

TESTIMONY TO JOINT FINANCE COMMITTEE**Wisconsin Dells, Wisconsin**

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Parent of 22 year old son with developmental disabilities; Co-Director of Family Voices of Wisconsin; and Chair, Board for People with Developmental Disabilities. Today, representing the Survival Coalition and the need for expansion within the Children's Long Term Support Waivers

I am pleased to be able to talk with you today. I believe that the citizens of Wisconsin deserve the opportunity to speak directly to legislators regarding the use of public funds. I appreciate this occasion and thank you for listening to me.

I am Barbara Katz, I live in Madison, and I serve as Chair of the Governor-appointed Board for People with Developmental Disabilities and am a member of the DHS Secretary appointed Council for Children with Long-Term Support Needs. I am also a member of the Survival Coalition, and I am speaking to you today on behalf of their platform on Children's Long-Term Supports.

First and foremost, I am the parent of a delightful young man, Ben, who is 22 years old and has significant cognitive disabilities. Since his birth, our private insurance, Medicaid, and the Madison Metropolitan School District have invested hundreds-of-thousands-of dollars in Ben so that he can be the most independent, productive and contributing citizen as possible. I am happy to report to you that today Ben holds four part time jobs in our community. Ben is a successful worker and is actively engaged. Ben's successes, in large part, are thanks to the support of the Children's Long-Term Support Waiver.

The waiting list for children in our state to receive long term supports is unacceptable. Since the program's inception in 1984, there have been only two appropriations to reduce the wait children have for needed services, in 2007/2009 and 2009/2011. Today, there are 3,000 children statewide who languish on waiting lists, waiting between 2-to-8 years before there is a waiver slot that is open for them. What this means is that children with disabilities are simply not getting the interventions they need at their appropriate developmental time. As a result, these children do not have the opportunity to reach their optimal levels of function and independence, requiring them to need more and more support for a longer time, thus increasing costs to the Medicaid program overall.

Many people will be talking with you about the need to expand Family Care and IRIS into the remaining 15 counties. I agree with them. But that request amplifies the extreme inequities that exist in Wisconsin between the long-term support systems for children and adults.

We have a generation of families who keep their children at home and in their communities, rather than placing them in an institution, which results in 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 you an in-home support to do that."

I urge you to renew the commitment to end waiting lists for children with significant disabilities by serving an additional 1,000 children during the next biennium. An increase of \$5.4 million over two years will reduce the waiting list by 1,000 children and will greatly shorten wait times for the remaining children.

Thank you for your consideration. You hold the keys to the future of Wisconsin's children with disabilities and their families.