise et al., 2017).

**Developing Direct Service Workforce and Clinical Capacity**

Developing direct service workforce and clinical capacity for individuals with I/DD and co-occurring MH conditions is a critical area that requires attention. The direct support workforce, which consists of professionals such as direct support professionals (DSPs), plays a vital role in providing care and support to individuals with I/DD. However, challenges persist in recruiting, retaining, and ensuring the competence of this workforce (Hewitt & Larson, 2007). The importance of attending to trauma is prevalent in the literature. Studies have highlighted the importance of trauma-informed organizational culture in promoting satisfaction, reducing fatigue, and enhancing the psychological wellness of DSPs working with individuals with I/DD (Keesler, 2020).

Additionally, specialized clinical training, such as subspecialty training in I/DD psychiatry, is essential to improve the quality of care provided to individuals with I/DD and MH conditions (Eagleson et al., 2019). Early diagnosis and intervention play a critical role in the lives of children with I/DD. Such interventions can improve immediate and long-term outcomes, including academic performance, community inclusion, and peer socialization. Moreover, they promote MH by addressing early signs of anxiety and depression. Unfortunately, individuals with I/DD often encounter MH professionals who lack sufficient knowledge about I/DD and their unique
needs, leading to misdiagnosis and inappropriate prescription of psychiatric medications. Prioritizing non-pharmacological interventions, such as social prescribing, behavioral and educational interventions, or psychotherapy, over pharmacological interventions is essential. This approach ensures that individuals receive the appropriate care that does not rely solely on medication. To achieve better MH outcomes for individuals with I/DD, there is an urgent need for increased emphasis on early and accurate diagnosis and utilization of nonpharmacological interventions (Zisman-Ilani, 2022).

Improving Service Access for Individuals with Disabilities

Improving service access for individuals with I/DD, especially those with co-occurring MH conditions, requires a multi-faceted approach. Cooper et al. (2015) emphasize the need for focused services for individuals with intellectual disabilities, regardless of their residential location, starting at an earlier age than the general population. Evans et al. (2012) advocate for improved policy, clear referral pathways, shared resources, and enhanced training for MH and disability service providers to enhance service access. Additionally, Schwartz and Hwang (2022) and Schwartz and Levin (2021) highlighted the importance of peer mentoring interventions for young adults with I/DD and co-occurring MH conditions, underscoring the value of involving individuals with disabilities in program development. Furthermore, Caoli et al. (2022) stressed the lack of guidance for healthcare providers to address the unique MH needs of individuals with I/DD. Zuurmond et al. (2019) emphasized the necessity of a comprehensive response to enhance health service access for people with disabilities, including those with I/DD. Improving policy frameworks, clear referral pathways, and specialized training for service providers are crucial for enhancing service access for individuals with I/DD and co-occurring MH conditions. Addressing the unique needs of this population through stakeholder-driven approaches and inclusive policy development is essential to bridging the existing gaps in service provision.

Promoting Collaboration and Knowledge Sharing

To enhance support for individuals with I/DD and co-occurring MH conditions, promoting collaboration and knowledge-sharing among stakeholders is crucial. Research indicates a need for improved collaboration between different entities involved in the care of individuals with I/DD and MH issues (Weise et al., 2017; Whittle et al., 2018). This collaboration should involve caregivers, support people, individuals with I/DD, MH professionals, and other relevant parties to ensure comprehensive and practical support (Drozd et al., 2021; Kaehne, 2011). Involving individuals with I/DD, their families, caregivers, advocacy group managers, and research supervisors in research studies is vital for meaningful collaboration and successful outcomes (Drozd et al., 2021). Engaging a person’s support network in MH services is also highlighted as a critical element in delivering quality care to individuals with I/DD (Dew et al., 2018).

Development of The Link Center

The Link Center, a national resource and technical assistance hub, is designed to address
the disparity in access to comprehensive, community-based, MH services for persons with I/DD, brain injury (BI), and other cognitive and communication differences. Funded through the Administration for Community Living (ACL), the 5-year grant aims to bridge gaps in service access by influencing systems change and building clinical capacity. This Center will continue the work of ACL’s UCEDD National Training Initiative to Support People with I/DD and Mental Health Disabilities in which multidisciplinary teams from state’s I/DD and mental/behavioral health agencies developed a shared training infrastructure for their staff that focuses on improving coordination of the services people with both conditions receive from these agencies (New UCEDD Grants Address Community Transitions, Mental Health | ACL Administration for Community Living, n.d.). The Link Center aims to elevate this existing body work and make additional calls for action, including developing resources and inciting discussions around necessary systems change as gaps and needs became evident.

The Link Center is guided by a steering committee of 12 individuals with lived experience in collaboration with three key partner agencies: National Association of State Directors of Developmental Disabilities Services (NASDDDS), the National Association for the Dually Diagnosed (NADD)—an Association for Persons with Intellectual Disabilities and Mental Health Conditions, and the National Association of State Mental Health Program Directors (NASMHPD). Additionally, the National Association of State Head Injury Administrators (NASHIA) has joined the effort. Products will include a website featuring resources and technical assistance, a policy academy, and a series of shared learning groups. The shared learning groups (SLG) will cover topics including supports for crisis, trauma, transition, and the whole person. The groups will function as a learning modality using a hub and spoke model with content adapted for numerous, specific audiences including individuals with I/DD, families, direct support workers, clinical professionals, and policymakers. The SLGs will also help inform further development of The Link Center in response to attendees and partners’ articulated interest areas. Collaboration with federal partners also guides the work of The Link Center. Dialogue with the Substance Abuse and Mental Health Services Administration (SAMHSA) is underway to find ways that The Link Center can assist 988 call centers and mobile crisis response teams to be better equipped to intervene when individuals with ID/DD reach out to the MH system.

Importantly, The Link Center has partnered with the Nisonger Center at the Ohio State University to conduct a robust evaluation of all Center activities, including the way the center successfully executes the steering committee and SLGs with a focus on continuous quality improvement and ongoing accessibility of activities to enable meaningful engagement. After each steering committee and SLG meeting, each attendee will receive a survey to complete based on their experience focusing mostly on the attendee’s perception of being included in decisions and priorities related to current and future work of The Link Center. Analysis of the responses are shared with the partners of The Link Center and are considered in the planning for successive steering committee and SLG meetings. Thus far, these analyses are invaluable and have encouraged modification of the steering committee meeting format significantly based on feedback from the evaluations.
Methods

To achieve its vision of equitable and effective support for individuals with I/DD, BI, other cognitive and communication differences and co-occurring MH or related conditions, The Link Center has three overarching goals: (1) realize systems change, (2) develop the capacity of the direct support workforce and professional clinicians, and (3) improve service access.

Realize Systems Change

The first goal, systems change, comes about with improvement in policy, service design, and service coordination. The Link Center steering committee and key partners will identify policy issues for system change efforts at state and federal levels, leveraging the strength and expertise of community leaders and other partners. These policy issues will emanate from the learning and resource curation of The Link Center and will contribute to the work of the Center to augment and adapt available resources. This continuous process will directly feed into the success measures related to improving policies, service design, and service coordination for individuals with I/DD and mental illness. For example, a couple of steering committee members have shared their own personal experiences related to being refused access to their communication devices when hospitalized. The Link Center has already begun conversations with federal partners about this significant concern and about the detriment of this practice in psychiatric hospitals hoping for change in policy and practices for people who rely on communication devices to articulate their wants and needs. Additionally, The Link Center will host a Policy Academy for six states to assist their multiple systems to better understand how they can include people with I/DD, BI, and other cognitive and communication differences into the policies and practices of their existing crisis continuum designed for people with MH conditions. It is anticipated that the work and outcomes of the participant states will serve as a model for other states in building and bolstering crisis services for people with I/DD, BI, and other cognitive and communication differences.

Develop the Capacity of Direct Support Workforce and Professional Clinicians

The second goal, the development of direct support workforce and clinical capacity, is multifaceted. Building a diverse workforce to support individuals with I/DD and MH or related conditions is a critical component of this effort. One major barrier to service access is an inadequate number of direct support and clinical staff who are trained, competent, and comfortable to support individuals with complex needs, specifically those with co-occurring I/DD and mental illness. Partner agencies will curate a wide range of key resources, including sample policies, tip sheets, toolkits, and examples of how to make evidence-based practices accessible for people with disabilities. Key project outputs include model policies and protocols for state systems and clinicians, and training curricula to support workforce competencies. Strategies to ensure the universal accessibility of these resources will be employed. A website will serve as a repository for this curated set of resources aiming to be an archive for those who are responsible for building capacity of the people who are providing supports and services to people with co-occurring I/DD, BI, and other cognitive and communication differences who also have MH.
conditions. The goal of the website is to be a dynamic, iterative, and meaningful resource accessible to a widely diverse audience, including individuals with disabilities and their families, researchers, practitioners, direct support professionals, and state and federal policymakers. The website will serve as the hub for The Link Center’s information dissemination activities and will be designed for ease of use with the aim of universal accessibility to the resources. There will be a technical assistance request form available to all visitors, and a topical search function.

The resources contained on the website are evidence-informed by robust research bodies and will be adapted to ensure full accessibility of materials, meeting all applicable standards, and using best practices for linguistic dissemination. Resources will be in a variety of formats, including reports, fact sheets, case studies, infographics, toolkits, articles, books, webinars, and resource links.

The strategies for identifying and then vetting resources are multifaceted, including identifying the categories of resources, employing sourcing strategies, and completing a comprehensive vetting process. The resources identified for the website fall into the following topical areas:

1. Systems Change, Policy, & Funding
2. Assessment & Diagnosis
3. Trauma and Trauma-Informed Practices
4. Health, Wellness, and Prevention
5. Therapies and Treatment
6. Services and Supports
7. Crisis Prevention & Response
8. Disability- & Condition-Specific Resources, including Prevalence and Data

The activities of seeking the resources incorporate a far-reaching investigation of viable resources from the existing body of research, clinical and organizational leaders, researchers, national organizations, and state and federal policymakers. It involves robust research and review processes by the project partner team member organizations.

Once resources are identified, we employ a comprehensive vetting process evaluating each resource through the analysis of an extensive set of criteria queries, including: was the resource published by a reputable source (e.g., SAMHSA, ACL, Centers for Medicare and Medicaid, NASDDDS, NASMHPD, NADDD, etc.); is the resource current; has it been peer-reviewed; is there a clear purpose; is it in clear language; can it be adapted to be in clear language; does it contain adequate resources; and is it evidence-based. After the identified set of resources has been vetted, we then submit them for a peer review process by having members of The Link Center partner team review each of them through the additional lens of specific partner expertise. Every aspect of identifying, vetting, and finalizing resources for inclusion on the website is a collaborative activity between the entire project partner team.

**Improve Service Access**

The third goal is to improve access to culturally and linguistically appropriate, person-centered, MH services and community supports. Leveraging the expertise and advice of the steering committee and a cadre of expert contributors, The Link Center will take tangible steps with federal and state policymakers and other key partners to increase pathways for individuals to access quality MH services and effective supports to live full lives in the community. This will
include ensuring that individuals with I/DD are represented, regardless of cultural and linguistic affiliation, and serve as a driving force in the development of the website, planning of the annual conference, and establishing the Center to improve access to culturally and linguistically appropriate services (CLAS) to all who experience co-occurring I/DD and MH conditions. As social determinants of health play a key role in individuals’ ability to access quality MH treatment, a focus on these issues in all project elements is critical.

**Steering Committee**

Unquestionably, the most pivotal aspect of this grant initiative and achieving the goals of The Link Center is the steering committee—a group composed of individuals who are experts in their path of living with a disability. The steering committee will lead and advise on all grant work and priorities, including providing their perspective on each phase of the work plan and project deliverables.

There was an overwhelming response of over 100 applications submitted for membership on this committee. Information related to their experiences and reasons for interest in this committee was collected from each applicant via Google forms, emails, texts, and phone calls. The Link Center partners reviewed this information with a focus on diversity specifically related to the person’s area of residence, race, culture, ethnicity, age, communication strategy, and lived experience. After careful review of the applicant information and after follow-up conversations with some applicants to clarify or expand upon their information, The Link Center selected 12 people with distinct and diverse backgrounds and experiences to serve on the committee. Figure 1 outlines the demographics of the steering committee.

**Figure 1**

*Demographics of the Steering Committee (n = 12)*

| Geography | Representing 11 different states: 5 urban, 4 suburban, 3 rural |
| Race | 6 identify as non-White |
| Communication Style | 4 identify preferred communication style as something other than verbal |
| Sexual & Gender Identity | 3 identify as part of LGBTQI+ community |
| Age | 5 under age 30, 2 over age 50 |

The Link Center compensates steering committee members for their time and for support staff they may need to participate in committee activities. More specifically, the members are paid for each meeting not contingent on participation. Also, if a member needs support staff to participate in the meetings, The Link Center also pays that staff for the time they support them. The members have committed to quarterly, virtual meetings with options to meet in advance to
prepare and preview information for the meeting and to meet after the meeting to debrief on what was discussed. There is a focus on ensuring that meetings and materials are accessible for all members to ensure full inclusion, engagement, and participation. To date, these steering committee meetings have been an opportunity for the partners of The Link Center to capitalize on the insightful and thoughtful feedback on topics including (a) language use, (b) engaging families and persons with lived experience in other grant activities, and (c) priority areas for resource identification and development. It has been abundantly clear that members feel passionate about this work based on their comfort and eagerness to share and express opinions and experiences in these meetings. Additionally, the Steering Committee has committed to an in-person meeting once a year for the life of the grant and The Link Center is exploring to respond to members desire to create community and engage with one another in various outside the structured meetings.

Conclusion

The Link Center partners’ members have noted that supporting individuals with both I/DD and MH needs is a huge challenge facing state systems. There is a commitment to this body of work and to coordinate partner efforts that will aid in the long-term sustainability of these critical investments to continue to scale and deploy strong practices nationally beyond the life of this grant. As mentioned throughout this paper, there are many activities and goals that drive the work of The Link Center (see Figure 2).

Figure 2

Activities and Goals of The Link Center

![Diagram of Activities and Goals of The Link Center](image-url)
Engaging expert contributors, learning from the steering committee, and identifying information, resources, trainings, and gaps are all major activities designed to create the synergy needed to achieve the key goals of realizing systems change, developing workforce capacity, and improving service access. These results will not only fill gaps in the field and address important public health needs by alleviating strains on the systems of care but, ultimately, allow individuals with co-occurring I/DD and MH challenges to attain better health outcomes and quality of life. The Link Center truly is a project of national significance.

References


