



*For people with intellectual  
and developmental disabilities*



# *Training Needs of Professionals who Serve People with I/DD and Mental Health Needs and their Families*

## *Acknowledgements*

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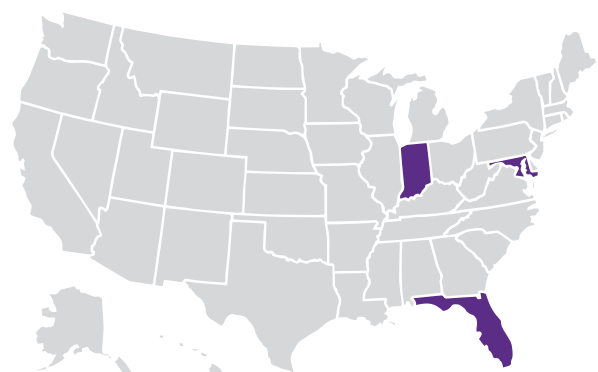
Up to 40% of people with intellectual and developmental disabilities (I/DD) experience co-occurring mental illness. Despite the prevalence of mental health needs among people with I/DD, little is known about the best approaches for supporting the needs of people with I/DD and co-occurring mental health 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 This uncertainty has led to the dependence on outdated and potentially bad approaches to mental health care, such as seclusion, restraint, and psychotropics, which may cause individuals with dual diagnosis an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. The Family Support Research and Training Center (FSRTC) has had the aim 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.

Previously, The Arc explored the family support needs of families that include a person with the dual diagnosis of I/DD and mental health needs. One critical recommendation coming from this investigation was the need for more training around I/DD and mental health for disability, mental health, and education professionals. In 2019 as part of its work as an FSRTC partner, The Arc conducted focus groups that probed the training needs of and barriers that disability, mental health, and education professionals face when serving people with I/DD and co-occurring mental health challenges. The focus of these groups included:

- Discussing and better understanding the training needs and challenges that disability, mental health, and education professionals face when serving people with I/DD and co-occurring mental health challenges and their families;
- Identifying key topics and issues that professionals should be trained on regarding serving people with I/DD and mental health challenges; and
- Developing recommendations on the best opportunities for training format and delivery across all professionals.

We explored these subjects via four focus group meetings with 66 stakeholders in **Maryland, Indiana, and Florida**. We partnered with local chapters, The Arc of Baltimore, The Arc of Indiana, and The Arc of Palm Beach County to hold focus groups and ensure we brought together key players in the community.



## Gaps in Professional Knowledge

Professionals identified five major gaps in professional knowledge.

- 1 Misperceptions around the capabilities of people with I/DD and mental health challenges:** Professionals may not know that people with I/DD may have co-occurring mental health challenges, they may not understand the abilities and challenges that people may have, they may ascribe behaviors or challenges with an I/DD diagnosis rather than a mental health challenges, may make other assumptions about a person (e.g., that their mental health condition cannot be treated), and they may not allow people to choose what treatment or support they want because they may believe a person cannot exercise self-determination. Professionals may not know how to effectively look at the whole person with I/DD and mental health challenges, take time to learn about each person, and work with the person to decide what the best course of support is for them. They may also not know that people with I/DD and mental health needs may take longer to achieve success and their success may not look quite the same as other clients that are being served.
- 2 Uncertainty on how to effectively communicate with people with I/DD and mental health:** Professionals may not understand how to understand people who may communicate in ways other than speaking, may not understand that all behavior is communication, and may not understand how to support people who are less traditionally verbal. Professionals may not understand that communicating with people with I/DD and mental health challenges may take longer, people may need more time to answer questions and review information, and people may need more flexibility in the amount of time and space given for treatment. Additionally, professionals may not know how to speak in a respectful manner to people with I/DD and mental health challenges.
- 3 No strength-based or keen understanding of the needs of people with both I/DD and mental health challenges:** While professionals may receive some education in either or both I/DD and mental health, they will often not receive any continuing training or education in how to identify or support people who experience both. Any training that is provided is often deficits-based, focusing on challenges and needs of people with I/DD and mental health challenges. Participants suggested that it is critical for training to be strengths-based, emphasize the abilities of people with I/DD and mental health challenges, and emphasize common strategies around how to support a variety of people with I/DD and mental health issues.
- 4 Lack of understanding of available programs and services and how service systems interact:** Professionals may not understand the availability of government programs and services and eligibility requirements around various programs. Professionals may also be unaware how I/DD, mental health, and education programs and service interact with one another. Participants also suggested that professionals often are unaware or uncertain of informal resources and networks (e.g., families, churches, community organizations, peer groups, alternatives to homebound suspensions for school-age children) that may be beneficial for people with I/DD and mental health issues.
- 5 Uncertainty on how to collaborate across the disability, education, and mental health systems:** Professionals may not know how to communicate across different systems or services that may be supporting a person.



Several other knowledge gaps arose during discussion. These included:

- Uncertainty around how to support people to plan for the future and develop friendships
- Lack of knowledge of how to support people before and during crises
- Uncertainty regarding the legal requirements around I/DD and mental health challenges
- Uncertainty on how to balance the needs of people with I/DD and mental health challenges and the needs of family
- Uncertainty around how to serve people and families in a culturally competent manner
- Uncertainty on which professionals in work setting are responsible for supporting people or training others
- Uncertainty around how to communicate with community members



## *Most Important Things for Professionals to Know*

Focus group participants identified five content areas in which professionals need training. These include philosophical understanding of people with I/DD and mental health needs, practical skills, communication skills, team-building skills, and knowledge of I/DD and mental health resources. Skill areas and content include:



### PHILOSOPHICAL UNDERSTANDINGS OF PERSON WITH I/DD AND FAMILIES

- Understanding the humanity and dignity of people with I/DD and mental health needs
- Understanding how to view people with I/DD holistically, looking at all their skills, abilities, challenges, and needs
- Understanding that – often - a person's behaviors or temperament is a result of trying to communicate or a result of challenges related to a disability, not obstinance or willfulness
- Understanding and respecting that families are doing the best that they can



### PRACTICAL SKILLS

- How to care for yourself as a professional to avoid compassion fatigue and best support client and family
- The scope of a professional's job and practice and an understanding of what is outside the limits of a professional's responsibilities
- How to address and manage crises, including writing and implementing a safety and de-escalation plan; understanding crises management systems available in the area
- How to protect the patient client rights, gain consent from a client for services, and protect the confidentiality of a person with I/DD

- Treatments and interventions that can help people with I/DD and mental health needs address trauma
- How to conduct Cardiopulmonary Resuscitation (CPR) on people with I/DD and mental health needs and how to respond to any medical issues that need to be addressed
- How to make treatment cognitively accessible to people with I/DD and mental health
- How to offer coping mechanisms, motivation, and education to people with I/DD and mental health so that treatments feel positive and encouraging
- How to help people with I/DD develop relationships and social connections with others in the community
- How to recognize professional limits, understand when a professional is not working well with a person with I/DD, and how to transition them to another professional that can provide services
- How to tailor services or treatments to align with a person and their family's cultural and religious beliefs
- How to handle any suicide threats and recognize issues around suicidal ideation
- How to ensure treatments and interventions align with the principles of trauma-informed care
- How to support families who may experience vicarious trauma when supporting a person with I/DD and mental health challenges
- How to gather feedback and tailor services and interventions based on continual feedback process
- Specific trends and studies in the field about how to serve people with I/DD and mental health
- How to help people build resiliency skills; identify, recognize, and celebrate their strengths and successes; and how to seek and attain support to de-escalate crises
- How to help support people with I/DD and mental health challenges and families to advocate or self-advocate for services and support they want



## COMMUNICATION SKILLS

- How to talk to the person directly and how to communicate information in a way that they person understands
- How to explain and manage expectations and boundaries with clients and families
- How to understand and recognize trauma that a person may be communicating
- How to develop a rapport and get to know a person with I/DD and mental health needs
- How to build trust with people with I/DD and mental health challenges and their families
- How to actively listen without ascribing challenges to a diagnosis
- Techniques for working with frustrated families and advocates
- How to communicate respectfully with a person with I/DD and mental health challenges and their families in a way that aligns with cultural and religious beliefs
- Understanding how to communicate with people with limited social skills and provide training around social skills
- How to work with a person and their supporters to identify goals
- How to ensure that all supporters are listening to the person with I/DD and mental health needs
- How to effectively communicate to a person with I/DD and mental health about treatment options and give people realistic depictions of treatment options available to them
- How to talk with people with I/DD about mental health crises, including bullying and suicidal ideation



## TEAM-BUILDING

- How to help identify all people, family members, supporters, and professionals who need to be a part of a team-building approach
- How to build a common language between the team and overcome different terminologies between disability, education, and mental health settings
- How to provide and coordinate a mental health, educational, or other support plans
- How to communicate across professionals and with the person and family so that routines and expectations are the same
- How to communicate when emergent needs or problems arise in order to make quick decisions
- How to work with other professionals and supporters to evaluate the effectiveness of interventions and supports and make changes as necessary
- How to talk with and recommend resources and services to people with I/DD and their families



## KNOWLEDGE OF I/DD AND MENTAL HEALTH RESOURCES

- How to bill services so that clients can get treatment they need and ensure it is paid by insurance
- Any non-government private insurance or resources that can be used to access services
- Understanding of available government resources, including how benefits and services work, eligibility for benefits and services (e.g., Medicaid, Medicare, Social Security, early childhood services, and school-aged services and support)
- Understanding how law enforcement protocols work when interacting with people with I/DD and mental health challenges and what resources exist during and after a crisis
- Understanding of how waiver funding is allocated and tension between providing services and support, including respite and/or behavioral support
- Understanding of acronyms used by various systems and the different language used across systems
- Understanding of other community resources available to people with I/DD and mental health and their families





## Best Training and Dissemination Formats

Focus group participants discussed the training formats that they felt would be most beneficial for disability, education, and mental health professionals. Across focus groups, participants noted that trainings should have the following characteristics:

- **Offer in various formats but shift depending on audience need:** Participants suggested several in-person and online formats for this training. This included online options like webinars and courses as well as in-person trainings at professional offices during work and non-business hours.
- **Offer across all professional positions:** Participants noted that it is important for training to have the buy-in of leadership, administrative staff, as well as people directly providing care, including paraprofessionals. Trainings should be tailored to each professional group being trained. This may include adjusting formats, timing, and specific content so all can participate.
- **Include a diverse set of leadership roles:** Consider including a self-advocate and family member to co-lead trainings so professionals recognize that people and families have expertise that should be respected and valued. Additionally, consider including a professional peer co-leader and a panel of peers across discipline to ensure the attendees would hear the recommendations of the peer leader as well as gain a breadth of knowledge of issues going on in the lives of people with I/DD and mental health challenges.
- **Include community-specific elements:** Participants agreed that training needed to be specific to the state and local community in order to be most relevant for professionals.
- **Include interactive elements and practical techniques:** Participants recommended that any training include interactive elements, including the presentation of cases for people to gain insight into real experiences, role-playing simulations of potential situations professionals may encounter, sharing of stories, and the opportunity to ask questions. This training should gradually ease professionals into scenarios that are increasingly complex. Participants recommended training include practical recommendations for people to use to ensure practices are adopted.
- **Offer as part of a licensing renewal option, as CEUs, or as part of a professional degree program:** Participants noted that professionals will be more likely to take a training if it is part of the professional development structure, either as part of formal training or continuing education. Participants also recommended that, where possible, training become required by state in order to practice.
- **Offer the opportunity for shadowing people and families, potentially as part of internships, mentorships, fellowships, or coaching opportunities:** Participants recommended that professionals be given an opportunity to shadow people and families in real-life scenarios in order to gain experience and understanding of the complexities and challenges people face. Participants recommended any training be paired with free internships, mentorships, or coaching opportunities so that professionals can ask for additional support to continue to improve their ability to support people with I/DD and mental health needs.
- **Pair with online resources and community:** Participants emphasized the importance of pairing training with the existence of an online application or online resources that would provide resources for professionals to use to stay updated on I/DD and mental health issues, that included links to local community resources, and that offered chat features for people to request support.





## *Other Issues to Consider*

Across focus groups, participants identified other groups that require training and education as well as systemic challenges that must be addressed in order to better serve people with I/DD and mental health issues.

### OTHER GROUPS NEEDING TRAINING



**Police and law enforcement:** Participants emphasized the need for police to have training around the I/DD and mental health challenges population. Participants were concerned about the tendency for police and first responders to feel threatened if they do not know or understand a person's diagnosis. Negative interactions with these groups can cause additional trauma for a person with I/DD and mental health challenges and may discourage families from reaching out to crisis support when it is needed.



**Self-advocates and family members:** Participants also stressed the self-advocates and family members and friends also need more training. Participants were concerned that people and families do not know their rights around health care and how to advocate for themselves in health care and school settings. Finally, participants noted that family members may need training how to deal with caregiver stress and burden.



**Lawmakers and government agencies:** Participants also noted that lawmakers and government agencies need more education around people with I/DD and mental health issues, their rights, and their experiences.

## SYSTEMIC CHALLENGES

Current systemic challenges make quality care more difficult to access and professionals less likely to provide quality care. Participants emphasized that more must be done to hold the system accountable for quality care.

- **Lack of funding for services:** This lack of funding was noted in both formal government systems as well as funding coming from philanthropic organizations. Additionally, existing funding may not be used advantageously, and participants emphasized that families may not have the ability to use available funding where they need it but rather must spend it in the way the system determines.
- **Current funding structure for public insurance disincentivizes professionals from supporting people:** Participants noted that the current waiver in some states require professionals to take on extra expenses, particularly for outpatient services. People with I/DD and mental health needs on public insurance often may be the lowest payer for services, and payment may not cover the cost of serving people with I/DD and mental health. As a result, many mental health professionals may not see or may avoid taking on people with I/DD and mental health needs on public insurance as clients.
- **Even when willing to serve people with I/DD and mental health on public insurance, administrative and procedural hurdles impede professionals from providing enough services:** Participants also noted that the structure of funding currently incentivizes professionals to limit the variety of services, intensity of services, and amount of time of services. As a result of these disincentives, professionals may struggle to understand and serve a person and their family.
- **Lack of feedback requirements lead to challenges around professional accountability:** Participants noted that there is not a current, effective feedback or accountability measure for professionals in the disability, education, or mental health fields. As a result, professionals may not get the information that they need to more effectively serve people and their families.
- **Inconsistent crisis procedures and measures cause confusion for people and families:** During crises, the criminal justice, disability, education, and mental health systems have different procedures and measures in place to de-escalate situations or to support a person in crisis. The lack of consistency in these measures and the general lack of training for professionals around I/DD and mental health in these system results in significant challenges for people with I/DD and mental health need in crisis.
- **Direct care worker crisis results in challenges receiving consistent support for people:** The current direct care worker crisis, resulting from a job that is demanding in its work and very low paying, means that direct support professionals for people with I/DD may change every six months. As a result, direct support professionals often do not have time to build rapport and provide consistent supports to people with I/DD and mental health challenges.
- **Lack of accessible public transportation and paratransit:** Participants recognized that people and families may not be able to get to/from appointments and activities. Even where paratransit services exist, people and families may not quality or be able to use services.



## Challenges

Focus group organizers reported challenges getting all focus group target groups in the room, particularly in attracting mental health providers to the focus group. This was often due to the need for a 4-hour time commitment over the day, when providers may be serving clients, as well as due to the high demand for the mental health provider time. To address these challenges and ensure that we heard from mental health providers, organizers sought out mental health provider opinions in the pre-meeting online survey and sought out the participation of students in the mental health field, who may have similar perspectives but not yet serve fully in clinical settings.

Focus group organizers and facilitators also mentioned challenges to keep people focused in on challenges impacting people with I/DD and mental health issues. Many participants often specialize in serving people with I/DD or people with mental health issues. Sometimes, when speaking in small or large groups, participants tended to focus on issues specific to one group, rather than people who experience both challenges. Focus group organizers and facilitators often needed to prompt and re-focus groups to support people at the intersection of I/DD and mental health challenges and to speak to topics that would be a focus for people experiencing both disabilities.

## Recommendations for Future Training and Other Activities

The Arc recommends a future training for disability, education, and mental health professionals that include the following:

- Training content should be multi-faceted and the following issues and skill-building areas: common misperceptions of people with I/DD and mental health issues; practical skills around emotional wellness, effective supports, and legal requirements; communication skills, particularly with people who are non-verbal or do not communicate in traditional manners; team-building skills to build an effective support network around a person and family; and knowledge of I/DD and mental health resources in the community. The content of the trainings should vary based on audience, time when a person is receiving training (before or after they have begun to serve a person with I/DD, and professional role).
- Trainings should be available in multiple formats, customized for audiences by profession and community, and include peers, self-advocates and family leaders. Training should include interactive elements and practical skills; it should be paired with opportunities for experiential learning and online resources. Training should be offered as continuing education or part of licensing requirements.
- In addition to training for disability, education, and mental health professionals, there should be training for police and law enforcement, self-advocates and family members, law makers and government agencies, and other groups.

**Other activities that must occur in order to provide more support to people with I/DD and mental health issues and their families include the following:**

- Education should occur to address funding challenges and administrative and procedural hurdles that disincentive professionals from providing services.
- Education efforts should also focus on developing feedback requirements into services, making crisis services more consistent, and addressing the direct care worker crisis and lack of public transportation and paratransit options.

