Persons with Intellectual and Developmental Disabilities in the Mental Health System: Treatment and Targeted Services

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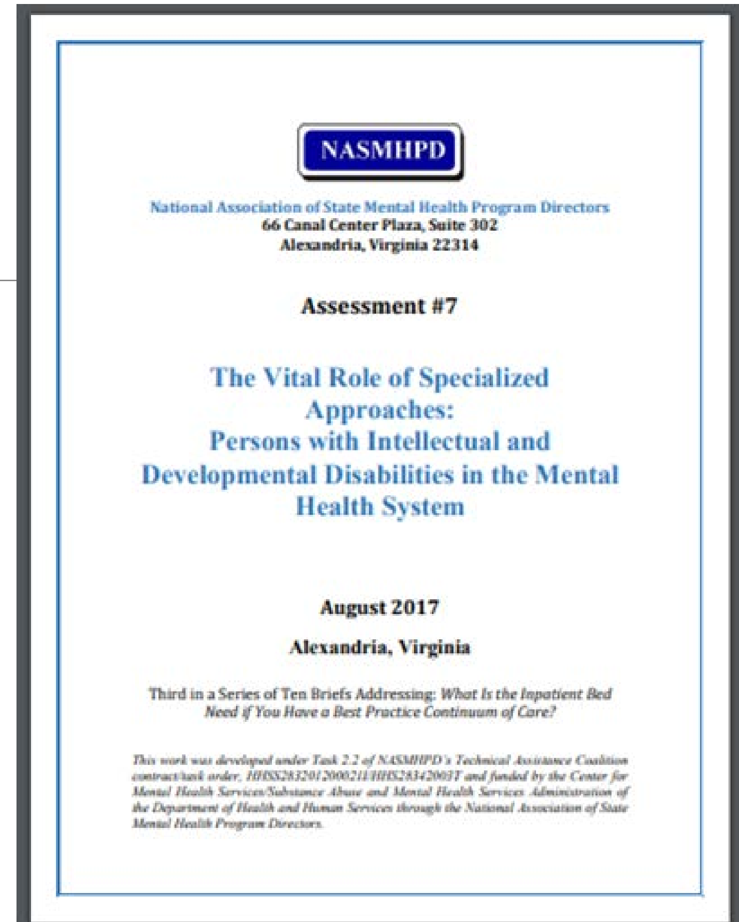

NASMHPD

National Association of State Mental Health Program Directors
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Assessment #7

The Vital Role of Specialized Approaches: Persons with Intellectual and Developmental Disabilities in the Mental Health System

August 2017

Alexandria, Virginia

Third in a Series of Ten Briefs Addressing: *What Is the Inpatient Bed Need if You Have a Best Practice Continuum of Care?*

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https://www.nasmhpd.org/sites/default/files/TAC.Paper_.7.IDD_.Final_.pdf

GOOGLE: "Vital Role and IDD and State Mental Health"

Persons with IDD and MH

High rates of comorbidity

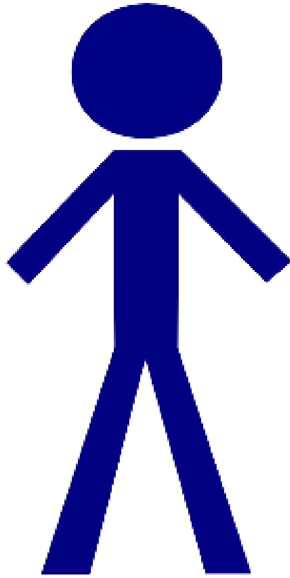
- Prevalence rates for mental illness among persons with IDD are about 2-3x higher than general population
- 30-70% of persons with IDD have co-occurring MI (NADD)
- ASD study found by age 16 prevalence of comorbidity is 49% (Rosenberg et al 2011)

Behaviors masked as or interpreted as mental illness become treated as mental illness across systems

Critical importance for:

- Increased understanding of the population and individual needs
- Increased resources to treat individuals across and within systems

Requirements for Training on IDD in General Psychiatry (and Other Disciplines)



Case Example 1: John

- Non-verbal young man in his 20's, low intellectual functioning
- Father as guardian, no longer able to care for him
- Was served by the public developmental disabilities agency
- In and out of adult foster care/group living placements related to aggression
- Residential providers come to a point where they feel they cannot support him after he was continually kicking walls, furniture, and staff
- John is brought by staff to the ED

Case 1 Continued

- In ED increased behavioral dysregulation
  - Bed wait
  - Difficulty identify placement
- No place to discharge him
- Decision to admit to inpatient psychiatric unit
- In ED, increasing doses of antipsychotics given

Case 1 Continued

- On unit John appears regressed (playing with excrement at one time, touching staff despite prompts)
- Periodically has aggressive “attacks” and reason is unclear to staff
- Property damage significant
- Placement waiting time is months. Many denials due to concerns about how to serve him. Options for placement include known DD homes.

Case Example 2-1

- 28 year old with ASD, minimal verbal skills, borderline IQ
- Diagnosed also with schizophrenia, seizure disorder
- Had a placement at home, specially outfitted after the ICF she had been in was closing
- Had in home positive behavioral tx plan
- Did well for about one year
- Had a period of regressed behavior
  - Banging head
  - Non-responsive to re-direction
  - ABA hired to help her and to develop treatment plans.

Case Example 2-2

- Staff support in her independent home quit
- Head banging continues and worsens, home support no longer viable
- Patient brought to ED, placement delayed
- Behavioral dysregulation becomes increasingly difficult to manage
- Held intermittently in ED with restraints for 3 weeks
- Placement in psychiatric hospital sought and repeatedly denied

Case Example 2-3

- Community agency “responsible” “gives up”
- Eventually arrives at state hospital where she has no desire to leave
- Head banging, tray throwing
- Far from home
- Discharge planning function carefully constructed
- Possible seizure, challenges in seeing neurology
- Hospital staff identify positive behavioral support plan
- Discharge planning function carefully constructed
- Slow transition back to community

Solutions, Opportunities

Complex system interface

Complex treatment framework

Complex ethical framework

Ensuring the properly trained workforce

Systems Issues – Weaknesses, Threats

Not enough staff

Not enough training and supervision

Not enough leadership

Improper placement - group of individuals

Over reliance on medication

Opposition to meds

Family participation

Fish tank analogy

Historical Chasm between Departments of Mental Health and Departments of Developmental Disability

-patients with “Dual Diagnosis” are at risk for “falling through the cracks” with each state agency trying to not have responsibility for the patient because of the other diagnoses

NADD

Mission Statement

To provide leadership in the expansion of knowledge, training, policy and advocacy for mental health practices that promote a quality life for individuals with dual diagnosis (IDD/MI) in their communities.

NADD

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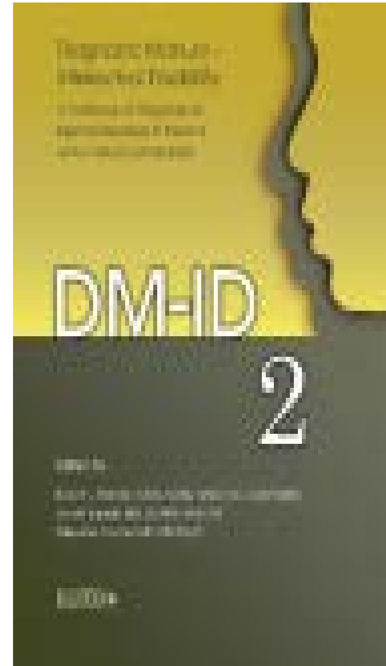


Diagnostic Manual–Intellectual Disability 2: A Textbook of Diagnostic of Mental Disorders in Persons with Intellectual Disability

Financing Barriers and Opportunities for People with Co-occurring IDD and BH Conditions

BARRIERS	OPPORTUNITIES
Siloed policy, regulatory, program and financing structures	Migration from targeted populations in limited waivers to Population Health basis for service delivery and payment reforms
Fragmentation of authority, accountability and resources	ACO, BH and LTSS provider partnerships in emerging service delivery structures
Exclusionary eligibility and coverage criteria overlooking prevalence of co-occurring conditions	Reexamination of need to regulate markets in specialty care
Limited rates, structural integration, review protocols and reimbursement guidance	

Why do people with co-occurring BH and IDD conditions struggle to access integrated care to meet their complex needs?

INDIVIDUALS IN NEED

Departments of Mental/Behavioral Health and Medicaid Managed Care Organizations

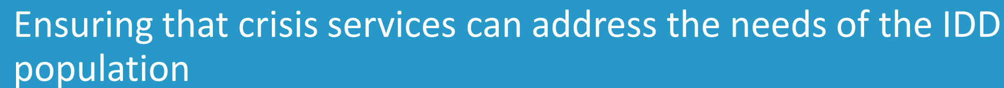
Departments of Developmental Disabilities and Global and Targeted Medicaid Waiver Programs

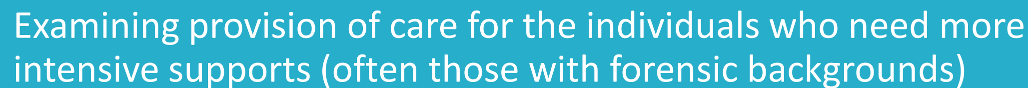
Narrowed eligibility criteria and medical necessity standards limit access to and coverage for behavioral health care.

Broader entitlement to developmental services but access is limited to waiver services for special needs subpopulations.

Slide Credit: Danna Mauch, Ph.D.

What the need is now….





Coordinating integrated care between behavioral health and physical health

Highlights

People with intellectual and developmental disabilities (IDD) often have co-occurring mental health conditions.

Getting treatment for co-occurring IDD and mental health conditions typically requires accessing bifurcated care across two siloed care systems.

Even though the lack of integrated care options for individuals with IDD and mental health conditions and the need for a skilled workforce have long been recognized, system structural problems and professional training gaps persist.

Individuals with intellectual and developmental disabilities (IDD) who have co-occurring mental health conditions must often seek treatment for these conditions by crossing over to the mental health system from the developmental disabilities system, where they are typically served.

Mental health and developmental disabilities systems have distinct legal, regulatory, policy, and practice protocols, which places the burden of care integration on the individual rather than on the systems.

Systems and policy changes can further integrate care for persons with IDD who have mental health conditions, and further efforts are needed to create a robust continuum of care for this population.

Recommendations

1. Specialization vs. generalization on inpatient psychiatric units and in other services with consideration for consultation

2. Create organizational structures and infrastructure to work across agencies (e.g., data sharing, leadership coordination, workforce development)

3. Provide opportunities for accurate assessments of biopsychosocial co-occurring conditions

4. Prioritize self-directed, trauma-informed and person-centered care

5. Enhance quality delivery of behavioral, environmental and pharmacological supports

6. Devise a targeted health management framework with sufficient financial and performance incentives with coordination across DD/MH/Medicaid

7. Systemic data collection and skill building

8. Attend to forensic and criminal-legal/juvenile justice diversion and intervention within these settings

9. Workforce development in the community must include attention to personal support, behavioral supports, techniques such as ABA, an understanding of biopsychosocial issues, and the requisite training, as well as salaries that support the challenging work

Questions?
Comments?