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# SURVIVAL COALITION

of Wisconsin Disability Organizations

## A Life in the Community for Everyone

The Survival Coalition budget priorities for the 2007-09 Budget are connected by one basic idea: **every person in Wisconsin has the right to live in the community**. Survival Coalition further believes that people with disabilities have the right to determine the way in which they live in the community, just like everyone else. This concept of **self determination** implies that people have more control over their lives, their services, and the funds allocated to pay for their services.

There are two obstacles to people with disabilities having a life in the community: inadequate funding for the services people need and inadequate concern for people's choices and preferences. So our proposal focuses on the funding people need for reducing long term care waiting lists, expanding special education services, and increasing specialized transportation. It also focuses on how this funding is provided, to ensure that it increases the autonomy of people with disabilities and supports recovery.

### Long-Term Care (LTC)

Survival Coalition believes that in order for LTC to be successful we need to strengthen the existing LTC system to ensure that:

"Each person may arrange for, manage and monitor his or her family care benefit directly, or with the assistance of another person." (*Statutory requirement within Family Care*)

There are opportunities to improve on Family Care and support our existing community-based long term care system. To do this we must:

- Have safeguards to ensure that **self determination** is available to anyone who wants it
- Provide **adequate funding** for services, including adequate pay and benefits for workers
- Expand capacity to **eliminate waiting lists**
- Provide sufficient funding to individuals currently living in institutions who choose to live in the community so that the **money follows the person**

by transitioning institutional capacity and resources to community services

- Provide adequate funding for **Ageing & Disability Resource Centers (ADRCs)**, so consumers in every county can easily access resources
- Continue **county government's role** in oversight, quality assurance and setting local LTC policy
- Incorporate **consumer involvement** and consumer control in Family Care planning and implementation
- Re-establish Family Care **independent advocacy**.

**Self-Determination** is the right of *all* people with disabilities (with their chosen allies) to make choices and direct all aspects of their lives, including how they are supported; and to control the funding to pay for that support.

In the words of a person with a disability "I, the people I care about, and those who care about me making a life that is good for me."

## A Life in the Community for Children with Disabilities

The Wisconsin Legislature made a commitment to a partnership with families whose children have significant physical, developmental and behavioral/emotional disabilities by passing legislation creating the Family Support Program (1987), and authorizing the Children's Redesign (2001), including the Children's Waivers (2004). This legislation was supposed to create a comprehensive array of supports for children with disabilities. Unfortunately, supports are not available to many families who desperately need them. The financial commitment to services and system improvement for children with disabilities has not kept pace with the need. Currently more than 3500 eligible children are waiting for supports and services that could better connect them to their life in the community. To address this urgent need we recommend the following:

- **Reduce waiting lists by two-thirds (supporting an additional 2000 families).** There are many families who simply cannot wait any longer. Legislators should allocate funding to address waiting lists for children needing access to long-term supports. DHFS should have the discretion to use funding to: address waiting lists for the Family Support program; respond to other unmet needs using the Children's waivers with priority for those with the most substantial wait, need or in crisis and;

*"We feel heart broken,"... SSI and CIP now pay for [our daughter] to stay with the foster family. But we really want to take care of [her] ourselves. No one will give us any money for her care, but they're willing to pay so much to let others care for her." Parent, Walworth County*

begin piloting managed care concepts in 2008. \$10 million of state funds would bring 2000 new children off waiting lists.

- **Improve the current system.** Direct DHFS to seek the needed federal authority to pilot the use of managed care to meet the long-term support needs of children and provide funding to pilot a system that provides information, assistance, advocacy, and access to supports and services that is responsive to the unique needs of children and families.

*"Even though we've been on waiting lists since she was a baby, we're still expected to wait. Almost everything in her life, from special clothes with Velcro, to the food she eats, costs more than it would for another child. And all we're told to do about it is wait." Parent, Dunn County*

- **Provide adequate health care coverage.** Many children and youth with special health care needs have inadequate insurance or are at risk of losing private coverage due to policy limits. A solution is to modify the proposed Badger Care Plus expansion to include these children with significant medical costs or disability (meet SSI criteria), but do not meet the level of care for Katie Beckett or the Children's Waivers. This group is at high risk for poor health outcomes, and eventual high cost to the public sector without expanded coverage. Examples include children with spina bifida, mild cerebral palsy, cancer, organ transplants, and hemophilia.

## Strong Schools Build Strong Communities

The right to receive a free appropriate public education (FAPE) is mandated in both federal and Wisconsin law. However, insufficient funding of special education, and an inadequately and inequitably funded general education system has resulted in school districts facing the hard choice of either violating special education law and failing to provide FAPE, or reducing funding for regular education programs in order to meet their legal obligations to students with disabilities.

- **Increase special education categorical aids.** We believe that perpetuating an under-funded system is unacceptable, which is why we urge the legislature to add more funding than the Governor has proposed. Cost is \$45 million in the first year of the biennium and \$55 million in the second year of the biennium.
- **Expand and improve inclusive early child care and learning--**for young children with disabilities by:
  - a) enhancing professional development in the area

of inclusion; b) establishing a child care quality improvement system, which would include rating child care centers on their capacity to include children with disabilities; and c) expand 4 year old kindergarten options which would allow more 4 year old children with disabilities to participate in regular education settings.

- **Reform school finance system**—Wisconsin's education system has been burdened by revenue caps for too long. Vulnerable populations, including children with disabilities are being harmed by these caps, as they do not allow school districts the necessary fiscal flexibility in order to meet the individual needs of their students. As a result, revenue caps, combined with chronic state and federal under funding of special education, results in widespread denial of children with disabilities right to a free and appropriate public education. We urge an end to a funding system which constantly forces districts to rob Peter in order to pay Paul.



## A Life in the Community for People with Mental Illnesses

People with mental illnesses can and do recover. But the treatment system for people with mental illnesses is inadequately funded. This prevents people from benefiting from the available effective treatments. Wisconsin has some excellent treatment models for adults and children with mental disorders, but these are not available everywhere in the state due to the funding structures.

- **The State will pay 25% of the non-federal share of Medicaid for Comprehensive Community Services (CCS).** The State requires counties to pay the non-federal share of Medicaid reimbursement for many mental health services. This places an inappropriate burden on the property tax and limits access to these critical services. A cost of \$2.5 million for the biennium for CCS non-federal share (about \$10 million for the biennium for all county matched services).
- **Expand collaborative systems of care (i.e., wrap-around) for youth with serious emotional disturbances.** Wraparound systems of care positively impact the functioning of children with serious emotional disorders and their families. By involving the family in all aspects of care planning, decision-making and service delivery, parents can start to regain a sense of control over what can be an overwhelming situation.

\$1.1 million would allow expansion to five new sites each year of the biennium.

- **Implement Comprehensive Mental Health/Substance Abuse Parity.** Inequities in the insurance statutes prevent many individuals with mental illnesses and substance abuse disorders from receiving medically necessary treatment on a par with treatment for other conditions. Experience from other states shows that parity will increase premiums 1% or less.
- **Improve mental health care in the criminal justice system so that these individuals can successfully regain their place in the community.** For too many individuals with mental illnesses prisons have become the primary locus of care. The State must address staffing issues by adding additional mental health staff to bring staffing ratios in alignment with recommended standards for correctional institutions. We also support creation of a Mental Health treatment facility equivalent to the Wisconsin Resource Center to meet the needs of women with mental illness.



**Survival Coalition supports the priorities of the Wisconsin Council on Mental Health.**

## A Life in the Community Requires Access to Community Resources

Available and affordable community resources can make a huge difference in the ability of an individual with a disability to live independently in his or her community.

### **Housing**

**Increase the availability of integrated, affordable, and accessible housing.**

- WHEDA should require housing developments that use tax credits to incorporate Universal Design for increased accessibility of new housing.
- Support an increase in the real estate transfer fee along with other dedicated funding streams to fund a state housing trust fund annually at the level of \$80 million. The state housing trust fund should be dedicated to increasing the availability of affordable, accessible, integrated and safe housing.
- Wisconsin received the highest federal Money Follows The Person award in part because of the commitment to the housing component. Wisconsin should honor that by dedicating funding to support housing in the community for people moving out of institutional living.

### **Transportation**

**Increasing the State's investment by \$6 million in the next two years would improve access to vital transportation services.**

- People with disabilities, particularly people with severe disabilities, cannot live independently in the community without transportation services. Access to employment, education, and health care are all affected by the availability of transportation for people with different mobility needs.
- The State's investment in the Specialized Transportation Assistance Program (85.21) for the elderly and disabled, however, is only a fraction of what is needed. Counties are forced to divert funds from other equally critical human services to make up the difference.
- Access to transportation services remains limited.

## Survival Coalition Members

American Association on Intellectual and Developmental Disabilities, WI • AARP– WI • Arc Dane County • Arc Wisconsin Disability Association • Autism Society of Southwestern Wisconsin • Brain Injury Association of Wisconsin • Coalition of Wisconsin Aging Groups • Community Alliance Providers of Wisconsin • Disability Rights Wisconsin • Easter Seals-Kindcare, Inc. • Epilepsy Foundation – South Central • Family Voices • Grassroots Empowerment Project • Hearthstone • Independence First • Independent Living Council of Wisconsin • Independent Living Resources • Learning Disabilities Association of WI • Mental Health Association of Wisconsin • Midstate Independent Living Consultants • NAMI - Wisconsin, Inc. • National Multiple Sclerosis Society, WI Chapter • Opportunities, Inc. • Options in Community Living • People First Wisconsin, Inc. • Rehabilitation for Wisconsin, Inc. • Residential Services Association of Wisconsin • Respite Care Association of Wisconsin • Service Employees International Union Local 150 • Society's Assets, WI • The Steinhauer Group • United Cerebral Palsy– WCW • Waisman Center • Wisconsin ADAPT • Wisconsin Coalition for Independent Living Centers • Wisconsin Council on Children and Families • Wisconsin Council on Developmental Disabilities • Wisconsin Council on Physical Disabilities • Wisconsin FACETS • Wisconsin Occupational Therapy Association

## Ensure Adequate Medicaid Funding

Medicaid is the primary health care system for many people with disabilities. In order to help Wisconsin maintain and expand its Medicaid program, the Survival Coalition supports increasing the tax on cigarettes and other tobacco products. For cigarettes, we support an increase of \$1.25 per pack. The Coalition also supports measures, such as placing the proceeds into a segregated fund, that would ensure that the revenue generated by the tax be used only for Medical Assistance and smoking cessation programs. Earmarking these dollars for these purposes must be a part of this type of tax increase.

A substantial increase in the cigarette tax is a win-win for the State and its residents because it will also decrease the number of Wisconsinites who smoke. With increased cigarette costs, smoking rates, especially among young people, are expected to decline. Research shows that a 10% cigarette price increase reduces youth smoking rates by 6.5% and adult rates by 2%. This will improve the quality of life for many Wisconsin residents and take further pressure off of the Medical Assistance program as less people access it to help pay for smoking-related illnesses and chronic diseases.



**The time is right for increasing the cigarette tax for a healthier and more fiscally sound Wisconsin.**

## Our Vision

The Survival Coalition of Wisconsin Disability Organizations is committed to creating a society in which:

- People with disabilities of all ages receive the services and supports needed, throughout their life span,
- people with disabilities can choose to live their lives as they wish and be full participants in community life.

### *Mission Statement*

The Survival Coalition of Wisconsin Disability Organizations will be a leader in influencing the political process about resource allocation, laws, and policies which will advance our vision.

### *Principles*

1. Survival Coalition is a cross-disability coalition which works in partnership with local organizations, coalitions, consumers, advocates, and families throughout the state and makes intensive efforts to ensure that our priorities promote and advance the wishes of people with disabilities and their families.
2. Survival Coalition will promote policies, programs, and practices that advance integrated, individualized, community-based supports and services.