

CHILDREN WITH DISABILITIES BUDGET PRIORITIES

STATEMENT

Children and youth with significant disabilities can need unique supports to fully participate and benefit from community experiences that benefit all children. Added responsibilities beyond typical parenting for families include critical roles as advocates, care coordinators, benefits navigators and 24/7 caregivers. They must leverage supports, services, community connections, and employment opportunities for their children. Supporting families in these roles and ensuring full community inclusion is cost effective and needs to become a major focus in our system of supports and services.

BACKGROUND

Families play key roles in identifying and securing opportunities for their children to participate in meaningful ways with in their community increasing the likelihood of having self-determined lives. A modest investment in families, so they have the support, skills, information and training necessary to be effective in their roles, results in the most efficient use of both formal and informal supports. Such an investment will help both families and children with disabilities live healthier lives. Historically we have invested more resources into designing systems and delivering services than in ensuring the best outcomes for families.

An investment in supporting families as they navigate school, health, community and disability resources ensures the right amount of support at the right time. This support reduces family stress and maximizes community connections for children with disabilities. Not all families need the same roadmap to be successful. The right support at the right time is critical.

Recent analysis by the Department of Health Services reveals that despite efforts to reach all eligible families, only 25% of children potentially eligible for long-term supports or other programs are actually connected to services. While not all families may need publicly funded supports, most benefit from information about resources and connection to other families.

- Thank you for championing an end the wait list for children and families needing long-term supports and services. Survival Coalition recommends DHS make this commitment to all newly eligible children by **including CLTS funding in the base Medicaid budget.**

- Survival Coalition recommends **DHS request an appropriation to plan and implement Family Support and Disability Resource Centers (FSDRCs) to supporting families and children with disabilities** FSDRCs will provide a central point of contact for:
 - Comprehensive Information and assistance for children with disabilities;
 - Family Navigators to help families access resources already available in their health, community and school systems;
 - Family Education to help families effectively work with schools, medical and community resources;
- Family-to-Family connection for mutual support and community engagement
 - Eligibility Determination for public and private programs
- Survival Coalition recommends **DHS monitor elimination of the waiting list** and initial enrollment in CLTS waiver to insure that all eligible children have access to the waiver regardless of county capacity to enroll new children from the wait list. The budget should reflect funding and staffing for this initiative as necessary.
- Survival Coalition recommends **DHS provide funding and staff to address the lack of access to Medicaid allowable services, particularly HealthCheck Other Services, to reduce delays, denials and cost shifting to the waiver for Medicaid services that are currently allowable but hard to access.** This includes developing an internal process and substantive outreach with guidance and tools for providers; provider education; service coordinator education and; family education on the use of the benefit. The budget should reflect funding and staffing for this initiative as necessary
- Survival Coalition recommends **DHS support a state and county infrastructure and needed staff to eliminate disparities to access and utilization of long-term supports** for children served in the children’s waiver. We believe all families, regardless of race, ethnicity or geography should have equal access to supports and services. Counties must provide uniform program implementation and assure that staff have the skills necessary to support families and children. The budget should reflect funding and staffing for this initiative as necessary.

FOR ADDITIONAL INFORMATION CONTACT SURVIVAL COALITION CO-CHAIRS:

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