MILWAUKEE CENTER FOR INDEPENDENCE REPORT ON CHILDREN WITH DISABILITIES

Addressing a growing epidemic

SOUNDING THE ALARM

A growing crisis of epidemic proportions is threatening the most vulnerable children in our community. For the first time, this report sounds the alarm for our community and state and offers realistic solutions to help manage the crisis. We have the choice to respond with rational and effective strategies, or we can choose not to respond, to ignore this epidemic and watch the cost to society and our community grow even greater.

This community-based report documents an alarming increase of children who are either born with disabilities or who have been diagnosed with disabling conditions later in childhood in southeastern Wisconsin.

KEY FACTS (as identified in the report on children with disabilities)

- Today's special needs kids will cost Wisconsin taxpayers \$15 billion in lifetime costs.
- A 2 percent to 5 percent reduction in that number, which can be achieved through better coordination of services, can result in savings between \$300 million and \$650 million.
- In Milwaukee, the percentage of children who have special health care needs is 23.5 percent; nearly double the national average (12.8 percent) and the state average (13.4 percent.)
- Services for children with disabilities are not organized from the perspective of children with disabilities and their families. Out of more than **80 percent** of families given a referral for special health needs, only **47 percent** follow through with the referral and only **17 percent** actually receive a treatment or care recommendation provided at the visit. **By this estimate**, **the efficiency of the system is only 10 percent.**

CALL TO ACTION

Our community and state must act now or suffer increasingly overwhelming costs and human tragedy that we simply can't afford. We recommend a family-centric approach designed to facilitate improved diagnosis, coordinated treatment, and referral, as this coordinated approach would eliminate duplicative costs and overhead and likely result in more comprehensive early diagnosis of disabilities. **We're not seeking to reinvent existing care systems.** We want to organize existing systems and funding allocations in a way that is more effective.

MEETING THE NEEDS OF CHILDREN

The proposed diagnostic center concept focuses on the needs of children and families to effectively coordinate diagnostics, treatment, outcomes, monitoring, research, and reporting in one geographic location, making the center more "user-friendly" and more efficient and effective.

The vision for a community-based diagnostic and treatment center for children would ideally emphasize three features. Underscoring those features would be facilitated access to a comprehensive expert diagnostic resource that could be leveraged on behalf of families to meet the recommended treatment for their child.

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- 1. A new children's diagnostic resource anchored by an interdisciplinary service program. This would provide families and children with disabilities a single, one-stop portal for accessing the diagnostic assessment, treatment planning, and functional outcomes monitoring services required to maximize the level of function and independence for the child.
- 2. **Coordinated program of diagnostic assessment services.** This might include any of the following depending on the presenting concerns and individual needs of the child:
 - Psychological assessment
 - Physical therapy assessment
 - Occupational therapy assessment
 - Speech therapy assessment
 - Audiology assessment
 - Recreational therapy assessment
 - Financial/life planning assessment
 - Vision assessment
 - Educational assessment
 - Dental assessment
 - Benefits counseling
- 3. Access to and coordination of treatment planning services.
 - These would be based upon an inter-disciplinary compilation of diagnostic assessment findings for each child;
 - Services would be laid out by a team meeting with all diagnosticians and the family for a
 prescribed period, including establishing initial appointments for each service needed, and
 ensuring follow through.

The goal of the treatment planning service component will be set to specific treatment and outcome objectives for a specified period for each child diagnosed with a behavioral, cognitive, or communication related disability.

SOLVING THE CRISIS – THE NEXT STEP

Developing and implementing a system as described above is an integral first step to turn the tide in favor of Wisconsin children and families born with disabilities, and the government programs, agencies and school districts that help care for them.

The concept of a model program and center that can show the measurable results outlined in this report is the first step to addressing this vital need in the community. The creation of a Diagnostic Center for Children to provide early diagnosis and a coordinated, integrated and measured program of services is a critical next step. This will take a partnership between the state, local medical and educational institutions and the private sector.

The case for action to improve the futures of children with disabilities is compelling. The professional, institutional and financial resources can be found. The only missing ingredient is an investment in and commitment to execution. Our goal is to outline and pursue a strategy that will result in the redirection of federal funds for families and children with disabilities, re-assigning funds to individual children with disabilities and allowing them access to the regional diagnostic, treatment and resource center.