



# I/DD and Mental Health: What We Are Learning About Challenges and Needs

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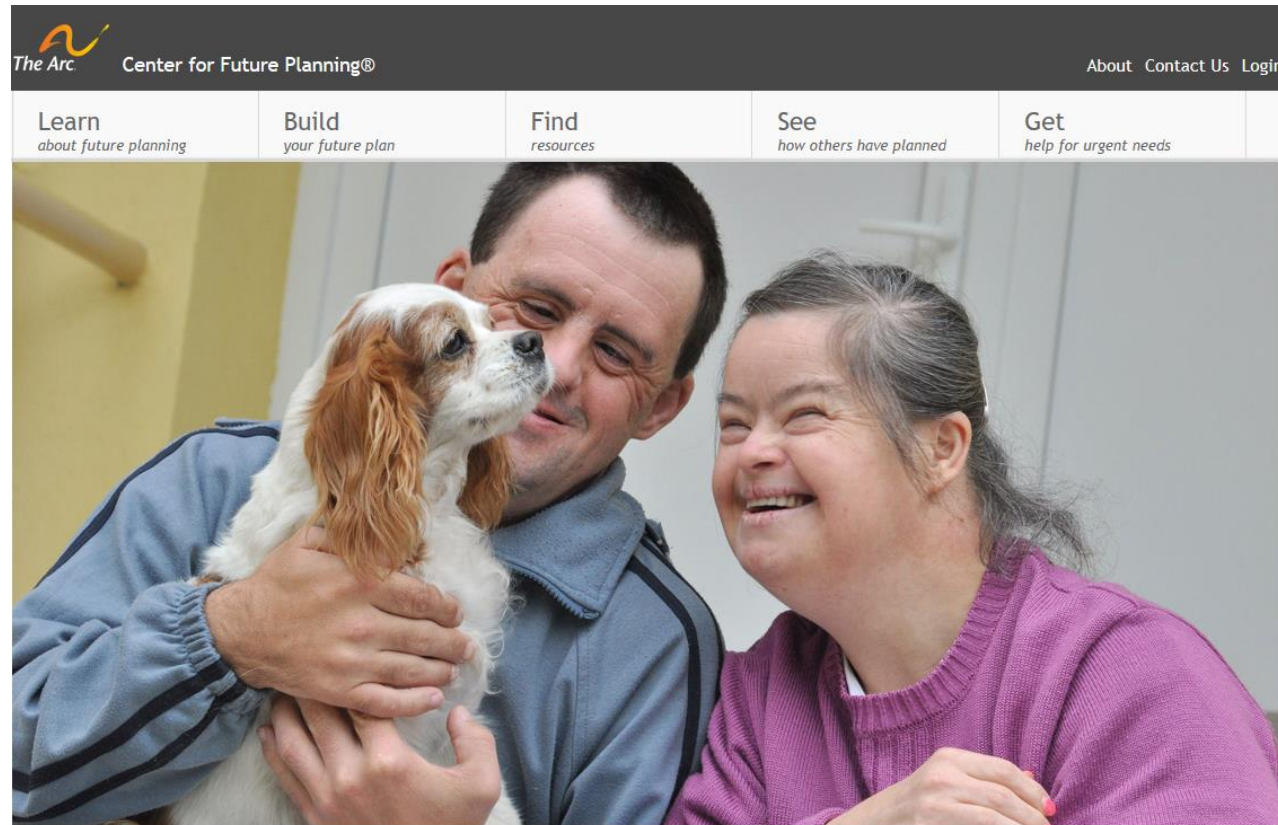
# About The Arc

We are the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families.

Our network includes over 174,000 employees and volunteers that support 1 million people with I/DD and family members at 660+ chapters nationwide.

[www.thearc.org](http://www.thearc.org)

# The Center for Future Planning



[futureplanning.thearc.org](https://futureplanning.thearc.org)

# Today's Big Questions

Why is it important to learn more about mental health challenges and needs of people with I/DD?

What have we learned about some of the concerns people with I/DD and mental health challenges and their families face?

What steps can we take to help people with I/DD and mental health challenges?

# Mental Health and I/DD

Good mental health and wellness is important for everyone

Problem-solving

Dealing with stress or trauma

Building self-confidence

Feeling happier



# Mental Health and I/DD

People with I/DD may struggle to build good mental health or wellness

May have experienced significant past trauma

May experience problem-solving issues

May not be able to control schedule or activities

Up to 40% of people with I/DD also experience co-occurring mental illness

# Mental Health and I/DD

Little is known about the best approaches for supporting people with I/DD and mental health challenges

Dependence on outdated approaches (e.g., seclusion, restraint, psychotropics)

Combined with a lack of family support resources and services, this puts a burden on people and their families

# Our Projects

The Arc set out to learn more about this issue in 2018

We wanted to learn more about:

the mental health needs of and experiences of people with I/DD and co-occurring mental health challenges

the family support needs and challenges of families that include a person with I/DD and co-occurring mental health needs

From this, we wanted to develop recommendations on practices, policies, or assistance would best help people and their families

We did this through two different but related efforts



# Family Support Research and Training Center Focus Groups

Worked with chapters of The Arc in Wisconsin, Colorado, and Oregon to host 5 half-day focus group meetings

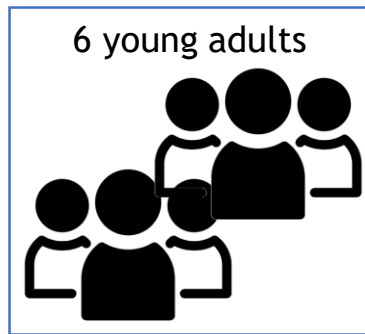
Engaged 80+ people, including people with dual diagnosis, parents, siblings, and professionals.

We asked people to share the challenges and successes they have had and to identify resources or steps that people could take to help their family



# IDD-MH Research Partnership

Intellectual and Developmental Disability Mental Health (IDD-MH) Research Partnership:



**Goal:** learn about the experiences and needs of young adults with IDD-MH while accessing and using mental health services.

# What We Did

Easy read web survey

76 young adults with IDD-MH who were:  
Ages 18-30  
Living in the United States

Story Telling Sessions

On the phone and at the 2018 SABE Conference  
10 young adults with IDD-MH  
6 parents of young adults with IDD-MH

Based on the survey and story telling sessions, we identified 8 priority topic areas for service providers, service delivery systems, and researchers

# What We Have Learned

Through both the FSRTC and IDD-MH Partnership, we have identified 9 areas where participants indicated challenges:

1. Transition to adulthood
2. Insurance and financial resources
3. Professionals' competence
4. Communication
5. Hospitalization
6. Medication and alternatives
7. Social supports
8. Lack of resources
9. Undue burden on family

# Transition to Adulthood

Transition to adulthood can be hard for everyone.

Lack of supports and services in areas like employment, independent living, and adult health care can contribute to a decline in mental health for young adults with IDD as they transition out of school and into adulthood.

# Transition to Adulthood

“It's difficult to find independent living that knowledgeably supports me with an IDD and mental illness. I'm living with my parents and would like to move out, but we can't risk a relapse.”  
*(National Web Survey)*

“Seeing all of their peers and siblings going off to college and having all of these major life changes and they are not, contributes to a lot of their anxiety and feeling different.”

*(Virtual Storytelling Session)*

# Insurance and Financial Resources

Insurance can limit young adults' choices for mental health treatment.

Accessibility to appropriate mental health treatment can be cost prohibitive, even with insurance.



# Insurance and Financial Resources

“I could not afford to get mental health treatment until I moved to a state where I could get Medicaid”  
*(National Web Survey)*

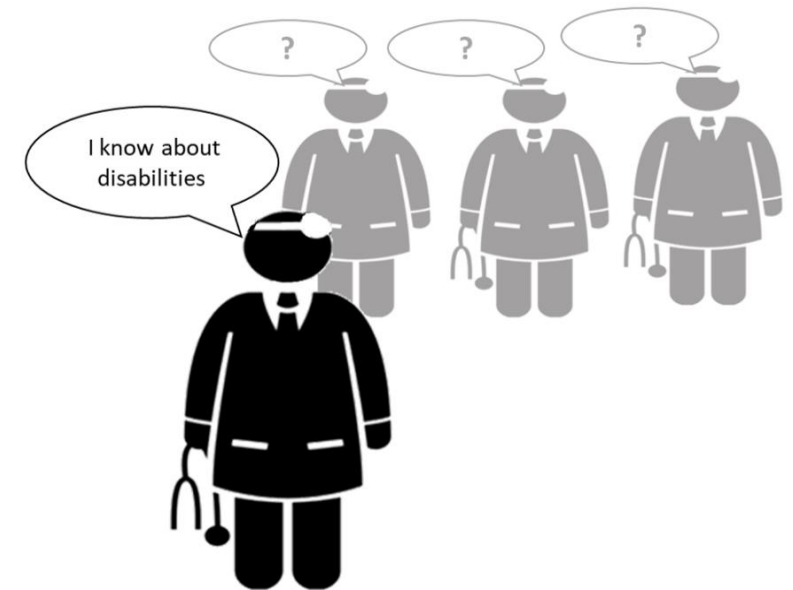
“I would have loved to have my son at home but there was no way to have him cared for at home. So, my only choice was for him to live in residential care. No family could pay over six figures a year for care...It takes money to take care of people with mental health and special needs, but their life matters, too”  
*(Virtual Storytelling Session)*



# Professionals' Competence

Not enough professionals have the appropriate skills and knowledge to work with young adults with IDD-MH.

This reduces the quality and appropriateness of the mental health treatment young adults receive.



# Professionals' Competence

“Doctors don't understand how autism, anxiety and depression can coincide.”  
*(National Web Survey)*

“I went to one therapist and I talked to them about all of the anger that I had...Instead of supporting me ...he attacked me.”  
*(Virtual Storytelling Session)*

“It's hard to find doctors because they go too fast (stressful and I don't understand) or speak like I'm a baby because they see I'm cognitively disabled.”  
*(National Web Survey)*

# Professionals' Competence

In the FSRTC focus groups, families indicated that that competence is not just an issue with health care.

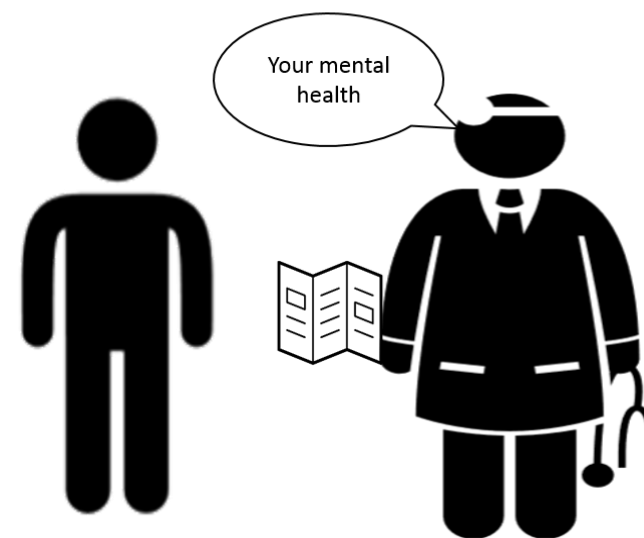
Education professionals, disability professionals, and mental health professionals all often do not have the training that they need to support people who have I/DD and MH challenges.

This results in difficult effectively supporting people and families in these competency areas as well as the setting of treatment plans or goals that are unrealistic for the family.

Families also reported that professionals may not provide services and supports in a way that reflected a family's religious or cultural beliefs around disability.

# Understanding the experiences of people who communicate differently

It can be hard to figure out if mental health treatment is effective when people with IDD have communication differences.



# Understanding the experiences of people who communicate differently

“Having a hard time explaining symptoms.”

*(National Web Survey)*

“We have to judge how medication is affecting our son based on his behavior, his facial expression, his body language. It's been a long and hard process.”

*(Virtual Storytelling Session)*

# Communication Challenges

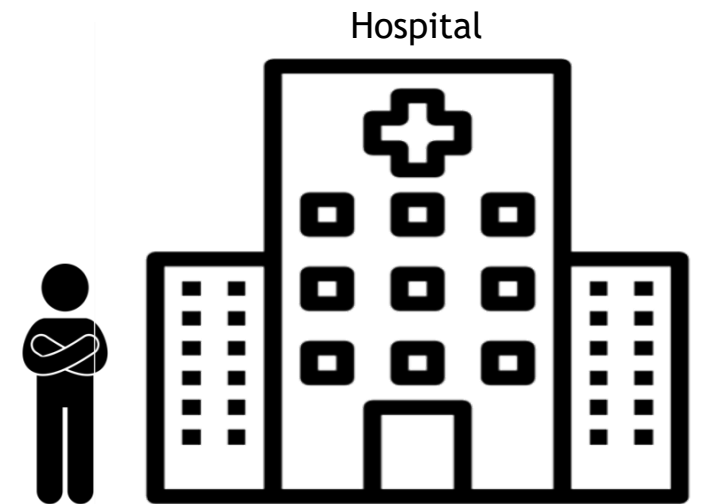
During the FSRTC focus groups, we learned that communications challenges not only exist between doctors and patients but occurs throughout the family itself and between the family and supporters.

People, families, and professionals struggle to communicate effectively with one another, which leads to a lack of effective coordination of supports and services. It can also sometimes lead to breakdown in family relationships when family members do not feel heard.

# Hospitalization

Lack of appropriately trained staff can make inpatient hospitalizations a traumatic experience for young adults with IDD.

Young adults want community-based options when their mental health is bad.



# Hospitalization

“[I] was in the hospital for over one month, because doctors did not know what medicine would work best.”  
*(SABE Storytelling Session)*

“I would constantly discuss how I wanted to die without being direct about it, out of a fear I would be hospitalized.”  
*(Virtual Storytelling Session)*

“I lived in an institutional orphanage for the first few years of my life, and so there's trauma around that. So, I do not like any type of institutional setting.”  
*(Virtual Storytelling Session)*



# Hospitalization

During the FSRTC focus groups, we learned that people with I/DD and co-occurring mental health often end up in a cycle of hospitalization, return to home, and re-hospitalization.

This often occurs because there may be no step-down supports that are available to people who have multiple diagnoses or challenges or may occur as a result of trauma experienced and compounded in the hospitals.

Many families reported that they often feel that they are in crisis and are continual cycling through crises - that they have no way to get out of the crisis situation after hospitalization.

# Medication

Young adults want choice and control over the use of medication.

They want their choice to be respected and supported.



# Medication

“Medication, at first, was a disaster, but once my dosage was adjusted and I grew to tolerate it, it worked *wonders* for me.”

*(Virtual Storytelling Session)*

“I need better medicine with fewer side effects.”

*(National Web Survey)*

“We did try medication ... It actually had an adverse effect because of how he was not able to metabolize the medication.”

*(Virtual Storytelling Session)*

# Alternatives to Medication

Young adults with IDD-MH use strategies, supports, and options other than medicine to help their mental health.

Many young adults reported that therapy and involvement in community activities helped their mental health.

Young adults especially need access to community activities and to high-quality counseling/therapy when their mental health is bad.



# Reported Non-Pharmacological Strategies

Relaxation strategies, such as deep breathing and meditation  
Therapy (therapists or counselors).

Doing activities they enjoy and make them feel good

Exercise

Doing art and other creative activities

Spending time with pets

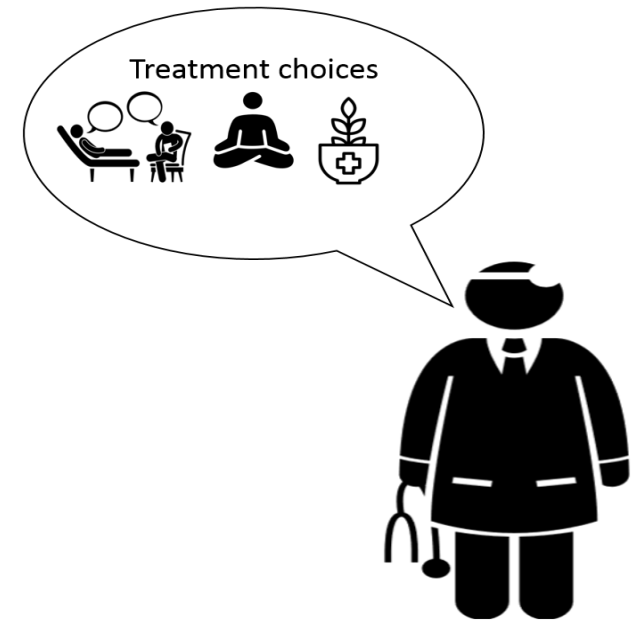
Spending time alone

Cognitive behavioral therapy

Listening to music or watching TV/movies

Medical marijuana

Involvement in self-advocacy to learn to stand up for themselves



# Alternatives to Medication

“I try to do something creative like writing or doodling to get my mind off things.”  
*(National Web Survey)*

I got started in the self-advocacy movement, and I stand up for myself and what I want for my treatment.  
*(SABE Storytelling Session)*

“She needs less medication and more hands-on kind of therapy other than taking more pills.”  
*(Virtual Storytelling Session)*

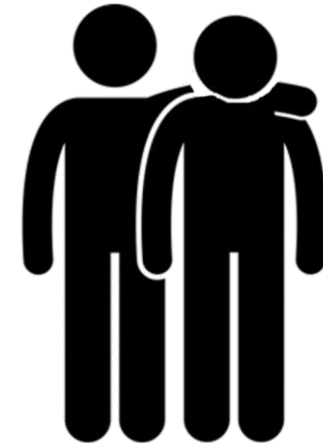
“My son... has the right to go to church but couldn't go. Pretty sure no one's mental health is better when you lock them up, take away everything that gives them life.”  
*(Virtual Storytelling Session)*

# Social Supports

Young adults with IDD-MH need support from people they can trust and who understand their experiences.

Family and friends can provide strong supports for young adults' mental health.

But young adults often don't get the social support they want and need for their mental health.



# Social Supports

“I like talking with and spending time with my family and my friends, a lot.  
‘Cause it helps me a lot...friends are always the best medicine”

*(SABE Storytelling Session)*

“[I am] always depressed and people are tired of hearing about it.”

*(National Web Survey)*

“It's been so helpful for us to have these other families that understand our daily frustration and can share information and also be part of our mental health team.”

*(Virtual Storytelling Session)*



# Social Supports and Training for Families

People with dual diagnosis, parents, and siblings may often feel lonely or isolated as a result of lack of understanding, difficulty communicating, discrimination, or stigma.

People with I/DD and mental health challenges need more opportunities for emotional support, inclusion, and building relationships.

Parents and siblings also need more opportunities for emotional support and peer mentoring.

Families need more training to help build social and independent living skills, deal with stress, and create plans to more effectively transition throughout their lives together.

# Lack of Resources and a Complicated System

Throughout focus groups, we heard repeatedly that there is often a lack of appropriate resources and services for families.

The disability and mental health systems are extremely complex and inflexible. Families struggle to navigate between the two, and care is often delayed or rejected because families are caught between the two systems on who would pay.

# Undue Burden and Stress Creating an “Un-Family”

Families are also often responsible for coordinating care between the two systems but do not receive support to learn how to navigate the system nor on what resources are available. Families have to be coordinator, communicator, financier, and support provider.

But, the system treats everyone as if they are an island unto themselves, which may result in care not being appropriate for the family or causing additional burden on the family.

Especially in cases where people have multiple children receiving support, some families reported a need to become an “un-family” in order to get the care for each member.

# Recommendations for Future Research and Activities

# Future Research and Activities

## Create and Develop Training:

Develop a nationwide, replicable training around I/DD and mental health for mental health, disability, and education professionals

Support trainings aimed at enhancing the cultural competence of disability, mental health, and education professionals

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

Expand trainings for caregivers that are intended to reduce caregiver burden

# Future Research and Activities

## Advocate for or Support 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

Support research activities that further develop evidence-based mental health treatments that are alternatives to medication and that are adapted to the dual diagnosis population

# Future Research and Activities

## Support the Development of New Resources, Including:

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

Support groups for people with dual diagnosis, siblings, and parents so that people can build more relationships and avoid feelings of isolation or loneliness

# Future Research and Activities

## Enhance Community Awareness:

Create public awareness campaigns to counteract stigma and misperceptions around dual diagnosis





# Answering Today's Big Questions

1. Mental health and mental wellness are really important for people with disabilities. This is an often overlooked part of a person's life.
2. We have learned a lot about the challenges that people and their families are facing in accessing mental health services that appropriate, holistic, respectful, and community-based and that support both the person with disabilities and their families.
3. There are several things that the disability community, health systems, and mental health professionals can do to make things better for people with disabilities and their families. More can and should be done to support people's mental health.

# Our Next Steps

- Holding focus groups with education, mental health, and disability professionals around I/DD and mental health conditions. We are seeking to identify training formats and issues to include in a curriculum. We will be releasing findings in fall 2019.
- Working with partners on grant proposals to fund additional self-advocate led research and support I/DD-MH research consortia.
- Raising awareness in our network through the release of findings and briefs as well as by gathering stories and promising practices within the network

# Resources

How to Support People During Psychiatric Emergencies: <https://aadmd.org/page/emergency-care-webinar-series>

Mental Health Wellness for Individuals with I/DD: <http://training.mhw-idd.uthscsa.edu/>

Trauma Informed Care: Perspectives and Resources:  
<https://gucchdtacenter.georgetown.edu/TraumaInformedCare/>

Center for START Services: <https://www.centerforstartservices.org/community-resources>

Accessing Home and Community Based Services: A Guide for Self-Advocates:  
<https://autisticadvocacy.org/resources/books/accessing-hcbs/>

# Questions?



# Questions for Reflection

- What types of complex needs or challenges do individuals and families bring to your agency?
- What are some ways to help individuals and families prioritize these types of needs?
- What kinds of problem-solving strategies can specialists bring to complex needs, especially when there are no ready resources?
- How can specialists support and empower individuals and families to navigate multiple, complex systems?
- Is your agency undertaking or participating in any initiatives to help address complex needs?
- Who in your community is it important to partner with to provide referrals/assistance with such needs?