

# Mental Health Outpatient Therapy for Individuals with Developmental Disabilities in Delaware

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ALYSSA COWIN

LAUREN BAUER, LCSW

BRIAN FREEDMAN, PH.D.

SARAH MALLORY, PH.D.



# Mental Health Services for Children with I/DD

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BRIAN FREEDMAN, PH.D.

# Co-Occurrence of Mental Health (MH) Challenges

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- Prevalence rates of MH challenges are much higher for children with I/DD
  - 40-50% for children with intellectual disabilities
  - 40-70% for children with autism
- Common co-occurrences with anxiety: sensory over-responsivity, sleep disturbance, aggression/defiance, and attention deficit/hyperactivity disorder
- Autistic people are four times more likely to experience depression in their lifetime than individuals without ASD
- Suicidal ideation is higher among people with I/DD than the general population

(Daveney et al., 2019; Hudson et al., 2019; Hull et al., 2020; Mevissen et al., 2020; Nieuwenhuis et al., 2019; Scotti et al., 2012; Totsika et al., 2022; Vasa et al., 2020)

# Higher likelihood of MH challenges due to...

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- As much as 70% of people with I/DD experience at least one *traumatic event* during their lifetime
  - PTSD prevalence rates range from 10-40%
- *Camouflaging* was associated with greater symptoms of generalized anxiety, depression, and social anxiety
- *Bullying* and *isolation* occurs more often for people with I/DD

(Daveney et al., 2019; Hudson et al., 2019; Hull et al., 2020; Mevissen et al., 2020; Nieuwenhuis et al., 2019; Scotti et al., 2012; Totsika et al., 2022; Vasa et al., 2020)

# Growing Evidence for MH Treatments in I/DD

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- Cognitive Behavioral Treatment – individual and group therapy
- Physical exercise
- Behavioral treatment for depression
- Mind-body stress reduction
- Mindfulness

# Challenges in Finding Services

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- Many families cannot find a therapist!
- Most frequently reported barriers from families:
  - lack of therapist knowledge or expertise in autism
  - inability or unwillingness to tailor approaches to support the child's needs
- Clinicians report less willingness to provide therapy to autistic clients even if the clients are presenting for traditional therapy conditions (e.g., anxiety, depression)
- Autistic people are turned away from therapists more frequently than neurotypical people when they request services

(Adams & Young, 2021; Camm-Crosbie et al., 2019; Jackson et al., 2020; Maddox et al., 2019; Maddox et al., 2020; Roudbarani et al., 2023)

# Why are children and families getting turned away from services?

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- Lack of training access
  - 54% of psychologists-in-training indicated they are interested in learning more about assessment and treatment for people with autism and other I/DD
- Professionals and families have been told that only “experts” can offer treatment
  - This limits the options!
- Ableism among professionals and systems – systemic bias toward people with disabilities; assumptions of differences and low expectations
- What is most needed for improvement in MH treatment – A STRONG RELATIONSHIP! Just like with any other therapy client

(Fagan et al., 2007)

# Systemic Challenges in supporting Mental Health

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- Public systems are VERY difficult to figure out
  - Some family navigation supports available for families impacted by autism
  - Fewer supports for families of children with other I/DD
- Dedicated state systems in Delaware have challenges in this area:
  - *Division of Prevention and Behavioral Health Services (PBH)* – historically has provided few supports; Those that receive training often turn over
  - *Division of Developmental Disabilities Services (DDDS)* – limited supports for kids; funding is dedicated primarily to adult services



# Hope for the future: Training in Delaware!

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- Delaware Network for Excellence in Autism
  - No-cost training and resources available for professionals in a variety of topics
  - Housed at the University of Delaware Center for Disabilities Studies (CDS)
- Leadership Education in Neurodevelopmental Disabilities (LEND)
  - Interdisciplinary training program on I/DD; Collaboration between UD CDS and Nemours
  - Short-term, medium-term, and long-term training programs available
- Nemours IMPACT Training Program
  - Training for Master's level therapists on behavioral health and mental health
  - Includes rotations for many trainees in Swank Autism Center and Down Syndrome clinic

# Intellectual and Developmental Disabilities & Mental Health: Ongoing Data Collection Efforts and Activities in Adult Systems

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SARAH MALLORY, PH.D.

# Background: Overview of Key Partners



## National Center for START Services (NCSS)

- Conducted a service system analysis of systems that serve individuals with IDD who have mental health needs

## University of Delaware Center for Disabilities Studies

- Supported implementation of NCSS's Service System Analysis and working across agencies to support related mental health initiatives

## National Association of State Directors of Developmental Disabilities Services (NASDDDS)

- Led *Capacity Building Institute for Individuals with I/DD and Mental Health Support Needs (CBI)*

# Engaged Stakeholder Groups

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## State and Local Partners

- *Division of Developmental Disabilities Services (DDDS)*
- *Delaware Department of Services for Children Youth and Families (DSCYF)*
- *Division of Substance Abuse and Mental Health (DSAMH)*
- *Division of Vocational Rehabilitation (DVR)*
- *Lt. Governor's Office/Behavioral Health Consortium*
- *Delaware Statewide Independent Living Council (SILC)*
- *University of Delaware*
- *School districts*
- *First responders, including adult & youth crisis response*

## Individuals with Lived Experience

## Advocacy Groups

- *Sussex County Health Coalition*
- *Community Legal Aid Society (CLASI)*
- *State Council for Persons with Disabilities (SCPD)*
- *Developmental Disabilities Council (DDC)*
- *NAMI Delaware*
- *Trauma Matters Delaware*

## Provider Agencies

- *Mental health providers*
- *Managed care organizations*
- *Hospital systems*
- *Adults service agencies*

# Service System Analysis: Activities

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**The IDD-MH Service System Analysis** was led by Delaware's Division of Developmental Disabilities Services ([DDDS](#)) and represented a partnership with the National Center for START Services ([NCSS](#)) and the University of Delaware Center for Disabilities Studies ([CDS](#))

## **Three Activities:**

- (1) Stakeholder meetings and focus group discussions;
- (2) Statewide survey; and
- (3) Analysis of statewide Medicaid claims data (ongoing)

**Preliminary Results** were shared in Summer 2023

# Service System Analysis:

## Overview of Findings (Beasley, Klein, & Kalb; 2023)

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### Service systems evaluated:

- IDD services
- Training services
- Child services
- Crisis services
- Mental health services
- Community services

### Participants rated different service systems as either being:

- Not available
- Available but not sufficient
- Available but needs improvement
- Works Well

### Significant findings:

- Greatest service gaps relate to crisis prevention and intervention services
  - Followed by mental health outpatient services
- Community services were the most highly rated type of service
- Need to improve cross-systems collaboration and communication in order to improve experiences for family caregivers and service users

# Service System Analysis: Overview of Findings (continued)

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## Five Themes from Study Results

1. There is an over-reliance on police and emergency departments
2. There are not enough outpatient mental health services for people with IDD-MH
3. There is a lack of adequate expertise for both mental health and IDD providers
4. There is a lack of linkages across systems
5. All services need improvement to better serve the IDD-MH population

# Service System Analysis: Recommendations

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## Three areas of improvement:

- Create **access** to the full array of mental health services for people with IDD
- Ensure **appropriateness** (i.e., goodness of fit) for these services to meet the needs of individuals with IDD
- Establish **accountability** for the service system as a whole to provide needed services to IDD population

## Recommendations:

- Policies and practices to offer full array of services to people with IDD
- Provision of reasonable accommodations to access care and expertise
- More inclusive and less restrictive practices with greater access to person-centered services
- Cross-system linkage and navigation support



# Capacity Building Institute (CBI): Institute Activities

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## **Activities had a strong focus on:**

- Individuals with complex behavioral health needs
- Creating a restorative environment
- Providing treatment for trauma

## **Cohort activities included:**

- Training and technical assistance in topics related to IDD and mental health (e.g., trauma, holistic approaches to intervention, psychiatric assessment, best practices)
- Learning collaborative consisting of peer exchange and mentorship
- State-specific team meetings to address state-level needs

**NASDDDS produced a report for each participating state**

# Capacity Building Institute (CBI): Overview of Findings

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## **The purpose of the NASDDDS report was to:**

- 1) identify the elements a service system needs to have in place in order to serve this smaller group of individuals with complex behavioral health needs; and
- 2) assist the state in identifying what improvements or changes are needed to successfully serve them. The elements fall into two domains that together promote mental health recovery: a restorative environment and treatment.

## **Delaware's CBI team (n=12) completed a self-assessment in order to rate areas as:**

- Presence is strong
- Presence is emerging
- Presence is weak/no response

# Capacity Building Institute (CBI): Report Findings: Presence is **Strong**

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Administrators recognize needs of population

Agency leadership and local management entities have training/experience

State initiatives to support individuals with IDD/MH

State agency champions

Regularly participate in workgroups focused on individuals with IDD/MH

Clear understanding everyone can live in the community

Person-centered approach taken in developing and implementing individual service plans and promoting community engagement

State promotes use of positive behavioral supports

Restrictions on rights or access require an assessment and plan

Restraint is only used for safety protections

Child Welfare has a practice and professionals to support assessing developmental disabilities and supporting services

Communicate community engagement and employment are important for adults

Supported in providing individually designed small living arrangements

Residential providers who provide a trauma informed environment

Providers understand developmental trauma and relationship to behavior

Engaged coordinator/case manager

Access to wide range of therapies

MH reimbursement

TA available for provider organization in relation to challenging behaviors

# Capacity Building Institute (CBI): Report Findings: Presence is **Emerging**

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Access to individual supported  
employment services

Access to adequate transportation services

Access to a full range of behavioral health  
services with a provider with training

Financial limitations impeding delivery of  
services

Minimum training requirements for  
providers that include training in mental  
health, person-centered practices, positive  
behavioral supports, and meaningful  
community engagement

Formal collaborations at state and local  
levels to support children and adults with  
IDD-MH

# Capacity Building Institute (CBI):

## Report Findings: Presence is **Weak** (or no response)

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Providers and support coordinators who know how to complete a biographical timeline

Range of living options

IDD system rates/rate structure allow for an individual living arrangement and adequate staffing

Reimbursement system allows for modifications

MH system reimbursement rates support an adequate network of provider services

Individuals responsible for service authorization, coordination, and mentoring receiving training

State has a method to recruit and train MH professionals to provide services to people with IDD-MH

Identify agencies in state with whom IDD agency should collaborate

# Common Themes of Both Studies: Report Activities

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## Service System Analysis

- **Focus:** Adults with IDD and mental health needs
- **Method:** Focus groups and statewide survey
- **Participants:** Delaware stakeholders evaluate different services based on:
  - Access
  - Appropriateness
  - Accountability

## Capacity Building Institute

- **Focus:** Adults with IDD and complex behavioral health needs
- **Method:** Likert survey with free responses
- **Participants:** CBI state representatives engage in self assessment with strong focus on:
  - Restorative environment
  - Treatment for trauma

# Common Themes of Both Studies: Report Findings

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**Both reports recognize Delaware has strong leadership and a foundation of existing resources**

**Work is needed to address:**

- Improved cross system collaboration and communication
- Better training for mental health providers and other mental health adjacent professionals
- Better training for IDD providers in topics related to mental health
- Increased staffing and number of providers with necessary expertise
- Removal of barriers to access (e.g., financial hardship, transportation)
- Need for meaningful community inclusion

**Service System Analysis highlighted:**

- Over-reliance on police and emergency departments

**Capacity Building Institute highlighted:**

- Need to evaluate waiver and reimbursement systems

# Other Statewide Initiatives

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**Multiple state entities are already leading initiatives focused on IDD and MH**

For example:

- Division of Substance Abuse and Mental Health (DSAMH) on crisis response
- Delaware Developmental Disabilities Council (DDC) on destigmatizing mental health among individuals with IDD
- UD Center for Disabilities Studies/Delaware Network for Excellence in Autism on improving providers' capacity to use evidence-based supports with individuals with autism and other intellectual and developmental disabilities



# Next Steps

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**DDDS is participating in Year 2 of the CBI with a focus on:**

1. Provider Capacity
2. Sustainability
3. State agency coordination

# Outpatient therapy for individuals with I/DD

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LAUREN BAUER, LCSW

# Signs to start Out-Patient therapy

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**Do I have these feelings most of the time:**

- Sad
- Angry
- Frustrated
- Unhappy
- Lonely
- Confused

**If you have these feelings are you hiding them from others?**

\*The National Center for Disability, Equity, and Intersectionality; 2023 [Help! I Need a Therapist!- Guide - The National Center for Disability, Equity, and Intersectionality \(thinkequitable.com\)](https://www.thinkequitable.com/help-i-need-a-therapist-guide)

# Signs to start Out-Patient therapy

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## Warning signs:

- Not sleeping or sleeping too much
- Eating more or less than usual
- Body aches
- Avoiding friends and family
- Avoiding work or chores
- Not showering or bathing
- Thinking about hurting yourself or someone else

If you notice these signs, talk to a trusted person you know

**If you are thinking about hurting yourself or someone else get help immediately**

**Call 911 or 988**

**Local crisis supports**

**Northern Delaware: 302-577-2484**

**Southern Delaware: 302-424-5550**

# Out-Patient Therapy – Before you start

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## **Out-patient therapy**

- Qualifications/Licensure: LCSW, LPC, LMFT, PsyD, PhD
- Mindful of setting (virtual or in person)
- Location
- Experience and skills/theoretical framework
  - DBT
  - CBT
  - Psychotherapy

## **Questions to ask before choosing a therapist:**

“Does this person have experience working with people who have similar identities as myself?”

“Does this person take insurance and what are payment options?”

# Out-Patient Therapy – Making contact

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## **What to do after finding a therapist**

- Good questions to ask the therapist:
  - Does my insurance cover?
  - What is the expected fee?
  - How do I schedule/cancel?
  - How long/often do I engage in care?
  - What happens if I miss an appointment?
  - What are my rights?
  - Transportation?

**This will help you stay engaged in care consistently.**

# Out-Patient Therapy – Preparation

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## **Think about what you need**

What goals do you want to work on?

What supports do you want help with?

- Mental health (Anxiety/Depression)
- Independence/Advocacy support
- Case management support

## **You can request any paperwork be sent to review prior to your appointment**

- Consent to treatment
- Release information
- Therapist's biography/photo

# Out-Patient Therapy – What to bring

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## **What to bring with you during your first appointment**

- Information about past care
- Prior evaluations or testing
- Referral information
- Contact information
- Information about your communication style
- Information about sensory needs
- Information about medication
- Information about providers who support in your care
- Trusted friend or family member, support person if you wish
- Any guardianship documentation information if applicable
- Snacks/water



# Out-Patient Therapy – First meeting

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## **Building the relationship**

- After meeting provider.....
  - Is this a good fit?
  - Does this person meet my needs?
  - Am I comfortable in this setting?
  - What may be helpful?

You can request a referral for another provider if it is not a good fit.

You don't have to be stuck with someone who does not meet your needs.

# Out-Patient Therapy – Ongoing care

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## **Multidisciplinary support**

- Your therapist is part of your team
- They should engage with your medical/case management/care team so needs are best met
- Help coordinate care and schedules
- Track and communicate concerns or changes

# Out-Patient Therapy – Example

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## **Example of support**

- In my current setting:
  - Staff engage in trainings to support individuals with unique needs
  - Everyone is welcome to receive emergency supports and care assessment
  - Care coordinator supports students to connect in the community if needed
    - Support with insurance information
    - Engaging family or supports
    - Help make appointments with community providers based on interests/need

# Out-Patient Therapy

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## I've tried everything and can't find support

- Contact local networks
  - Autism Delaware
  - DDDS
  - State or local disabilities council offices

\*The National Center for Disability, Equity, and Intersectionality; 2023 [Help! I Need a Therapist!- Guide - The National Center for Disability, Equity, and Intersectionality \(thinkequitable.com\)](https://www.thinkequitable.com/help-i-need-a-therapist-guide)

# Finding Mental Health Services

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ALYSSA COWIN, SELF-ADVOCATE

