



*For people with intellectual  
and developmental disabilities*



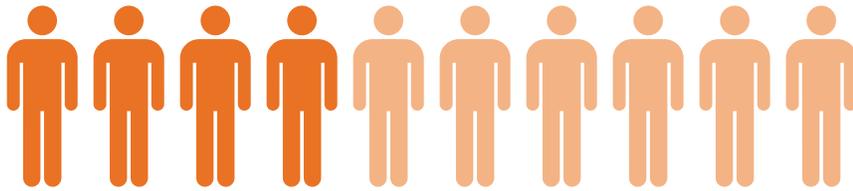
## 2018 Support Needs of People with I/DD and Co-Occurring Mental Health Challenges and their Families

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Submitted by The Arc of the United States



*Up to 40% of people with intellectual and developmental disabilities (I/DD) experience co-occurring mental illness.*

Despite the prevalence of mental health needs among people with I/DD, little is known about the best approaches for supporting the needs of people with I/DD and co-occurring mental health challenges and their families. This uncertainty has led to the dependence on outdated and potentially bad approaches to mental health care, such as seclusion, restraint, and psychotropics, which may cause individuals with dual diagnosis an increase in their struggles with poor mental health, as well as a lack of family support resources and services available for people and their families.

This uncertainty puts an undue burden on the families of people with I/DD and co-occurring mental health challenges. Family members provide the majority of support to people with disabilities across their lifespan. Often, family members play the primary role in raising children and youth with disabilities, provide a broad range of supports to adult family members with disabilities (contributing a considerable amount of their own resources to provide care), and provide critical support to older family members, many of whom require additional support as they age.<sup>1</sup> The Family Support Research and Training Center (FSRTC) aims to learn more about families' needs in supporting family members with all types of disabilities across the lifespan, as well as current promising family support practices around the country.

As an FSRTC partner, The Arc, along with several groups, including Boston University, explored the family support needs of families that include a person with the dual diagnosis of I/DD and mental health needs. The purpose of this exploration included:

- Discussing and better understanding the family support needs and challenges of families that include a person with I/DD and co-occurring mental health needs;
- Discussing and better understanding the mental health needs of and experiences of people with I/DD and co-occurring mental health challenges; and
- Developing recommendations on what practices, policies, or assistance families that include a person with a dual diagnosis would best help families to address their challenges.

**We explored this subject via two separate but related activities.**

- First, The Arc worked with The Arc of Weld County and The Arc of Arapahoe & Douglas Counties in Colorado; The Arc Oregon and The Arc of Lane County; and The Arc Wisconsin and the Waisman Center to develop partnerships and host 5 half-day focus group meetings with people with I/DD and co-occurring mental health challenges; parents; siblings; and professionals. These focus groups engaged over 80 stakeholders around what challenges and successes they have had in receiving family support and what steps

<sup>1</sup> These general themes come from the Caregiving in the US 2015 - Executive Summary report (National Alliance for Caregiving and AARP Public Policy Institute, 2015).



people could take to help their family. We gathered transcripts and notes from all the meeting and conducted a qualitative analysis of major themes and recommendations, which have been presented below.

- Second, Boston University, Self Advocates Becoming Empowered, and The Arc partnered together to launch the I/DD - Mental Health Research Partnership. This partnership set out to learn more about the experiences and needs of young adults with I/DD and co-occurring mental health challenges while accessing and using mental health services. This partnership engaged an advisory panel of six young adults and five professionals in the field to develop a plain language nationwide survey and several story telling sessions. The survey was completed by 76 young adults in the US, 16 young adults and parents participating in story telling sessions. Based on the survey and sessions, the partnership identified 8 priority topic areas for service providers, health systems, and researchers to further examine.

While the focus groups, survey, and listening session series described several unique challenges and potential solutions, many commonalities could be seen across all avenues of exploration.

### *Findings*

- **Disability, mental health, and education professionals lack key knowledge about people with I/DD and mental health challenges.** All participants acknowledged that disability, mental health, and education professionals frequently lack training or knowledge around dual diagnosis and do not understand that all behavior is communicating an issues or challenge. Family members who shared stories also reported that doctors and therapists sometimes do not know how to help young adults with I/DD and mental health conditions.
- **There is often a lack of appropriate, available resources or services for families.** Participants identified that access to appropriate mental health treatment can be unaffordable, even with insurance. Some young adults could not get the treatment they wanted because their insurance would not pay for it. They identified that there is a lack of availability of alternative treatments covered by insurance and many medical professionals are too quick to suggest medication.
- **The disability and mental health systems are extremely complex and inflexible.** Participants acknowledged that the disability and mental health systems are extremely complicated to work with and navigate. Participants noted that it is a challenge to identify

resources or services, to determine eligibility for these resources or services, and to determine whether state insurance will pay for the services that the person and family needs. Participants also noted that the disability and mental health systems do not often talk with each other to determine eligibility and payment and that the family is frequently caught in the middle of a debate about who will pay for services, the result of which is that people may sometimes wait a long time to receive services or may have to pay out of pocket. Participants also indicated that making and keeping mental health and medical appointments may be difficult for people to do on their own, and the actual systems of providers are often inflexible. Families who are late for an appointment or people who may struggle to get transportation to/from appointments may find themselves removed from a patient list and not be able to access care.

- **People, families, and professionals struggle to communicate effectively with one another.** Participants identified that communication with professionals is a challenge. While focus group participants indicated that facilitation of consistent communication across families and support professionals is a challenge, young adults with mental health challenges went further to explain that simply being able to understand professionals and be understood by professionals is a challenge. More specifically, they indicated that professionals should gain a better understanding of accessibility and alternative communication with people who have I/DD and a mental health need.
- **People with dual diagnosis, parents, and siblings may often feel lonely or isolated as a result of lack of understanding, discrimination, or stigma.** Participants cited that social support is an essential part of well-being and mental health, and that often family members feel lonely and isolated. Many participants suggested that they often feel that they are not believed or valued when they communicate with professionals, and even sometimes with other family members. Tension between family members may sometimes also result in the breakdown of family relationships, leading to further isolation and loneliness.
- **Professionals need training on how to more effectively support people and families.** Participants identified that additional training for disability professionals, mental health professionals, medical doctors and therapists, and education professionals is essential. Very few professionals have received training on the treatment for people with dual diagnosis; as a result, many people and families feel like they do not get adequate support or that professionals may set unrealistic goals or targets for families. Participants also felt that professionals often lack knowledge regarding how to support families in ways that reflect a person's and family's religious and cultural beliefs.
- **People with disabilities and families need training and education.** Participants also felt that there should be more trainings available to people with I/DD and mental health challenges to build their social and independent living skills, to caregivers to help them address caregiver stress and burden, and to families so that they can better and create transition and future plans for people to live well throughout their lives.

- **Peers, professionals, and family members working together as a team is important for helping families feel supported and successful.** Participants highlighted that team building and support groups are important for the well-being of all family members. Young adults with I/DD reported that peer-led support groups and parent-to-parents supports were essential in helping their families. Focus group participants indicated that peer support groups led by and for families who experience I/DD and mental health challenges would be most beneficial for the family overall, as members may often struggle to explain mental health challenges to the I/DD community, and vice versa.
- **People with I/DD and mental health challenges need more opportunities for emotional support, inclusion, and building relationships:** Participants expressed consensus that people with I/DD and mental health needs should be provided with supports and opportunities to use a range of coping strategies and alternatives to medication in their everyday life. This may include emotional support groups, community activities and social supports. Participants also expressed that people with I/DD and mental health needs need to be empowered and supported by all to fully engage in school, work, and their community and overcome stigma that they experience as people with multiple disabilities.

## Challenges

It often was difficult to identify a large amount of people with I/DD and mental health challenges to take part in these efforts. This may be due difficulty accessing online survey or online listening sessions or difficulty in attending and actively participating in 4 hours of discussion. It also may be because people with I/DD may not actively seek or receive a diagnosis for mental health, and vice versa. Both diagnoses often carry stigma and may make people a target of discrimination or misperceptions, and, as mentioned in the report, there are not many highly qualified professionals who know how to serve both populations. As a result, it often became challenging to find people who had received both diagnoses.

Similarly, while the focus groups with sibling groups to recruit sibling participants, it was often more challenging to identify siblings who were willing to participate in focus groups. This may be due to siblings of younger people with dual diagnosis being less interested in participating in focus groups, due to siblings often being out of state and unable to participate physically in discussions, or due to tensions between the sibling and their family member with dual diagnosis.

While the focus groups and I/DD-MH Partnership were successful in engaging parents and professionals and fully engaged the siblings and people who participated, there is still significant progress to be made to fully engage people with dual diagnosis and their siblings in discussions around family support needs.





## Opportunities for Future Research and Activities

Based on the many themes identified and outlined in this research, The Arc recommends the following future research and activities. These activities fall into three categories (1) training, (2) systems change, (3) creation of new treatments or resources, and (4) public awareness.

### Training

- **Develop a nationwide, replicable training around I/DD and mental health for mental health, disability, and education professionals:** Lack of knowledge was mentioned several times in both the focus groups and during the I/DD-MH Partnership as a reason for poor quality treatment, over-medicalization, and refusal of services. Training appears necessary to counteract misperceptions by professionals and to improve the quality of treatment and care provided to people with dual diagnosis and their families.
- **Support trainings aimed at enhancing the cultural competence of disability, mental health, and education professionals:** One important theme that The Arc heard was the need for services and supports to be provided to people and their families in a manner that reflects the person's and family's religious and cultural beliefs. It appears important to support and enhance efforts that aim at support professionals to become more culturally competent as well as hiring practices that seek to ensure that professionals reflect the diversity of the community that they serve.
- **Expand future planning training and resources to target and support families of people with dual diagnosis to create transition plans for each part of the families' lifespans:** Both young adults with I/DD and focus group participants identified transition planning and future planning as areas where people need more support. Many future planning trainings exist for people with I/DD, including The Arc's Center for Future Planning. It may be possible to expand these training to target and support people with dual diagnosis and their families.
- **Expand trainings for caregivers that are intended to reduce caregiver burden:** In the focus groups, parents consistently expressed difficulty managing stress and burden. Expanding existing evidence-based trainings aimed at helping caregivers identify and manage stresses may help families feel better supported.

### Systems Change

- **Support the development of and improve policies and procedures that provide for easier access, communication, and navigation between the I/DD and mental health service systems:** Many participants identified navigation between the I/DD and mental

health systems as a critical issue and one that often leaves families disillusioned and disinclined to further engage with the service system. It is important support the development of policies, procedures, demonstration programs, and other activities that seek to improve communication between these systems and support families to navigate between service systems.

- **Conduct research activities to support the further development of evidence-based mental health treatments that are alternatives to medication and that are adapted to the dual diagnosis population:** While some adapted mental health therapies exist, these are often not known to the population of professionals and may not exist for every available therapy. The Arc recommends that more research be done to develop and adapt evidence-based, non-medication mental health treatments so that people and families may be able to choose from an array of options to address mental health challenges that arise.

### **New Treatment or Resources**

- **Support the development of policies and programs that will allow all people with dual diagnosis and family members the ability to access quality mental health care, regardless of whether they have private or public insurance:** Both young adults with I/DD and focus group participants identified that people often cannot access quality care due to providers not carrying public insurance or not carrying the specific private insurance that the family has.
- **Support the development of support groups for people with dual diagnosis, siblings, and parents so that people can build more relationships and avoid feelings of isolation or loneliness:** Both young adults with I/DD and focus group participants noted that people with dual diagnosis often do not feel that they have all the support that they would like. In focus groups, siblings and parents often expressed the same challenges. We recommend the creation of more support groups for people who experience I/DD and mental health challenges and their families.

### **Community Awareness**

- **Create public awareness campaigns to counteract stigma and misperceptions around dual diagnosis:** Stigma and misperception was perceived by many to be a predominant reason for stress and poor-quality treatment. Improving community members' knowledge generally around the challenges and successes of people with dual diagnosis and their families may help counteract these misperceptions.

## *Acknowledgments*

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- Disability Rights Wisconsin
- Parent University
- U.S. Department of Health and Human Services, Administration for Community Living
- University of Illinois at Chicago
- University Center for Excellence in Developmental Disabilities at the University of Wisconsin, Waisman Center
- The Arc of Arapahoe & Douglas Counties
- The Arc of Lane County
- The Arc of Weld County
- The Arc Oregon
- The Arc Wisconsin
- Patient-Centered Outcomes Research Institute
- Boston University

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