

State of Connecticut
GENERAL ASSEMBLY



Medical Assistance Program Oversight Council

DEVELOPMENTAL DISABILITIES WORK GROUP

**Findings and Recommendations to Improve Care for Children with Developmental
Disabilities and Their Families:**

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About the Developmental Disabilities Work Group

Families who have children with developmental disabilities, including Autism Spectrum Disorders and Intellectual Disabilities, often struggle to access services that they need to support their child's learning, development and mental health. The lack of access to necessary and high quality care can have devastating impact for children and their families, up to and including the repeated or prolonged hospitalization or institutionalization of children with complex needs. While Connecticut continues to examine and improve the manner in which services are delivered to children with complex disabilities, the state needs a more robust and coordinated system of care to address the needs of children with developmental disabilities and their families.

Consequently, the Developmental Disabilities Work Group was formed under Public Act 16-142 to examine our service system for children age birth to twenty-one who have developmental disabilities. The Work Group includes representatives from various stakeholder groups, including families, service providers, advocates, and lawmakers. The Work Group held its first meeting in September, 2016, and over the ensuing fifteen months identified various issues of concern and invited local and state agencies to share information, barriers to care, and recommendations to improve services for children.¹

The Work Group is required to issue successive reports that will make recommendations regarding how to “promote effective service delivery for children [with developmental disabilities] and their families,” including recommendations regarding how to better evaluate the quality of state-funded services to children, and how best to address gaps in services so that Connecticut can realize a comprehensive and coordinated service system for children and their families. The following is the second of the required set of recommendations.

Core Values about People with Disabilities

The Work Group members are committed to problem-solving and increasing access to critical care for children with Intellectual and Developmental Disabilities and their families. As a foundational matter, members adhere to the following core values:

1. People with intellectual and developmental disabilities are defined by their own strengths, abilities and inherent value, not by their disability.
2. People with disabilities need real friendships, not just relationships with paid staff.
3. People with disabilities are entitled to the full meaning of the right to free speech. The ability to communicate, in whatever form, must be available to every person with a disability.
4. People with disabilities must be able to enjoy full mobility and accessibility that allows active participate in community life.

¹ Specifically, the Work Group received information and presentations from the Department of Social Services (DSS), the Department of Developmental Services (DDS), the Department of Children and Families (DCF), the Department of Education (SDE) and the Office of Early Childhood (OEC), service providers from The Connecticut Children's Medical Center, Yale New Haven Children's Hospital, Beacon Health Options, Wheeler Clinic, Clifford Beers Clinic, Adlebrook, The Center for Children with Special Needs, The CT Medical Home Initiative for Children and Youth with Special Health Care Needs, the Child Health and Development Institute, The Children's Center of Hamden and the City of Meriden Public Schools.

5. People with disabilities belong in the community and have fundamental moral, civil and constitutional rights to be fully included and actively participate in all aspects of society.
6. People with disabilities must be treated with respect and dignity.
7. People with disabilities must have the freedom to choose how they want to live their lives and receive the support they need.
8. People with disabilities must be able to enjoy the benefits of true productivity through employment and/or contributions as members of their communities.
9. People with disabilities are served better when the Life Course model is used to guide decision making.

Phase Two Findings and Recommendations from the Work Group

In July of 2017, The Developmental Disabilities Work Group issued its first report. Based on extensive analysis of services for children with developmental disabilities, the report made findings and recommendations on Connecticut's existing system of services and supports. Members found that the current system for Children with Developmental Disabilities has inadequate/disparate access to state-funded voluntary services (DCF/DDS), that availability of needed services remains limited for children with intellectual disability, that families' have a critical need for high-skilled care coordination, and inconsistent that children have uneven access to educational services that they are entitled to under federal law. Recommendations were made, which align with the goals of improving service delivery, care coordination, and outcomes.

Throughout the months the group has met, members received significant information regarding families and children that are in crisis due to the lack of timely access to critically needed services. Children with developmental disabilities and mental health needs are disproportionately reliant on emergency room care, and some children became "stuck" in emergency rooms for days and even weeks on end due to the lack of an appropriate discharge plan and the families' need for help. Families in crisis, community-based providers and health care professionals throughout Connecticut shared information with group members regarding their frustration with the lack of a well-coordinated and lead-agency approach to treatment planning for vulnerable children with developmental disabilities.

The working group decided to conduct a focused review on children with developmental disabilities who are accessing crisis support and stabilization in local emergency departments. Specifically, the group sought information regarding 1. Children and families who present to a hospital emergency department for the first time with an acute behavioral health crisis; and 2. Children with developmental disabilities whose care and safety needs are highly acute, resulting in lengthy or repeated ED stays as well as prolonged or repeated inpatient hospitalizations.

While acknowledging that the work of this group has not yet been completed; the following outlines key findings and recommendations based on the entirety of the examination the work group has made on Children with developmental disabilities.

FINDINGS

1. Based on data provided by Connecticut Children's Medical Center and Yale New Haven, it seemed apparent that children with developmental disabilities spent a longer time in the ED compared to their peers without developmental disabilities.
2. **Data shows that 578 of Medicaid-eligible children with I/DD/PDD were admitted to hospitals during CY2016 time frame. Data shows that 42 Medicaid-eligible children with I/DD/PDD were delayed in the ED with I/DD/PDD as the barrier.**
3. **The cost of in-patient psychiatric hospitalization for Medicaid-Eligible children with I/DD/PDD during CY2016 time period was \$6,576, 862 dollars.** Previous reporting in Connecticut has found that "youth with an ASD diagnosis stay longer in inpatient care than their peers not identified as having ASD while utilizing the same services." (See Autism Feasibility Working Group Study, 2013). USE DATA/CITE FROM M POWERS BRISC REPORT.
4. Per information from families and hospital providers, children with I/DD who get stuck in emergency rooms are unable to be discharged for reasons related to family crisis, lack of family resources, and lack of 24-7 support for children with complex care and safety needs.
5. Hospital personnel report that they lack a "go to" system coordinator or lead agency for children with I/DD and behavioral health treatment needs who present to the emergency department.
6. Children presenting to the emergency department cannot timely access high-skilled care coordination to assist with discharge, transition, and treatment planning.
7. There are few in-state hospital beds for a child with complex developmental disability and acute mental health treatment needs.
8. The State Operated or three private Psychiatric Residential Treatment Facilities are not staffed to meet the needs of children with a comorbid psychiatric and intellectual disability. Through state funds, two of the three PRTFs have received support and consultation in order to provide services to children with a psychiatric condition and autism spectrum disorder.
9. There is only one residential treatment facility in the state that is designed to serve the needs of children with developmental disabilities—insurance typically will not cover this service; and residential treatment is *not* a Medicaid-funded service; leaving the state agencies (DDS and DCF) as the only available funders of this level of care.
10. DDS Voluntary Services (called the Behavioral Support Program) is not able to provide services to new, yet eligible, families due to budget cuts.
11. Per family and provider input, DCF Voluntary Services frequently denies eligibility for children with developmental disabilities.
12. While the adult service system has some capacity to provide respite to families, there is no current system for providing respite to families as part of a child's treatment plan, even where brief respite is identified as *essential* to maintaining the child in a non-institutional setting.
13. There is no health care funding stream (other than Voluntary Services) which allows a family, in conjunction with a child's treatment team, to direct treatment and support dollars to where they are most needed for the child and family (e.g., treatment hours, child care support, respite, pro-social support). The lack of flexibility in treatment dollars can result in expensive treatment plans and unsuccessful outcomes.
14. There is a significant need for capacity building and technical assistance within the provider community to better support children with developmental disabilities and their families.

15. Children are at risk for poor treatment outcomes, unnecessary or prolonged hospitalization.
16. Multiple community-based providers, with the support of DSS, are piloting or beginning innovative treatment models for children with I/DD and their families, including the provision of intensive technical support to existing programs (CCSN), intensive care coordination for families (Clifford Beers), and a whole-family approach to care for children with complex needs (Clifford Beers).

RECOMMENDATIONS

1. Children presenting to the emergency room with I/DD and acute mental health treatment needs require access to intensive care coordination to support discharge and connection with appropriate community-based supports.
2. As part of Connecticut's strategy to maximize federal Medicaid reimbursement for children with I/DD, the state must develop a specialty Psychiatric Residential Treatment Facility that has capacity to serve children with psychiatric conditions and intellectual disabilities.
3. As part of Connecticut's workforce development strategies to serve children with I/DD, the state should continue and scale up capacity-building technical assistance programs such as the BRISC framework funded by DSS. The BRISC model uses locally-based, nationally-recognized experts to assist community-based mental health treatment providers with serving children with developmental disabilities.
4. To facilitate caregiver and provider training needs, the state should support creation of Regional Training Academies. Such training academies would build on successful resource models such as the Southern Connecticut State University Center for Excellence.
5. To further develop an appropriate continuum of services for children with I/DD and their families, it is recommended that the state support development and reimbursement strategies for a) specialty extended day treatment for children with I/DD and b) maximizing capacity of Federally Qualified Health Centers to provide in-home services to children with I/DD and their families.
6. To ensure children with complex I/DD can remain in their homes, the state must support provision of respite services to families. The sub-group strongly recommends that state health care policymakers conduct a cost-benefit analysis to determine the efficacy of providing competent and reliable respite services as a means of reducing emergency or institutional care for children.
9. The subgroup recommends that state health care policy makers, in coordination with the Office of Healthcare Strategies review the cost effectiveness of providing intensive case management/care coordination to children with complex I/DD and their families as a means to reduce reliance on emergency room and hospital admissions.
10. State-funded Voluntary Services/Health Care programs must prohibit denial of eligibility to children based on I/DD status. The cost effectiveness of state voluntary services must be improved through a systematic approach to third-party payer reimbursement—expand scope of OHA reimbursement work for DCF to include other state agencies. The OHS should assist with examining whether provision of state-administered Voluntary Services reduces the frequency and duration of hospitalization for children with I/DD.

11. The state facilitated voluntary services programs, in coordination with DSS (where applicable), should permit greater flexibility for families to direct dollars to community and home-based supports that will support a “whole-family” approach to caring for a child with I/DD. OHS should work with state health care policy makers to examine cost-effectiveness and outcomes achieved by providers who are or could provide “whole family” services where a child has complex I/DD. As an example, Clifford Beers is utilizing a new and innovative model of service delivery for children with ASD and their families that incorporates both intensive care coordination and a whole-family approach to service delivery.
12. The MAPOC subgroup on children with developmental disabilities should work closely with the Office of Healthcare Strategies to assist with an analysis of the state’s return on investment for well-coordinated, flexible and wrap-around service delivery for children with complex I/DD and their families.
13. The MAPOC subgroup on children with developmental disabilities should work with OHS to examine other states’ strategies for financing effective service delivery for children with complex I/DD and their families that increases individual functioning and reduces reliance on institutional care.

NEXT STEPS FOR WORK GROUP

1. Propose and support Legislation and policy changes related to the Recommendations that have been made.
2. Work with other groups, which are working on similar goals for Children with Developmental Disabilities, to share resources and collaborate on effective solutions to barriers of care.
3. Further analysis the current system of care including capacity, coordination, necessary services and supports, and quality metrics.
4. Develop partnership with the Office of Health Care Strategies to assist with a comprehensive and data-driven cost benefit analysis of the delivery of health and support services to children with I/DD and their families, as well as an examination of alternative financing systems to support more effective service delivery and improved outcomes for children’s health care and family functioning.