People with I/DD Who are Dual Diagnosed with Mental Illness:
Characteristics and Outcomes

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NCI
NASDDDS & HSRI

Overview

- Introduction to NCI
- Rationale for the analysis of individuals who are dual diagnosed with I/DD and mental illness
- Review of the NCI Consumer Survey and the elements used for the analysis
- Data on characteristics of individuals with and without a dual diagnosis
- Summary of data analysis
- Implications for policy

Background

- The idea that people with I/DD could also be diagnosed with mental illness is a relatively recent.
  - until the last ~40 years, it was assumed that people with I/DD could not also have a mental illness.
- I/DD and mental illness were thought to be two separate conditions
- Behavioral challenges were seen as a consequence of cognitive limitations
  - Not symptoms of an underlying psychiatric condition.
- Response to symptoms
  - restraints, medication and punishment

How Big is the Issue?

- The exact prevalence of individuals with I/DD who also have a mental illness is debated among researchers.

- Estimates range from 14-70%.
  - NADD estimates that the prevalence is somewhere between 30 and 40%

- Determination of prevalence is crucial:
  - to identify community supports needed
  - to provide information to support collaboration between MH and DD agencies

Data Based on a Recent NCI Data Brief

NCI™
NASDDDS & HSRI

National Core Indicators™

DATA BRIEF

OCTOBER 2019

What Do NCI Data Reveal About People Who Are Dual Diagnosed with ID and Mental Illness?

What is NCI?

- NCI is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.

- Collaboration coordinated by HSRI and NASDDDS began in 1997

- Currently 46 states and Washington D.C. represented plus 22 sub-state entities

- **Goals:**
  - Establish a nationally recognized set of performance and outcome indicators for DD service systems
  - Use valid and reliable data collection methods & tools
  - Report state comparisons and national benchmarks of system-level performance
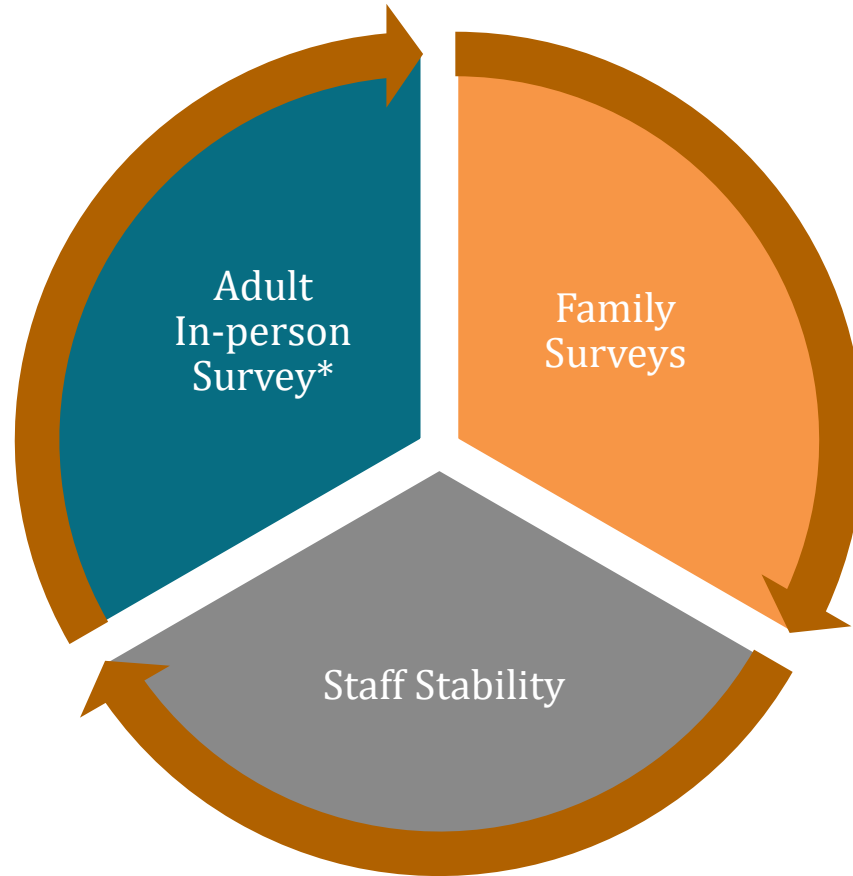
Survey Tools

*Formerly the Adult Consumer Survey (ACS)

Rationale for NCI Analysis

Data on individuals with dual diagnosis such as:

- Outcomes data (e.g., employment, place of residence, choice, etc.)
- Data on demographics and personal characteristics

1) Are an important contribution to better understanding experience of people with dual diagnosis
2) Provide the foundation for both policy and clinical implications.

In-Person Survey: How is it Administered?

- Respondents
  - Over 18
  - Receiving at least one service from the IDD agency, beyond case management
- Survey includes three main parts:
  - Background information –
    - From existing records
  - Section I – Subjective questions only the person can answer face-to-face
  - Section II – Objective questions can be answered by a proxy when needed

What Data Were Used?

- Data on the characteristics of people who were dual diagnosed were drawn from the 2017-18 In Person Survey
  - included 35 states and the District of Columbia
- Dual diagnosis: Info in BI section
  - reported to have an ID diagnosis and
  - were reported to have at least one of the following diagnosis
    - Mood disorder
    - Anxiety disorder
    - Psychotic disorder
    - Other mental health diagnosis
- Of the 22,513 survey respondents, 10,729 (approximately 48%) met the criteria for dual diagnosis
- Those data that show a significance level of $p \leq .000$ are included.

Characteristics of Those With/Without Dual Diagnosis

	With dual diagnosis	Without dual diagnosis	N
Mild ID	48%	42%	20,778
Profound ID	7%	12%	
Autism Spectrum Disorder	20%	14%	21,750
Cerebral Palsy	12%	20%	21,872
Down Syndrome	6%	13%	21,835

Characteristics: With/Without Dual Diagnosis (DlDi)

Mobile without assistance	• Without DlDi : 74% • With DlDi: 82%
Using self directed supports option	• Without DlDi: 8% • With Dldi: 6%
Has a behavior plan	• Without Dldi: 16% • With Dldi: 43%

Need for behavior support

Self-injurious
- With DlDi: 31%
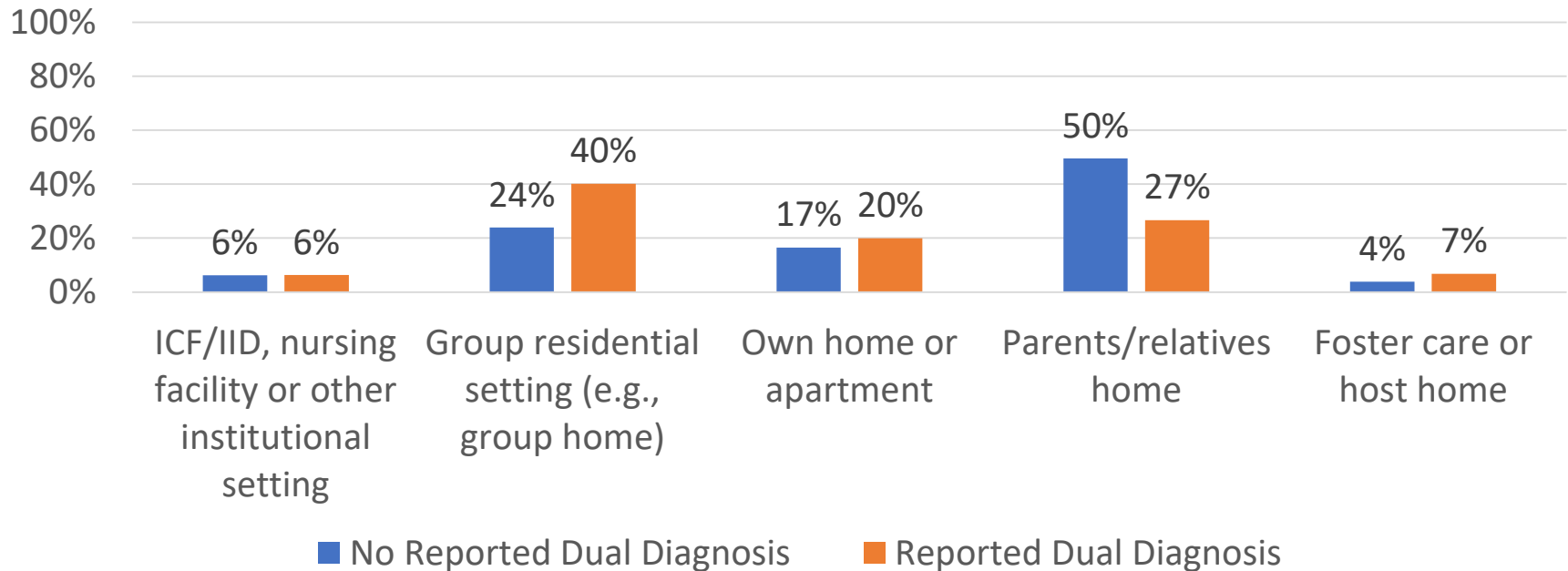- Without Dldi: 14%

Disruptive
- With DlDi: 58%
- Without Dldi: 27%

Destructive
- With DlDi: 41%
- Without Dldi: 16%

Where Do People Live (N=22,018)

People with dual diagnosis are significantly less likely to live at home with parents and significantly more likely to live in aa group residential setting.

Choice

| Chose, or had input in choosing….	WITHOUT Dual Diagnosis	WITH Dual Diagnosis	N
Home (if not living with parents or relatives)	54%	58%	12,417
Daily Schedule	82%	86%	21,914
What To Do in Free Time	89%	93%	21,941
Day Activity	55%	57%	13,772
What to Buy with Spending Money	83%	89%	21,795

Medication

- Reported to take **medication to treat mood disorders, anxiety and/or psychotic disorders**.
  - 14% of those without a dual diagnosis
  - 82% of those with a dual diagnosis took such meds (N=20,307)
- Reported to currently take **medications to treat behavior problems**
  - 11% of those without a dual diagnosis
  - 36% of those with dual diagnosis were reported to currently take such medications. (N=20,231)

Community Inclusion, Participation and Leisure
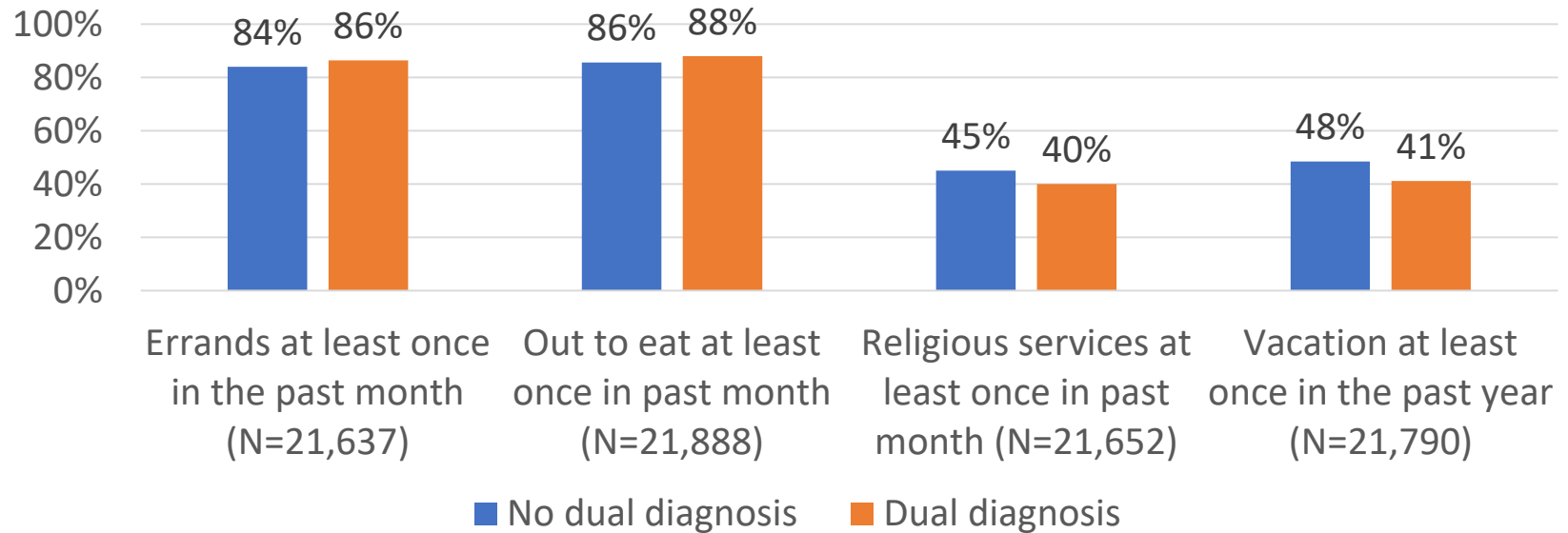
Rights and Respect

	WITHOUT Dual Diagnosis	WITH Dual Diagnosis	N
There are rules about having friends or visitors in home	33%	36%	12,494
Staff treat with respect	95%	92%	12,886

Employment

- Around one-fifth (19%) of those without dual diagnosis and 17% of those with dual diagnosis report having a paid job in the community (N=21,953)

Relationships

- Friends other than family or staff:
  - 79% of those without dual diagnosis 77% of those with dual diagnosis (N=14,669)
- Want more help to contact friends
  - 40% of those without dual diagnosis
  - 47% of those with dual diagnosis (N=13,945)
- Able to see friends when wants
  - 83% of those without dual diagnosis
  - 79% of those with dual diagnosis (N=12,653)
- Often feel lonely
  - 8% of those without dual diagnosis
  - 13% of those with dual diagnosis (N=14,214)

Summary of Characteristics of Individuals Who Are Dually Diagnosed

Respondents with dual diagnosis in the NCI sample were:

- Less likely to live at home with family

- Considerably more likely to need some or extensive support for both self injurious behavior and disruptive behavior.

- More likely to take medications for a co-occurring mental health condition, but also more likely to report taking medications for a behavioral challenge.

- More likely to report wanting additional assistance staying in touch with friends.

- Less likely to have a community job

- More likely to report feeling lonely.

Implications

- Are sufficient reviews performed to ensure that medication prescribed for people with dual diagnosis are appropriate including medication types, dosage, etc.?

- Are services in place to support people with dual diagnosis to participate in their communities and to develop relationships?

- Are diagnostic techniques in place to determine whether behavior challenges are in fact manifestations of mental illness?
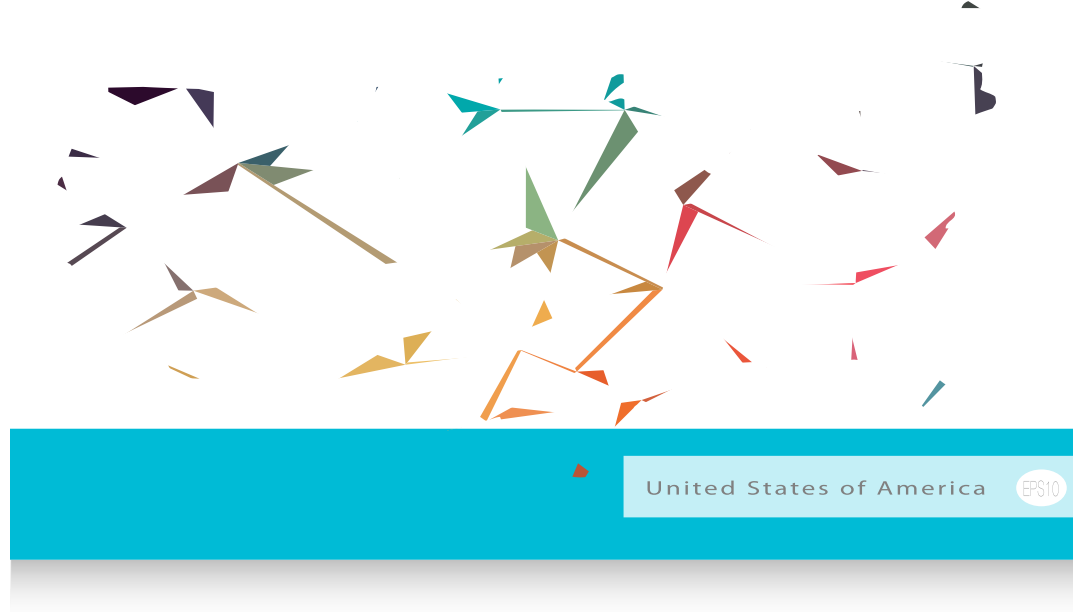
NATIONAL TRENDS REGARDING PEOPLE WHO ARE DUALLY DIAGNOSED WITH IDD AND MENTAL ILLNESS

Jeanne M. Farr, MA
CEO

An association for persons with developmental disabilities and mental health needs.

Overview

Landscape

Demographics

Recent Convenings

Themes and Trends

Tying it All Together

United States of America   EPS10

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LANDSCAPE

- Growing national consensus that people with disabilities are not one-dimensional

- Nation still struggles to provide community mental health services for individuals with ID

- Need alternative approaches to meet needs and support people to have real, meaningful lives

- People with ID/MI Dual diagnosis stretching systems of care

- Lawsuits relating to care

DEMOGRAPHICS AND DRIVERS: IMPACTING EMERGING TRENDS IN SUPPORTING INDIVIDUALS WITH I/DD

- Projected and current year demands for supports outstrip available resources

- States are exploring ways to achieve better integration (in all senses), improve person-centered approaches, and build programmatic and fiscal sustainability
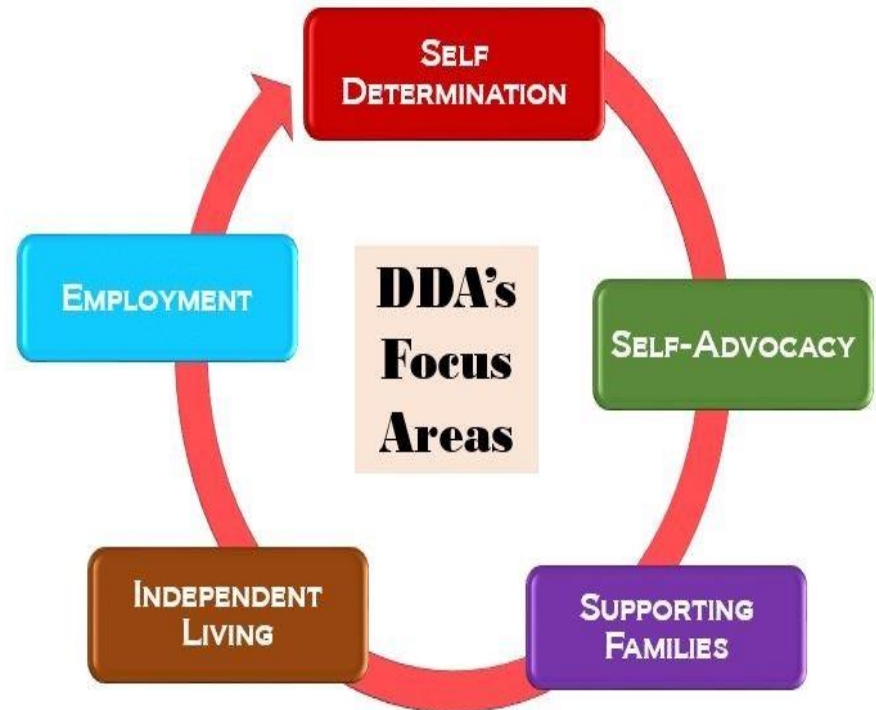
Demographic & Economic Factors Impacting Social Services

- Shortages of care givers as America ages
  - Demand for LTSS (Long Term Services and Supports) will more than double by 2050

- Growth in public funding for services diminishing

DEMOGRAPHICS: WORKFORCE SUPPLY

BY THE NUMBERS: DIRECT CARE WORKERS

4.4 million

Number of direct care workers across home and community-based settings, nursing care facilities, assisted living facilities, group homes, intermediate care facilities, and hospitals. Source: PHI, 2017

5.2 million

Number of direct care workers needed by 2024 across all settings. Source: PHI, 2017

88 million

Projected population of people aged 65 and older in 2050. Between 2015 and 2050, this population will nearly double, growing from 47.8 million to 88 million. Source: U.S. Census Bureau, 2014

NASDDDS
National Association of State Directors of Developmental
Disabilities Services

CONVENINGS

- SAMHSA – ACL Gathering - Expert Panel

    The State of Mental Health Services for Individuals with Serious Mental Illness and Intellectual Disability and/or Autism Spectrum Disorder

- August 2018

- Published summary in early 2020

- Experts from diverse disciplines

- Purpose

SAMHSA-ACL CONVENING

- Discussion focused on

  - Gaps in services

  - Barriers to care

  - Model programs

  - Self-advocate and family perspectives

  - Suggestions to improve access to mental health services for individuals with SMI and ID and/or ASD and their families

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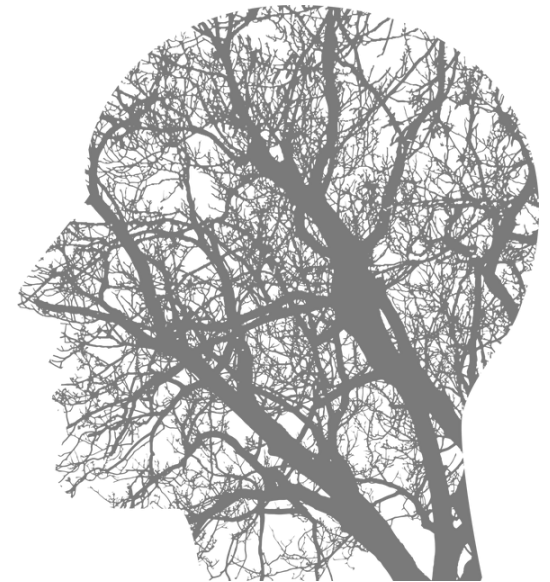# SAMHSA-ACL Convening

Reflections from the gathering

- De-institutional movement
  - Presumption of adequacy of resources

  - Assumption that people with ID and MI could not benefit from treatment

  - Ineffective diagnostic/assessment tools

- Overburdened ER's

- Social Marginalization

SAMHSA-ACL CONVENING REFLECTIONS

- Lack of Access to Mental Health Services for people with ID

  - Shortage of DSPs

  - Shortage of MH or BH Practitioners

  - Shortage of Psychiatrists

  - Insufficient Supports and Services

SAMHSA-ACL CONVENING REFLECTIONS

- Siloed Mental Health and DD Systems

  - Departmental Funding Streams

  - Eligibility Restrictions

  - Very Few Funded Programs Focused on Coordination

 - Lack of Protocols

SAMHSA-ACL CONVENING REFLECTIONS

Future Directions

- Initiatives to Address the Shortage of Direct Support and Mental Health Professionals

- Initiatives to Address the Lack of Coordination between the State and Federal Mental Health and Developmental Disability Service Systems

- Promising Next Steps

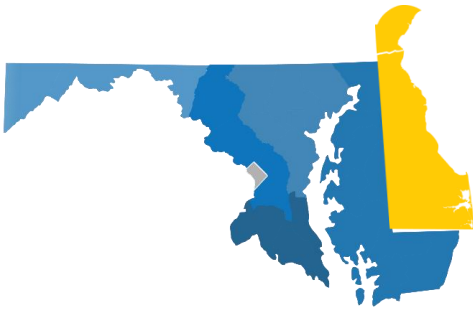# CONVENING: NASDDDS, NADD, NASMHPD COLLABORATION REFLECTIONS

- Came out of SAMHSA Meeting

- Hosted a Five-State Invitational Roundtable Series

- Three 90-minute Webinars
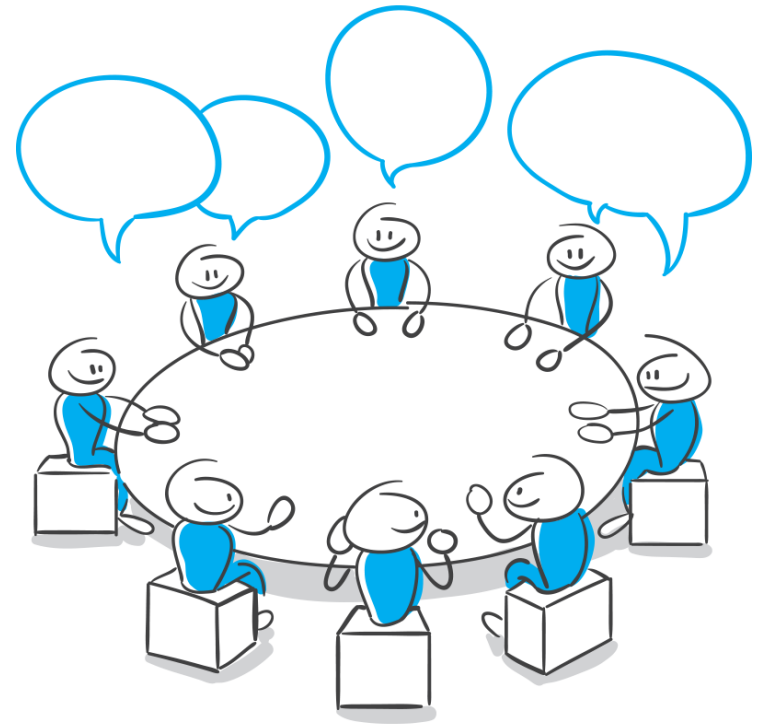
Convening: NASDDDDS, NADD, NASMHPD Collaboration reflections

o The states participating in the roundtable each have their own unique state agency infrastructure, financing mechanisms, and service delivery systems.

o Emphasis on strategies helping states overcome organizational impediments, transcend the challenges and provide strong practices for emulation in any state financing and structural ecosystem.

CONVENING: NASDDDDS, NADD, NASMHPD COLLABORATION REFLECTIONS

Delaware

Maryland

Michigan

New Mexico

Ohio

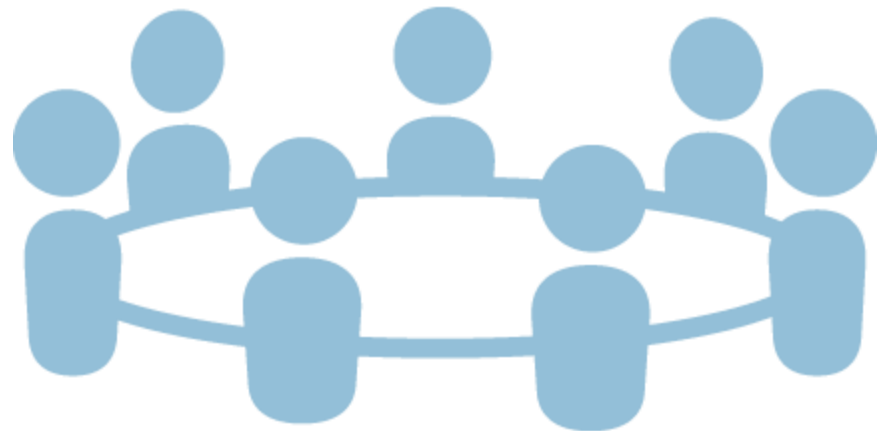# CONVENING: NASDDDS, NADD, NASMHPD COLLABORATION REFLECTIONS

Three Primary Areas of Focus

- State organizational structure, financing, payment approaches, and policies: *Opportunities to Transcend Structural Stovepipes and/or Misaligned Incentives*

- Access to skilled clinical capacity and specialized support/training for direct support workforce: *Clinical Capacity Building and DSP Workforce Development Efforts*

- Identification and design of effective service modalities: *Service Design Innovation Opportunities within State Medicaid Programs*

CONVENING: NASDDDDS, NADD, NASMHPD COLLABORATION REFLECTIONS

Roundtable I:

State organizational structure, financing, payment approaches and policies: *Opportunities to Transcend Structural Stovepipes and/or Misaligned Incentives*

CONVENING: NASDDDDS, NADD, NASMHPD COLLABORATION REFLECTIONS

Specific Questions for Roundtable 1

- How are your state agencies that are supporting individuals with I/DD and individuals with mental health structured within your state? Same agency? Separate agency, same department? Separate department? Others?

- In consideration of your specific state structure, what strategies have you employed to overcome potential system silos? Which strategies have proven most effective?

- Have you established joint regulations, operating policies, or memoranda of understanding that govern your collective work together?

CONVENING: NASDDDS, NADD, NASMHPD COLLABORATION REFLECTIONS

Roundtable 1 Themes

- Leadership and Commitment to Collaboration

- Consistent Communication and Mutual Education

- Tenacity and Creative Solution Identification

CONVENING: NASDDDDS, NADD, NASMHPD COLLABORATION REFLECTIONS

Roundtable II:

Access to Skilled Clinical Capacity and Specialized Support/training for Direct Support Workforce

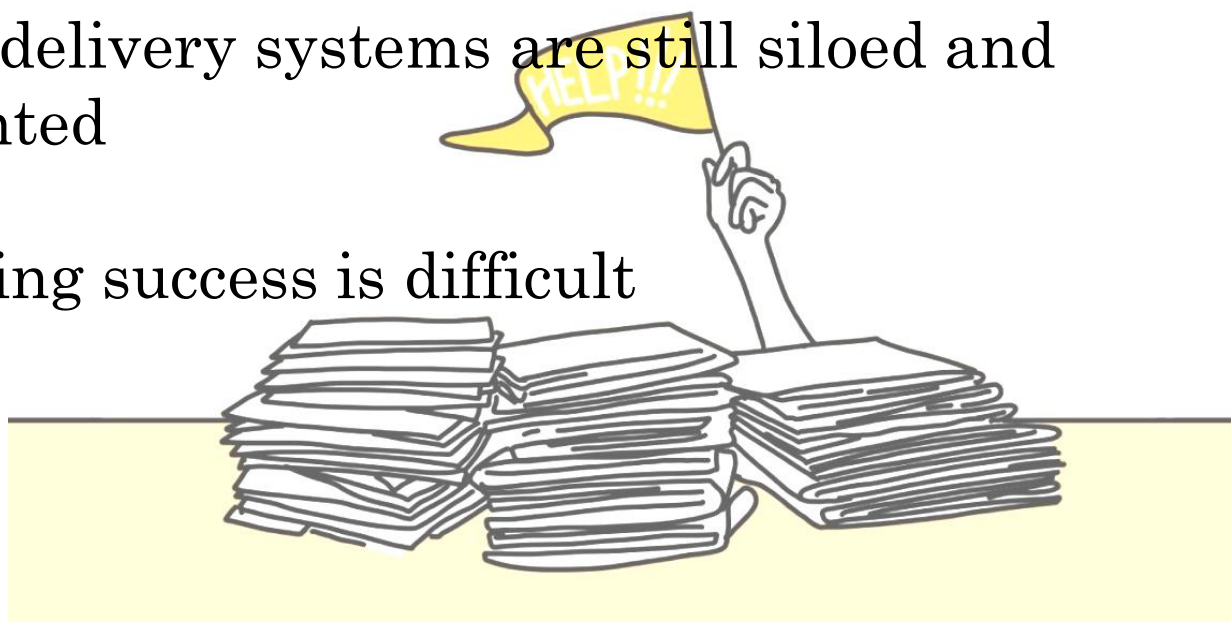# CONVENING: NASDDDDS, NADD, NASMHPD COLLABORATION REFLECTIONS

Specific Questions for Roundtable 2

- How would you describe the clinical capacity within your state to meet the needs of individuals with I/DD and mental health support needs?

- What strategies have you used to bolster the availability of clinicians? Which strategies have proven most effective? How are you measuring success?

- Have you established joint regulations, operating policies or memoranda of understanding or other efforts to work across the mental health and I/DD agencies?

- Have you undertaken any efforts to improve the skillset or knowledge base of direct support professionals in the field? If so, please describe.

- Have these proven effective? How are you measuring success?

Roundtable 2 Themes

- There are significant limits in clinical capacity

- Mental health services are scarce

- Service delivery systems are still siloed and fragmented
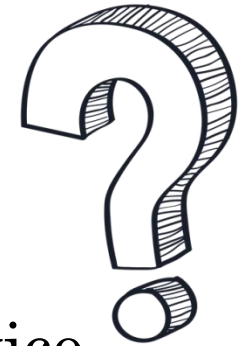
- Measuring success is difficult

CONVENING: NASDDDS, NADD, NASMHPD COLLABORATION REFLECTIONS

Roundtable 3:

Identification and design of effective service modalities: *Service Design Innovation Opportunities within State Medicaid Programs*
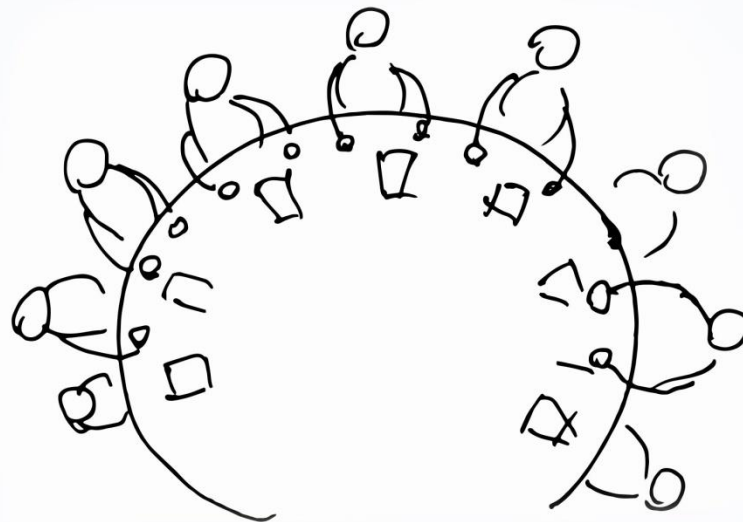
CONVENING: NASDDDDS, NADD, NASMHPD COLLABORATION REFLECTIONS

Specific Questions for Roundtable 3

- Has your state identified specific effective service modalities to support individuals with co-occurring I/DD and MH support needs? Please include both clinical services and/or community-based support.

- What are your next frontiers for service delivery improvements?

- What service capacity areas are your most pressing priorities and what tools/support would be helpful to you in these pursuits?

CONVENING: NASDDDDS, NADD, NASMHPD COLLABORATION REFLECTIONS

Roundtable 3 Themes/Summary

- All states agreed it would be helpful to create a resource library of best practices, research, and articles (NADD Center for Inter-System Collaboration)

- There was agreement that it would be helpful to have ways to learn about new resources, trainings and programs existing in other places that might be implemented in their state

CONVENING: NASDDDDS, NADD, NASMHPD COLLABORATION REFLECTIONS

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Roundtable 3 Themes

- There is an existing gap in training for those general practitioners who see individuals with I/DD among those with typical intellectual abilities

- The need to learn about successes states have had in collaboratively working with MCOs to meet the needs of individuals was identified

- States are interested in learning more about creative use of Medicaid and how to connect with Managed Care Organizations (MCOs)

SUMMARY: General Themes & Tying it all Together

- Reflective systemic analysis to identify areas of needs and strengths upon which to build collaboration and problem solving across and within program agencies

- Identification of multi-level system interventions to enhance overall capacity

- Commitment to person-centered practices to provide support and treatment to individuals in a manner that meets their specific needs

- Collaboration and Coordination within Departments & Across Silos Essential

- Opportunities to Utilize Technology

- Developing New Models/Approaches

- Explore Opportunities within Medicaid

- Leadership & Commitment

- Learning from Others

- Enhance Training

- Incentivize Providers

- Need is Growing

- Awareness also Growing

- Keep the Conversation Alive!

Ohio

Supporting Individuals with Mental Illness and Intellectual & Developmental Disability

Tina Evans
Cross-System Initiative Manager
Ohio Department of Developmental Disabilities

State & Local Structure

- Ohio Department of Developmental Disabilities (DODD) and Ohio Department of Mental Health & Addiction Services (MHAS) are stand alone cabinet departments

- DODD oversees 88 County Boards of Developmental Disabilities & has approximately 400 intermediate care facilities & over 8,000 waiver providers

- MHAS oversees 51 Alcohol, Drug Addiction, and Mental Health Boards & approximately 600 provider agencies providing prevention & treatment services for MH, drug & other addition services

Partnership

▶ Several partnerships between Ohio Department of Developmental Disabilities and Ohio Mental Health & Addiction Services

▶ Projects and initiatives for youth and adults

  ❖ Trauma Informed Care

  ❖ Extension for Community Healthcare Outcomes (ECHO) for Multi-System Youth

  ❖ Strong Families, Safe Communities

  ❖ Coordinating Center of Excellence (CCOE) for MI/ID

Coordinating Center Of Excellence for Mental Illness & Intellectual Disability

- Partnership between DODD, MHAS, Wright State University & Access Ohio Mental Health Center of Excellence

    - ❖ Second opinion psychiatric assessments
    - ❖ Telepsychiatry for youth & adults with MI/ID
    - ❖ Assist local partners to form cross agency MI/ID teams
    - ❖ Psychiatric Residency Training Program to build capacity of providers

Training & Education

- Ohio NADD Conference
- MI/ID CCOE website
- Trauma Informed Care (in-person, webinars, e-books)
- Multi-System Youth (in-person & online modules)
- MI/ID best practices (in-person, webinars & conferences)

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