NASMHPD

National Association of State Mental Health Program Directors
66 Canal Center Plaza, Suite 302
Alexandria, Virginia 22314

Assessment #8

Serving Youth with Co-Occurring Developmental and Behavioral Disorders

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Authored by Linda Henderson-Smith, PhD, LPC and Diane Jacobstein, PhD, Georgetown National Technical Assistance Center for Children's Mental Health, September 2015

Public systems are challenged by obstacles when providing for children with co-occurring developmental and emotional and behavioral disorders. Among this very diverse group of children and youth, many encounter restricted access to essential supports. Their behavioral difficulties and distress are often misunderstood and sometimes ignored. Since our public and private systems and categorical funding are not structured to address their needs, these young people are at high risk of expensive and preventable out-of-home placements in foster care, juvenile detention, psychiatric institutions and developmental disabilities centers, as well as homelessness or incarceration as adults. Many individuals face a series of disrupted placements and long-term confinement. Children and youth with developmental disabilities experience serious trauma at rates far higher than their peers, including bullying, teasing, and physical, emotional and sexual abuse, that often do not receive needed attention. As a group, they may suffer from significant medical problems as well. Stress for parents can be severe and unrelenting, especially when their children are excluded from public programs or offered services that do not match their needs. In some states families find they are unable to obtain intensive services that their children need unless they relinquish custody to state authorities.

Prevalence

Approximately 13% of children under 18 in the US have a developmental disorder (CDC, 2012). Reliable population-based estimates are not yet available to clarify the proportion who also have mental health disorders. Studies have documented that 30-50% of children and adolescents with Intellectual Disability (ID) have co-occurring mental health disorders or challenging behavior. Very high rates of co-occurring emotional disorders are also found among children with developmental disorders such as Autism Spectrum Disorders (41-70%), Cerebral Palsy, and Epilepsy, including those who have normal intellectual levels. Since there are many children with developmental disorders and with emotional disorders in child welfare and juvenile justice settings, it is probable that there are many with co-occurring disorders, as well. The limited data available on prevalence of developmental disorders among children in mental health clinics and hospitals suggests that there are many more than generally recognized.

Rationale for Learning Community

In July 2014, 33 Children's Mental Health Directors convened for a bi-annual meeting and were polled on their three top concerns or issues. The population of children with co-occurring developmental and behavioral disorders was one of the top three. The Children's Directors recognized the need to develop systems to provide services and supports for this population (funding, services, etc.), as well as the need to develop infrastructure for cross-agency planning, since barriers and service gaps affect all agencies.

Methodology

Learning Community Application Process

An email invitation to apply to be a part of the Learning Community was sent to the identified Children's Mental Health Director for each state and US territory. As part of the application, each children's director was required to identify a cross-agency team that would participate in the Learning Community. They also provided information about the status of their current planning for the identified population and their goals for participating in Learning Community. Required members of this team were representatives from state level Medicaid, Education, and Developmental Disability agencies. Others were encouraged to be a part of the team, including parents, youth, community stakeholders, and other state initiative representatives.

Learning Community Participants

Three states were chosen, all of which were in different stages of planning for the identified population.

State A - State A's team consisted of representatives from Behavioral Health, Child Welfare, Education, Developmental Disability and Financing agencies, the System of Care Expansion Grant, a large Community Mental Health Center, the Developmental Disabilities Council, the Federation of Families Statewide Chapter, and a University Partner. State A had no System of Care infrastructure established in the state for any population, however, they were poised to roll out a state-wide initiative. They realized that this population was frequently coming to the state level of planning, with little ability for the state to find appropriate services and supports, especially in rural areas. State A had one major goal with several objectives. The goal was "functional, short-term implementable approaches to help better serve children, youth and their families." The objectives were to:

- "Increase co-occurring treatment competencies within both the developmental disability (IDD) and mental health (MH) treatment systems and strengthen system partnerships for enabling youth to receive services with increased collaboration within both systems when clinically indicated."
- "Strengthen our system to more effectively meet the needs of children and youth in the child welfare system who have co-occurring IDD and MH treatment needs."
- Receive "technical assistance regarding the limited use (4-8 youth a year) of residential placement for children and youth with symptoms and behaviors that are so severe that our existing systems are not equipped to meet their needs."

State B - State B's team consisted of representatives from Behavioral Health, Developmental Disabilities, Education, System of Care Expansion Grant, Developmental Disabilities Council, Medicaid, Local Community Mental Health Center, Early Childhood and the Federation of Families Statewide Chapter. State B had a System of Care infrastructure at both the local and state levels; however, there was limited connection between the two levels. Some local communities had long-standing and well-developed SOC implementation and the state is working to expand services and supports state-wide over the next several years. State B indicated in their

application that they realized this population was currently excluded from their existing System of Care and had several goals for their request for technical assistance:

- "Identifying evidence-based treatment and therapeutic services is the uppermost concern for addressing this population."
- Determining "qualifications of all staff and the appropriate composition of a treatment team, as well as what should residential services look like and what meaningful activities should be provided when individuals are not in school."

State C - State C's team consisted of staff representing Behavioral Health, Child Welfare, Juvenile Justice, and Financing agencies, local stakeholders and a university partner and a University Center of Excellence in Developmental Disability (UCEDD). State C had a fully implemented System of Care infrastructure for children, which included the identified population, however, they indicated that they wanted information on how to cross-train and ensure appropriate services were being provided for this population. Their identified goals were to:

- Develop a training plan.
- Identify evidence-based treatment and therapeutic services.

Learning Community Process

The Learning Community was established with a clear process: three webinars, one provided each month, three one-hour coaching calls, an on-site technical assistance and planning visit for all three states and resource sharing throughout. To begin the process, each of the three teams was polled for topic areas that would be most helpful. Three topics were agreed upon by all: (1) an overview of the population, (2) best practices in services, supports and workforce development, and (3) financing. These themes were carried throughout the webinars, coaching calls and on-site visits.

Results

Webinars

Three webinars were created and provided to the Learning Community on the identified themes. *Webinar #1 - Defining Needs* provided an overview of the population, including prevalence, common challenges, public health implications, and impact of system barriers on families and children. *Webinar #2 - Best Practices and Workforce Strategies* specified

recommendations for comprehensive assessment, supports, service array, and outlined service delivery models, including the System of Care and START approaches. *Webinar #3 - Financing* provided information on cross-agency funding opportunities and provided resources, i.e. joint bulletins from the federal government. All three webinars contained additional resources that the state teams could share with others in their state to assist with their planning.

Coaching Calls

The coaching calls for each state were different; however, they yielded some shared results. For two of the states, resources and financing became very apparent as needs to be explored, so a resource matrix and financing matrix were developed for their use. The goals for the Learning Community and on-site technical assistance were modified by each of the state teams as they discussed their needs. States A and B elected to focus on a cross-agency implementation plan for policy, state and local infrastructure, and services and supports with a 12-month timeline on it. State C decided they wanted to obtain buy-in from local partners within their established System of Care and to develop a plan for the state could assist system partners in serving the identified population.

On-Site Visits - Common Themes

Although the three states originally designated workforce development as the target of their planning for the on-site technical assistance visit, some broader needs emerged during the coaching calls. A structured process was used during the site visits to help each team of 10-50 people develop a shared mission statement or vision. Then a detailed analysis of strengths, barriers and opportunities or recommendations was conducted, tailored a bit differently for each state. States A and B designed strategies to address their teams' mission, which was in both cases related to serving children with co-occurring disorders within a SOC framework. State C, having already included this population within their SOC, used the site visit to elicit detailed feedback from partners and other stakeholders and then planned an itemized response to the barriers, concerns and recommendations enumerated. Examples below illustrate strategies designed by the three states to address (1) Policy, (2) State and Local Infrastructure, and (3) Services and Supports, including workforce preparation. The chosen strategies were followed by detailed action steps.

Examples of Strategies Related to Policy
- Review all funding streams for MH and IDD services and align them as best as possible.
- Review Medicaid policy for potential barriers to serving those with co-occurring disorders.
- Cross-walk clinical eligibility requirements for all funding potentially available for this population.
- Review emergency commitment regulations for needed language change for this population.
- Consider how policy may allow for funding of services and supports for those in this population who are also undocumented.
- Explore possible policy change to include intensive home and community based behavioral health providers as providers in the developmental disability service system.

Examples of Strategies Related to State/Local Infrastructure
- Build on existing state and local System of Care infrastructure to include this population.
- Develop feedback and communication loops between state and local structures to provide gap/needs information and to educate the local levels as to changes being made at the state level.
- Develop a comprehensive needs assessment for this population.
- Develop a multi-disciplinary team of providers and state officials (pediatricians, psychologists, dentists, physical therapists, occupational therapists, educators, etc.) to develop strategies for serving this population and to discuss policy barriers to service.
- Support resource networks for all counties.

Examples of Strategies Related to Services/Supports, Including Workforce
- Complete a survey on what practices are currently used for this population.
- Develop or modify educational materials, including provider manuals, best practice guides, and family handbooks, for families, providers, and the community on resources for this population and how to access the system, as well as best practices.
- Develop cross-sector training that also serves as relationship building opportunities for those in the behavioral health and developmental disabilities systems as providers. This can include, but is not limited to learning communities, cross-sector training opportunities, webinars, etc.

- Develop a comprehensive training plan for providers, communities, parents and other stakeholders, including a cross-walk of all training opportunities across agencies. Build on training opportunities that already exist, to include online training platforms, training conferences, provider meetings, etc.
- Develop Continuing Education trainings for professionals to learn the needs and how to serve this population.
- Develop a communication and/or marketing plan to ensure that providers and families are aware of training and technical assistance opportunities.
- Expand use of telehealth consultation to increase access to specialists for rural providers and families.

Lessons Learned

1. When reflecting on successful planning for this population, the importance of broad cross-agency collaboration cannot be over-emphasized. In each of the three states, thoughtful representatives of many systems participated in all phases of the Learning Community process, gave up time for the two-day planning session and committed to ongoing collaboration on behalf of this population.

2. This is not about integrating two or even three systems. It is rather about creating a comprehensive System of Care with multiple agencies working together to serve children with complex needs. It was noteworthy that the teams were eager to embrace System of Care values and principles as the foundation for their efforts, as well as to use its well-articulated framework to structure collaboration on behalf of families.

3. Children with complex developmental and behavioral needs should not be considered a separate population. An important theme in each state was inclusion of this population within existing programs and structures, by addressing eligibility issues, providing additional expertise and workforce training and expanding the array of services and supports. There was a fundamental recognition that these are children with many of the same needs as any other children and that working with them is not hard once staff are trained and have appropriate supports.

4. The leadership of the Children's Directors was critical, not only because they convened the cross-system alliance, but because they had developed long-standing partnerships and cordial relationships with representatives of other agencies that proved crucial to the outcome. Support at the Commissioner level was significant and led to cross-agency discussions about this population at the highest levels.

5. It was recognized that it is also critical to have buy-in from leadership of all child-serving systems at state and local levels. State team members planned after the meetings to reach out to their own leadership and to local interagency teams, providers, and family organizations.

6. Significant cross-agency efforts were devoted to painstaking examination and alignment of policies and financing in order to eliminate barriers to improved outcomes for this population.

7. This was not necessarily about increased funding. All three states were hopeful they would be able to address many needs of these children through coordinated use of existing funds.

8. It proved worthwhile to undertake a systematic analysis of service gaps across systems. The states devised creative strategies to address these gaps. One state, for example, got permission from the Centers for Medicare and Medicaid Services to add a nurse and wellness coach to each Wraparound team to better support children with medical or developmental needs and worked out a plan to better support undocumented refugees who were eligible for some services and not others.

9. Each team requested technical assistance around best practices in comprehensive assessment for this population with the intent of augmenting expertise at the local and state levels.

10. Because programs are so complex in each state, it rapidly became clear that people were unaware of many resources provided by other agencies. It proved important for the agencies to discuss their programs to understand where funds and resources reside in each state.

11. Planning for cross-system workforce development addressed multiple levels, in recognition of the need for training for state policy makers, administrators at the local level, providers and families. Creative strategies were proposed, such as working through interagency teams already in place, infusing sessions into numerous annual conferences already in planning, and developing regional or state-wide Learning Communities.

12. The three states discussed a desire to increase their attention to issues of trauma in among children and youth with co-occurring IDD and MH needs.

13. The states developed strategies to share information across their traditionally segregated workforce, such as infusing information through county-based resource networks, developing resource dissemination protocols prepared for all provider agencies and family service agencies, etc. As an example, behavioral health providers were not aware of resources in the IDD "world," such as the University Centers for Excellence in Developmental Disabilities (UCEDDs).

14. Each state discussed ways to strengthen feedback loops to ensure ongoing information to/from the field and state. It seemed important to develop or augment a communication plan that could be tracked, for example using a Google Doc form for communication of problems and concerns.

15. Communication with families was addressed. There was discussion on the importance of engaging parents as early as possible, educating parents on navigating the system and developing communication strategies specific to family organizations, including supports for their work with families in educational settings.

16. Although long-term goals were sometimes articulated, it was proved important to focus only on change that seemed "doable" within a twelve month period and that was within each planning team's sphere of influence. There was a recognition that many well-intentioned planning efforts fail when the goals are too broad. Improved services and supports for young people with co-occurring IDD and MH needs will require a culture change that will take time, perseverance and support.

For Further Information

- *For further information about the three states,* contact David Miller at NASMHPD at david.miller@nasmhpd.org

- *For general information about individuals with co-occurring I/DD and behavioral health disorders*, contact Robert Fletcher, PhD at NADD rfletcher@thenadd.org and visit www.thenadd.org.

- *For information about the Learning Community process, webinars and resources provided to the states*, contact Linda Henderson-Smith, PhD, LPC or Diane Jacobstein, PhD at Georgetown University's National Technical Assistance Center for Children's Mental Health, Linda.HendersonSmith@georgetown.edu and jacobstd@georgetown.edu.