Ohio | Department of Developmental Disabilities

DODD's Vision for Supporting Multi-System Youth

I. Multi-System Youth with I/DD: Definition and Position Statement

Multi-system youth (MSY) are children and adolescents who have complex needs that require the coordinated services of multiple partners within the child-serving system. These care delivery systems include Ohio Family and Children First, Child Protective Services of the Ohio Department of Job and Family Services, the Ohio Department of Developmental Disabilities (DODD), the Ohio Department of Mental Health and Addiction Services (OhioMHAS), the Office of Juvenile Justice of the Ohio Department of Youth Services, and the Ohio Department of Medicaid (ODM), among others. Some youth have such complex physical, emotional, and behavioral needs that a single agency alone is not able to support them. There is an overwhelming need for interdisciplinary and multidisciplinary community partners to provide adequate services for youth with complex needs.

Most, if not all, youth who require these services are involved in more than one system, principally the medical and education systems. While these are the cornerstone systems with which parents and their children interact, they rarely coordinate with one another. Additionally, these systems often focus exclusively on a child's individual needs instead of understanding and supporting the family unit. These disparate systems are navigable for many families, but additional supports and coordination are required for families who face more complex issues.

Many youths who have intellectual and/or developmental disabilities (I/DD) and co-occurring mental or behavioral health conditions are eligible for and receive support from Ohio's county boards of developmental disabilities (CBDD). However, due to multiple factors, they may not be connected to other agencies or services. However, about one-third to one-half of the youth who are served by the CBDD system also have a co-occurring mental or behavioral health condition. Also, according to ODM data, 58% of children who are on a DD waiver are taking pharmaceuticals for behavioral health needs. Youth in need of services from both CBDD and mental/behavioral health services, or who are involved in the child protective services or juvenile court systems, are considered to have complex, multi-system needs.

II. Youth with Co-occurring I/DD and Mental Health/Behavioral Health Conditions

Youth with both I/DD and mental or behavioral health conditions, often referred to as having a dual diagnosis, are those:

- For whom the serving agencies find the most difficult to adequately serve.
- For whom parents are most likely to relinquish custody in order to receive needed services.
- Most likely to utilize an inordinate amount of local resources, creating a deficit for other youth in the same geographic location.
- Most likely to enter the juvenile justice or child protective services systems.
- Most likely to be in out-of-home supported residential placements; and
- Most likely to seek emergency and inpatient care.

Research and experience show that multi-system youth need coordinated services, services provided pre-emptively before crises occur with attention to risk factors and evidence-based services and supports, as well as intervention services when needs are significant.

The coordination of services for youth with complex needs is challenging, and the challenges increase based on:

- The complexity of the needs of each child (e.g., deficits in expressive language skills and the inability to identify and communicate emotions and needs, age, history of violence, aggression, self-injurious behavior, inconsistent or insufficient sleep habits, chaotic or fragmented relationships, poor attachment patterns, trauma history);
- Family variables (financial stress, isolation, lack of education, limited access to health care and employment, informal and formal support systems, lack of resilience, transportation difficulties); and
- The number of agencies or systems providing services, including the policies, protocols, funding sources, and interpretations of these by local personnel.

The systems designed to provide supports are not intentionally designed to be complicated. Still, each operates with different definitions, philosophies, eligibility standards, and rules for service delivery.

Because these systems are largely designed to treat illness, disease, or deficits, services to address the underlying child or family risk factors are often not eligible for coverage under the current funding structure, are not considered, or are not available. Parents and family members in crisis may not be eligible for supports or may be compelled to coordinate services for the child themselves. Though care coordination and crisis intervention services can at times quickly stabilize a child's health, these services are not readily available to the families who need them. Many children who are at risk for out-of-home placement are not engaged in treatment or intervention programs and may not be known to the community agencies until a crisis unfolds. According to ODM data, 13% of children in the child welfare system are in congregate care, and for children older than 15, this number increases to over 40%. Furthermore, 140 youth every day are receiving care in out-of-state residential settings.

[1] https://www.aecf.org/resources/every-kid-needs-a-family/; https://pediatrics.aappublications.org/content/138/6/e20163216

Gaps in services and supports, including uncoordinated services, may negatively affect the education, health, and employment of youths or lead to retraumatization or criminal justice involvement. State and local agencies must take the lead in coordinating efforts rather than expecting families to identify and coordinate the resources on their own. Support for these families will reduce the risk of harm and facilitate the family remaining together. These services and support must be grounded in evidence and must focus on maintaining family unity.

III. Families – Where Children Belong [1]

Parents of children with co-occurring developmental disabilities and mental illness face the daunting task of finding professional help for assessment and meaningful intervention. They also face the challenges of coping with major conditions and complicated systems of services and care. Frequently, these parents are faced with crises that lead to the relinquishment of child custody, loss of employment, and destabilization of primary needs, including food, shelter, and finances.

To the greatest extent possible, multi-system youth in Ohio's DD system will be supported in their communities, in their homes with their families. Achieving this vision will take significant effort and collaboration. It will require building new capacity while meeting immediate needs, reimaging how we support families, and strengthen communities.

DODD is committed to supporting multi-system youth and their families through guidance and technical assistance to local teams and families, keeping the following values at the forefront:

- Children with or without disabilities belong with their parents and families. Children have the best outcomes when they live with their families and have consistent access to the supports and resources they need and deserve. Research shows that children do best when they live as part of a family unit with a trusted, committed parental figure. Therefore, when children cannot remain with their family, an alternative family setting will be selected, such as kinship or foster care.
- When supporting a child, it is imperative to support the whole family.
- Services and supports for the child and family must be holistic, trauma-informed, and evidence-based.
- To achieve DODD's mission of supporting community participation, that support must begin with the family and the family's community.
- Services, supports, treatment options, and alternatives have been provided in the family home and were not successful before considering removal (barring an emergency or court order)
- When it is necessary for a child to leave their family to receive out-of-home residential treatment for stabilization, the placement should be:
    - Temporary, less than six months.
    - Priority should be given, and every effort will be made to find a family setting, such as kinship or foster care.
    - When all other options have been exhausted and when an institutional setting is necessary. The setting must provide:
        - Evidence-based treatment that addresses the child's trauma history, including

diagnosis, behavioral, and environmental issues that led to out-of-home placement.
    - Developmentally and age-appropriate services and the development of a plan to return to family or non-institutional congregate foster care setting, including aftercare support, beginning within the first week of placement.
- Every effort will be made to keep the youth in the same community, to allow for continuity of community connection, including attending school and regular visitation with family and caregivers.
- With a plan to transition back to the family home that includes cross-agency, holistic, trauma-informed supports for both the child and family, including crisis intervention, respite, physical and behavioral health treatment, home modifications, and parent and peer supports.
- To a residential setting that provides an evidence-based treatment that addresses the child's trauma history, diagnosis, and behavioral and environmental issues that led to out-of-home placement.

IV. DODD Plan for Supporting MSY and their Families (See appendix for details)

To accomplish this vision to support MSY, DODD has established the following goals and activities:

Keeping youth with their families and in their communities

i. Current Initiatives
    a. Project ECHO (Extension of Community Healthcare Outcomes) for MSY
    b. Telepsychiatry for Mental Illness/Intellectual Disability (MI/ID)
    c. Virtual Reality Project for Direct Support Professionals
    d. MSY Training developed and delivered
    e. Youth Respite Grants
    f. Technical Assistance for Youth
ii. Next Steps
    a. Ensure that families and providers who support MSY, in both ICF and waiver settings, have Supporting Youth with Intensive and Complex Needs Training.
    b. Create a regional structure of family coaches to support families who are struggling to meet the needs of their children with complex behavioral health needs and intellectual disabilities, so they can remain involved with their children and do not have to relinquish custody to receive needed services.

https://www.psychiatryadvisor.com/home/topics/child-adolescent-psychiatry/early-childhood-out-of-home-placement-associated-with-adverse-outcomes-in-adulthood/;
https://scholarworks.law.ubalt.edu/cgi/viewcontent.cgi?article=2087&context=all_fac;
https://www.casey.org/placement-stability-impacts/;
https://www.wsipp.wa.gov/ReportFile/748/Wsipp_Placement-Decisions-for-Children-in-Long-Term-Foster-Care-Innovative-Practices-and-Literature-Review_Full-Report.pdf;
https://everychildtexas.org/wp-content/uploads/2017/08/Precarious-Pathways-Literature-Review-CC-2010.pdf

c. Create a multidisciplinary team of experts who will support families by recommending resources, strategies, and interventions that will help prepare families and providers to support their children in their family homes.
d. Build capacity of respite providers for youth and families. Develop and make available mental health training for providers supporting MSY who have MI/ID.

B. Supporting youth in a home or community-based settings or Intermediate Care Facility (ICF) settings
   i. Current Initiatives
      a. Project ECHO (Extension of Community Healthcare Outcomes) for MSY
      b. Telepsychiatry for Mental Illness/Intellectual Disability (MI/ID)
      c. Virtual Reality Project for Direct Support Professionals
      d. MSY Training
   ii. Next Steps
      a. Ensure that families and providers who support MSY, in both ICF and home or community settings, have Supporting Youth with Intensive and Complex Needs Training.
      b. Provide a flexible funding source for county boards of developmental disabilities to utilize to support youth and their families by providing services for youth in waiver settings, outside of the family home, and supports for the families to which they will return.
      c. Develop a protocol and procedures for the selection and training of ICF providers who will provide short-term, evidence-based services when children cannot remain in home settings.

C. Supporting ICF providers to build needed capacity
   i. Increase outreach and education about Intensive Behavior Support Rate Add-On availability.
   ii. Training and best practices developed to support DSPs to provide intensive services in ICF settings.
   iii. Provide ongoing support to improve transition services to less-restrictive environments.

Appendix

Projects and Initiatives

In collaboration with other entities, DODD has implemented the following projects and initiatives to support keeping youth at home with their families.

Project ECHO (Extension of Community Healthcare Outcomes) for MSY

DODD and OhioMHAS created the System of Care ECHO for multi-system youth. ECHO sessions occur twice per month and include a brief didactic and a case presentation from a local team that is heard by a panel of clinicians with expertise in trauma, psychiatry, pediatrics, autism, parent peer support, and systems of care, as well as individuals across child-serving systems. The intent is to build capacity for those who are supporting multi-system youth across the state.

Telepsychiatry for MI/ID

DODD partners with Wright State University & Access Ohio Mental Health Center of Excellence to provide telepsychiatry services for youth who are enrolled in Medicaid with a dual diagnosis of mental illness and intellectual disability. This telepsychiatry service provides youth access to high-quality psychiatric care with a specialty in the dual diagnosis of MI/ID.

Virtual Reality Project for Direct Support Professionals

DODD collaborated with OCALI to develop a virtual reality training experience for direct support professionals. This pilot includes a 20-minute training module and four virtual reality scenarios to help staff to notice, understand, and respect people and their communication preferences; to build better relationships with the people they service; to feel valued; to recognize how they impact others.

MSY Training

DODD, in partnership with OCALI, has developed an evidence-based training curriculum for providers serving youth with complex behavioral health needs. This training curriculum is available both in-person and online. The content centers around supporting youth as it relates to trauma, communication, sensory, emotional & environmental needs through practical strategies and interventions.

Youth Respite Grants

DODD awarded seven grants across 13 counties for Planned Respite and In-Home supports for youth with complex behavioral health needs. The planned respite grants are local collaborative projects among county boards of developmental disabilities, councils of government, DD providers, Ohio Family & Children First, and mental health agencies.

Technical Assistance for Youth

To help families support their child in their home, DODD created a new technical assistance process across the divisions of Policy and Strategic Direction and Residential Resources for youth ages 10-17. The change has increased opportunities for resource sharing and communication among county boards, providers, and families.

Tiffin Developmental Center

DODD provides limited beds at Tiffin Developmental Center for youth with the most complex behavioral health needs who are not able to be supported in a community setting. These short-term stays are for crisis stabilization until the youth can be returned to his or her family or a less-restrictive setting.