Intellectual and Developmental Disabilities Interest Group

National Trends in Mental Health
Introductions

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Agenda for Today’s Meeting

1. Introductions
2. Purpose of the Group
3. IDD Mental Health
4. In-Person Meeting at NatCon20
5. Interest Group Meeting Schedule
National Trends Regarding People Who Are Dually Diagnosed with IDD and Mental Illness

Presented to the NCBH - Intellectual Developmental Disabilities Interest Group Forum

Jeanne M. Farr, MA
CEO
Overview
Background

NCI Data
Special Thanks to HSRI (Val Bradley) and NASDDDS

Recent Convenings
Themes and Trends
Tying it All Together
BACKGROUND

- IDD/MI prevalence is between 30 and 40%
- 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
- Growing national consensus that people with disabilities are not one-dimensional
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 developmental disability or cognitive limitations
  - Not symptoms of an underlying psychiatric condition.

- Response to symptoms
  - restraints, medication and punishment

Val Bradley HSRI
BACKGROUND

• 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
BACKGROUND: 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
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

Val Bradley, HSRI
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.

Val Bradley HSRI
NCI - 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)

Val Bradley HSRI
NCI - 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)
NCI - 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)

Val Bradley HSRI
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
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
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
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
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
CONVENING: NASDDDDDS, 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

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

- 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: NASDDDDS, 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

Roundtable 1 Themes

- Leadership and Commitment to Collaboration
- Consistent Communication and Mutual Education
- Tenacity and Creative Solution Identification
Roundtable II:

Access to Skilled Clinical Capacity and Specialized Support/training for Direct Support Workforce
CONVENCING: NASDDDDS, NADD, NASMHPD
COLLABORATION REFLECTIONS

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: NASDDDDS, NADD, NASMHPD
COLLABORATION REFLECTIONS

Roundtable 3:

Identification and design of effective service modalities: *Service Design Innovation Opportunities within State Medicaid Programs*
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
Roundtable 3 Themes, continued

- 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: Tying it all Together

- IDD/MI Prevalence is significant and there is an increasingly urgent need to enhance services to address the needs of this group

- NCI Data Shows: People with a dual diagnosis less likely to work in the community, more isolated, more likely to have medication to address symptoms

- Reflective systemic analysis to identify 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, Explore Opportunities within Medicaid and Develop New Models/Approaches and Incentivize Providers

- Awareness & Need is Growing: Must Keep Conversation Alive!

- Leadership & Commitment Essential

- Learning from Others

- Enhanced Training Essential
Group Discussion

- What are you seeing in your state related to the intersection of mental health?
- What are best practices you have found for supporting this population?
- What successes have you had?
In-Person Meeting at NatCon20

There will be multiple touchpoints throughout the year to discuss and explore topics within this group.

Of note is a special networking and learning session at NatCon20 in Austin, Texas, to be held April 5-7.

This is your chance to connect with colleagues, build your network and lead the conversation around this interest area.

What would you like to experience during this on-site event? How can we make this meeting impactful for you?

Learn more by visiting www.natcon20.org
To keep the conversation going, we will conduct bi-monthly chats.

At left is a tentative schedule outlining our conversations around this area of interest.

- Is this level of engagement helpful?
- Have any agenda ideas?

Within this group, we will explore behavioral health care and move the field forward.

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<th>Meeting Month</th>
<th>Group Activity</th>
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<tr>
<td>March 2020</td>
<td>IDD Awareness Month</td>
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<tr>
<td>April 6th, 2020</td>
<td>Meet and Greet at NatCon2020</td>
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<td>May 2020</td>
<td>Webinar</td>
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<td>June 2020</td>
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<td>October 2020</td>
<td>Webinar</td>
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<td>December 2020</td>
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