Behavioral Health is Essential To Health

Prevention Works

Treatment is Effective

People Recover
Serving Youth with Co-Occurring Developmental and Behavioral Disorders

Diane Jacobstein, PhD, Georgetown University Center for Child and Human Development
Elizabeth Manley, LSW, Division of Children’s System of Care Services New Jersey Department of Children and Families
Lynda Gargan, PhD, National Federation of Families for Children’s Mental Health
Children with Co-Occurring Developmental and Behavioral Disorders

- How needs differ from “typical” population of children with serious behavioral health conditions
- Importance of addressing this population
- What states are doing
- Resources
- Example from New Jersey
- Q & A
How Needs Differ:
Issues that Affect Planning at the Systems Level
Co-Occurring Disorders Are Common

• 30-50% of children and adolescents with intellectual disability (ID) have co-occurring behavioral health (BH) disorders or challenging behavior (studies vary widely)

• 40-70% with autism spectrum disorders have co-occurring psychiatric disorders (anxiety, depression and others)

• High risk for BH disorders with other developmental disabilities (e.g., epilepsy, cerebral palsy)

• Prevalence much higher with some genetic syndromes
BH Issues Commonly Overlooked or Misunderstood, So Not Addressed

- Symptoms may present very differently
  - Reduced verbal skills
  - Behavior as communication
  - Non-specific symptoms
  - Exacerbation of old behavior

- Heterogeneity
- “Diagnostic overshadowing”
- Inadequate screening
- Limited training of professionals
“Cascade of Disparities”

In health and health care access

(Krahn, Hammond and Turner, 2006)

Families bear the brunt of pervasive systems issues
Significant Medical Disparities

- Known medical issues associations with genetic disorders
- Overuse of medications
- Often sedentary lifestyle
- Higher rates of obesity, mobility problems, diabetes, early cardiovascular disease in young adults
- Limited health care access

Common triggers for crisis admissions:
- Pain or discomfort (gastro-intestinal, dental)
- Adverse effects of medication
Significantly Higher Risk of Trauma

- Emotional neglect, serious injury  (Sedlak, et al, 2010)
- Trauma related to seclusion and restraint  (Sullivan, 2006)
- Abuse  (Child Welfare Information Gateway, 2012)
- Sexual victimization with ID or BH – 4.6 X risk  (Lund and Vaughn-Jensen, 2012)
- Serious harm
- Medical procedures
“Hidden” in Other Systems

- Juvenile Justice
- Child Welfare
- Mental Health
Common Myths

- No alcohol and drug involvement
- No suicide
- Psychotherapy ineffective
- Not like other children, hard to serve
- Not safe in the community
- Poor quality of life
Common System Barriers Across the Nation

- Fragmented service delivery
- Different language and regulations in each system
- Multiple plans and care coordinators
- Gaps in services
- Layered on social disparities
- Inflexible financing
- Focus on “Who will pay?” rather than needs
Gaps in Access and Eligibility

- Restrictive eligibility criteria
  - “wrong” diagnosis
  - IQ “too high” or “too low”
  - “wrong” age
- Poor continuity of care at transitions
- Long waiting lists for Medicaid waivers
- Hard to get comprehensive evaluations
- Private insurance often inadequate – restricted provider panels, limited treatment
Stress on Parents is Often Extreme

Parents often feel:

• Blamed for the behavior
• Isolated
• Totally consumed by care of the child, searching for services
• Sometimes faced with terrible choices, such as custody relinquishment, food versus therapy
• Financial burden
Importance of Addressing the Needs: “A Public Health Crisis”
Our Most Vulnerable

• High risk for institutional placement, child welfare, juvenile justice, homelessness

• Get stuck in emergency rooms or jails – “high-flyers”

• Reliance on reactive approach and institutions

• Culture of institutionalization rather than home-and community-based services in many places
System of Care Approach Can Make a Difference

Potential to reduce costs and vulnerability to legal action

System of care framework can make a huge difference
What States are Doing:

Three Necessary Features of Successful Programs
1. Specialized Expertise

• Disability-specific expertise required at the clinical and programmatic levels

• Comprehensive interdisciplinary evaluations (medical, genetics, dental, psychology, speech-language, occupational therapy)

• Multidisciplinary consultation team

• Intensive crisis support and prevention planning

• Care coordination – specialized training and low case load
2. Workforce Training

Most effective with ongoing support, consultation

- State office
- Multidisciplinary evaluation and consultation teams
- Wraparound/care coordinators across agencies
- Therapists
- Parents
- Schools
- Managed care
3. Expanded Service Array

- Psychotherapy (sometimes adapted)
- Evidence-based treatments for autism spectrum disorder (not only Applied Behavior Analysis)
- Intensified supports for parents and siblings
- Respite care (with specially trained staff)
- Functional communication supports (Augmentative and Alternative Communication – AAC) – speech and language therapy
- Occupational therapy – sensory strategies
- Dental
Two Main Organizational Approaches

1. System of care extended to include this population
   - Implemented in several states, New Jersey example

2. Tertiary system development, system linkages
   - Center for START Services (Systemic, Therapeutic, Assessment, Resources & Treatment), University of New Hampshire
National START Network: Tertiary System Development and Linkages Approach
START Model

- Mission is tertiary system development
- Goal is to train and support local leaders who work to provide safety net and enhance capacity in their communities
- The program is part of a national “network”
- Evidence-informed – Data collection through the START Information Reporting System (SIRS)
- Extensive National Learning Community

www.centerforSTARTservices.org
Resources
LEARNING COMMUNITY SUPPORTS INTERAGENCY PLANNING FOR
Youth with Co-occurring Intellectual/Developmental Disabilities and Mental Health Disorders

Public systems are confronted with obstacles when providing for children with intellectual/developmental disabilities (IDD) who also have mental health or behavioral disorders. Many among this very diverse group of children and youth encounter restricted access to essential supports. Their behavioral difficulties and distress are often misunderstood and sometimes ignored. Since our national and states’ public and private systems and facilities are designed to serve children with disabilities, they are ill-prepared to serve children with co-occurring disabilities.

Effective Strategies Checklist

Children and youth who have intellectual disabilities or developmental disorders are at elevated risk for co-occurring psychiatric or behavioral problems. These young people pose a serious challenge for administrators, program directors, and clinicians, especially when they present with aggressive or disruptive behaviors. When appropriate community services have not been organized, these youth can be among the most difficult and costly to serve. Across the country, their families report

Critical Information for Administrators and Clinicians

- This is an extremely heterogeneous group of individuals with differing strengths and needs. There is no one-size-fits-all approach, but effective interventions have been developed.

- The prevalence of psychiatric disorders is much higher than generally recognized among children and youth with intellectual disability (ID), estimated to be between 30%-50% (Einfeld, et al, 2011). The diagnoses may reflect “classical” psychiatric disorders as well as behavioral responses to stress in individuals who lack functional communication. That said, people with developmental disorders are subject to the full range of psychiatric disorders. Co-occurring conditions (for example, anxiety and attention deficit/hyperactivity disorder) are very common in children with autism spectrum disorders (Simonoff, et. al, 2008, Leyfer, et. al., 2006) and also among children with other developmental disorders such as cerebral palsy and epilepsy.

http://gucchdtacenter.georgetown.edu/publications/Effective%20Strategies%20Checklist%20FINAL.pdf
Readiness and Implementation Checklist: Serving Children, Youth, and Young Adults with Co-Occurring Intellectual/Developmental and Behavioral Health Disorders and their Families

Created by Linda Henderson-Smith, PhD, and Diane Jacobstein, PhD, August 2016

This tool was created to support the initiation and implementation of services and supports for children, youth, and young adults with co-occurring intellectual/developmental and behavioral health disorders and their families. It is designed to assist states, counties, tribes, and territories to assess their readiness for implementing the system changes and changes in services needed to more effectively meet the needs of this population with complex needs. It is grounded in the framework of the system of care approach, which provides a comprehensive array of home- and community-based services that are individualized, family-driven and youth-guided, coordinated, and culturally and linguistically competent.¹

<table>
<thead>
<tr>
<th>Cross-Agency Change Team</th>
<th>Not in Place</th>
<th>Needs Work</th>
<th>Functioning Well</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. A cross-agency change team is in place to address system-level and service delivery-level changes needed to provide effective services for children and youth with co-occurring intellectual/developmental and behavioral health disorders.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. The cross-agency team is either part of or linked to existing teams responsible for developing, expanding, and sustaining systems of care, if applicable.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. The cross-agency change team includes representation from youth,</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
https://theinstitute.adobeconnect.com/p7n4ctrqnmp/

Understanding Children and Youth with Co-occurring Developmental & Behavioral Disorders, Part I: Defining Needs (Georgetown, Jacobstein, April, 2016)
http://georgetownuniversity.adobeconnect.com/p4hcdqz1upt/?OWASP_CSRF_TOKEN=8179368ba2ec68ca31b28d55b3a7ab0265fb53387f0f3441d43a5f4f70c6f056

Understanding Children and Youth with Co-occurring Developmental & Behavioral Disorders, Part II: Best Practices and Workforce Strategies (Georgetown, D. Jacobstein, L. Manley, K. Weigle, June 2016)
Developmental Disability Programs in Each State

University Centers on Excellence in Developmental Disabilities Programs (UCEDD) Listing by State
https://www.aucd.org/directory/directory.cfm?program=UCEDD

LEND Programs by State (Leadership Education in Neurodevelopmental Disabilities)
https://www.aucd.org/template/page.cfm?id=6

Protection and Advocacy Centers by State - National Disability Rights Network
http://www.ndrn.org/index.php

Trauma-Informed Care: Perspectives and Resources – See sections on *Intellectual/Developmental Disabilities and Trauma* and *Safety without Seclusion and Restraint* (video and written resources in web-based tool), Georgetown National TA Center for Children’s Mental Health and JBS International, 2015.
http://gucchdtacenter.georgetown.edu/TraumaInformedCare/Module2.html
Important National Resources

NADD- National association that promotes understanding of and services for individuals who have developmental disabilities and mental health needs.

www.thenadd.org

The Center for START Services, University of New Hampshire http://www.centerforstartservices.org/


jacobstd@georgetown.edu
202 687-5372
New Jersey System of Care
New Jersey Department of Children and Families

Children’s System of Care (formerly DCBHS)

Division of Protection & Permanency (formerly DYFS)

Division of Family & Community Partnerships (formerly DPCP)

Division on Women

Office of Adolescent Services

New Jersey Department of Children and Families
Commissioner
Children’s System of Care Objectives

To help youth succeed...

At Home
Successfully living with their families and reducing the need for out-of-home treatment settings

In School
Successfully attending the least restrictive and most appropriate school setting close to home

In the Community
Successfully participating in the community and becoming independent, productive and law-abiding citizens
New Jersey’s Core Components

• Single Point of Access for All Youth and Families – PerformCare
• Single Assessment – CANS (Child and Adolescent Needs and Strengths)
• Emphasis on Crisis De-Escalation – Mobile Response and Stabilization Services
• Consistent Practice Model – Wraparound within the Context of Child Family Team – Care Management
• Consistent Training and Support for Workforce
• Community Voice – Children’s Interagency Coordinating Councils
• Youth and Family Voice and Choice – Family Support Organizations
New Jersey Children’s System of Care

The New Jersey Children’s System of Care serves:

- Behavioral Health: Youth with moderate and complex needs, entire New Jersey population
- Behavioral Health Home
- Child Welfare: Youth with child welfare involvement and a treatment need
- Developmental Disabilities: Youth eligible for services based on regulatory definition of functional impairment
- Substance Use: Youth who are underinsured and have a treatment need
Communication

- Make the most of technology: website, family portal and notifications within the electronic record
- Close communication
- Acknowledge when there is no answer
- Know who is responsible for the messaging
- Be consistent
- The squeaking wheel problem: Let complaints inform, but let data drive practice changes
Leadership Strategies

How to handle uncertainty, ambiguity and rapid change?

• Understand and communicate the vision of where we are going. Recall the vision when things get mucky.
• Find your champions and engage new partners.
• Be transparent to families, providers, staff, and state giving current status and acknowledging challenges.
• Share and report progress regularly.
• Develop partnerships with family and advocacy and provider groups and organizations.
• Be flexible and acknowledge what we don’t know yet.
Important Considerations

- Parent and Youth Culture
- Provider Culture
- Advocates Culture
- Data Use and Challenges in Integration
- The Challenge of Quality within Transition
- Privacy
Behavioral Health is Essential To Health

Prevention Works

Treatment is Effective

People Recover