



of Wisconsin Disability Organizations

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SUPPORTING CHILDREN WITH DISABILITIES AND THEIR FAMILIES

STATEMENT

Almost 2800 children and youth with significant disabilities and their families are waiting for essential support and services such as specialized equipment or home modifications. The wait time for children ranges from 1 to 8 years depending on where a family lives. Over one third, (37%) of children eligible for long-term supports are waiting, compared with less than 6% of adults eligible for long-term care (Family Care and IRIS).

BACKGROUND

Children and youth with significant disabilities can have extraordinary needs that require unique supports so families and their children can fully participate and benefit from the typical community experiences that all children enjoy. Families who are well informed and have access to supports can play key roles in identifying and securing opportunities for their children and youth with disabilities.

Waiting for services means missed opportunities for: cognitive, physical and behavioral development, and learning skills for independence. An inability to meet less costly needs now can lead to expensive crises and higher future costs, in addition to significant stress for families affecting their ability to work and provide support.

BUDGET RECOMMENDATIONS

- Reduce Wait Lists by 1000 Children. Ensure that new funding is equitable to address the needs of all children, regardless of specific disability or diagnosis.
- Provide short term assistance to families who are waiting. Families say having a person who can help them navigate services and supports is their primary need. This assistance assures families access to information on a broad range of school, community and private sources of supports and services.
- Expand COMPASS Wisconsin Threshold statewide (now only available in 13 counties) and build on efficiencies experienced in counties using this single point of entry for eligibility. Threshold has improved families' access to information and supports and has streamlined the eligibility process for families in need.

- Improve the Medicaid prior authorization process and reduce Medicaid administrative costs and stress for families by reducing the frequency of repetitive reviews for services deemed medically necessary; increase the duration of Medicaid funded services for children who meet eligibility for long-term supports.
- Evaluate the CLTS programs and direct DHS to work with stakeholders to develop specific family outcomes measures and implement a family-based outcomes survey. The survey would: a) identify gaps in family knowledge and gaps in the types of services currently needed by and provided to families; b) be part of a continuous quality improvement process for children with significant disabilities.

POLICY RECOMMENDATIONS

- Develop a clear process for access and approval of Health Check Other Services (EPSDT) for children who are Medicaid eligible.
- Assure a positive impact on families who have children with autism participating in treatment services as these services are transitioned from CLTS waivers to Medicaid state plan services.
- Direct DHS to report on seclusion and restraint in child-serving agencies and CLTS waivers.
- Direct DHS to report on out-of-home placements for children, both those that are and are not court ordered.
- Assure any new funding is equitable based on disability and geography for all families and children who are eligible and want assistance.
- Improve access to helpful people, supports and service for families who interact with CLTS. Refocus role of front-line CLTS staff on relationships and support to families rather than burdensome paperwork and regulatory processes for counties.
- Align CLTS home and community-based services with the new home and community-based settings rule (that prohibits HCBS funding in isolating settings).
- Improve coordination with other key players in a child and family's life, including DVR and schools to support community-based employment outcomes and "shut the front door" to placement in segregated employment facilities.
- Maximize the best possible outcomes for children and their families who access public supports. Educate, support and empower families.
- Improve efficiency and reduce duplication of effort in DHS to increase county capacity and focus on direct support to families and creative problem-solving that facilitates inclusion of the child and family in their home and community.

Contact Survival Coalition Co-Chairs for additional information

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