



# Children with Disabilities The Forgotten Population in Long Term Care

*Families with children with severe disabilities struggle with many every day needs to care for their children at home. Supporting families raising children with disabilities at home is good for children, good for the economy and good for Wisconsin!*

## THE ISSUE

Except for one segment of the population (children with autism), the state of Wisconsin has largely ignored the long term support (LTS) needs of children with disabilities for the last ten years. In stark contrast to the Family Care program, which has received \$65 million of new GPR funding since 2001 to provide LTC services for adults, the Family Support Program and the Children's Medicaid Waiver program combined have only received \$2.3 million of new GPR funding over the same period. This extreme age disparity in LTC funding over multiple biennial budgets has had a cruel impact on an increasing number of children with disabilities and their families. This is a generation of families who kept their children at home rather than placing them in an institution, resulting in a great savings for the state and taxpayers. But being on a waiting list for years with no prediction of when services will be available sends a contradictory and disheartening message to families: "We want you to keep your child at home and not consider an expensive out-of-home placement, but we won't provide any in-home support to help you do that."

- 56% percent of families raising children with disabilities report financial hardship related to the care of their child. (SLAITS 2003)
- 54% of caregivers stop working or reduced hours to care for a child. (SLAITS 2003)
- The average cost of care in an institution is \$268,000/year. (Dane County LINK 2006)
- The average amount a family receives from Family Support is \$1650/year. (DHFS, 2006)

## THE FACTS

- There are 3500 children with disabilities (other than autism) on waiting lists for LTS services in Wisconsin, which include home modifications, respite care, special equipment, in-home care, and assistance with challenging behaviors.
- Many children and families wait 3-5 years for services, and some up to 10 years
- "Early intervention" is important for all children with disabilities– waiting lists inevitably result in missed opportunities for cognitive, physical and behavioral development, and for learning skills for independence.
- Although most children with disabilities have a disability other than autism (e.g. cognitive disabilities, cerebral palsy, Down Syndrome, spina bifida, brain injuries, epilepsy, severe emotional disabilities, muscular dystrophy, and metabolic disorders), the majority of LTS resources has gone to this group of children.
- Waiting for services means an inability to meet less costly needs now, creating more costly needs in the future.

## ACTION NEEDED

The Legislature sets priorities and makes decisions about how to spend public dollars. Your representatives will only know what children with disabilities need if you tell them!

- **\$10 MILLION IN NEW STATE DOLLARS WOULD SERVE 2000 ELIGIBLE CHILDREN AND FAMILIES CURRENTLY WAITING FOR SUPPORTS! THIS NEW FUNDING SHOULD BE PRIORITIZED TO SERVE THOSE FAMILIES WITH THE MOST SUBSTANTIAL WAIT, NEED, OR IN CRISIS.**