



of Wisconsin Disability Organizations

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## **CHILDREN'S LONG-TERM SUPPORTS BUDGET PRIORITIES**

### **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 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 Waiting Lists by 1000 Children. Ensure that new funding is equitable to address the needs of all children, all disabilities.
- Provide short term assistance to families who are waiting. Families state 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.
- Build on efficiencies experienced in counties using a single point of entry for eligibility. COMPASS Wisconsin Threshold (now only available in 13 counties) has improved families' access to information and supports and has streamlined the eligibility process for families in need. Wisconsin should expand this efficient single-point-of-entry model statewide.
- Reduce Medicaid administrative costs and stress for families by reducing the frequency of repetitive reviews for services deemed medically necessary (reduce to minimum review allowed by state statute.) Increase the duration of Medicaid funded services for children who meet eligibility for long-term supports.

- As an evaluation strategy for the Children's Long Term Services (CLTS) programs, 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.

## **ADDITIONAL PRIORITIES**

- 1. Maximize the best possible outcomes for children and their families who access public supports. Educate, support and empower families.**
  - a. Assure that annual planning for current and future needs of a child and family is based on the family identified outcomes, not a menu of services. Shift conversations from services to supports for the family's vision.
  - b. Start early and continue often to help families shape a positive vision for the future and actualize that vision as partners and advocates with schools, CLTS, and their communities.
  - c. Support opportunities for families to acquire skills and knowledge to be effective partners and advocates.
  - d. Develop an integrated, web-based CLTS information technology system that improves data reporting that describes CLTS including elements such as; numbers served and on waiting lists, costs, spending trends, service utilization and demographics.
- 2. 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.**
  - a. Prioritize values-based, family-centered training that is focused on increasing skills and knowledge of CLTS service coordinators to partner with families, use culturally effective practices, identify family outcomes and increase family access to generic community and natural supports, Medicaid covered services, private insurance, school supports and futures planning.
  - b. Provide regular learning opportunities for families and ensure ongoing interactions with service coordinators include information about connecting with other families for emotional supports, a vision for the future, partnering with professionals, and maximizing school and community resources.
- 3. Make sure the system is equitable for all families and children who are eligible and want assistance. Provide the right support, at the right amount, when it is needed.**
  - a. Assure that all children have equal access to eligibility determination using the functional screen with particular attention to children with severe emotional disturbance.
  - b. Assure families have access to information that is understandable, reliable and culturally appropriate. This is accomplished by improving the competencies of those working with families as well as the quality and consistency of information available to families.

**4. Improve efficiency and reduce duplication of effort. Eliminate barriers to coordination within DHS.**

- a. Address barriers that prevent service coordinators from creative problem-solving that facilitates inclusion for the child and family and maximizes access of neighborhood and community supports.
- b. Minimize burdensome paperwork and regulatory processes for counties to allow them to redirect their time and resources to direct support to families.
- c. Make self-directed personal care, incontinence supplies and Non-Emergency Medical Transportation (NEMT) available to families.

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**Contact Survival Coalition Co-Chairs for additional information**

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