

DIRECT CARE WORKFORCE BUDGET PRIORITIES

STATEMENT

The state of Wisconsin is in a Workforce Crisis. Direct-Care Workers, otherwise referred to as Personal Care Aides, Home Health Aides, Nursing Aides, Orderlies, Attendants, Therapy Aides, Job Coaches, Peer Mentors and Respite Workers are the backbone of Wisconsin's Long Term Care system. Wisconsin's Direct Care workforce is essential to the health and independence of people with disabilities and the elderly. This workforce network is also essential to meeting the expectation of the Olmstead decision and to keep the promise of access to services through the statewide expansion of Family Care, IRIS and Children's Long-Term Support Waiver.

Unfortunately, due to low wages and inadequate Medicaid provider rates the industry is experiencing record turn-over with some agencies experiencing turnover rates of 67%. A growing number of direct care workers continue to seek employment outside of healthcare into other industries offering better hours, wages, and benefits. Providers and consumers statewide are reporting great difficulty in recruiting and retaining quality direct care workers. The inability to attract and retain direct care workers has resulted in many long term care recipients going without essential care compromising their health, safety, and their ability to live in the community.

BACKGROUND

Wisconsin's direct-care workforce reported by PHI totals more than 39,000¹ workers and is larger than any other occupational grouping in the state. By the year 2022 the need for personal care workers is projected to increase 26.4 %. In the next 30 years, the ratio of Wisconsin's residence age 65 and older to the entire state population will grow from 1 in 7 to 1 in 4.⁴

Long Term Care recipients continue to report difficulty in finding personal care workers. Many consumers are forced to be without assistance. A recent Survival Coalition survey revealed that 85% of long term care recipients don't have enough workers to work all of their shifts.² 60% also report that they get sick more often when they don't have enough workers.²

Professional Healthcare Institute (PHI) and other nationally recognized workforce experts report at least 51% of direct-care workers in Wisconsin and surrounding states rely on some form of public assistance such as food stamps or Medicaid. The estimated fiscal cost to the state of providing these benefits in 2009 was upwards of \$180 million.³

The current funding available in the long-term care industry make it fiscally impossible for service providers to provide training, competitive wages, and benefits to this workforce. After

nearly 14 years, Medicaid reimbursement rate for personal care services were increased by 2% (\$.32 per hour or \$16.40) in 2017 and another 2% increase in 2018 (\$.33 per hour or \$16.73), and there have been no rate increases since July 1, 2008. This long awaited increase is helpful but continues to be inadequate. The impact of prolonged insufficient rates has resulted in personal care agencies closing and unable to meet the infrastructure costs needed to maintain their businesses

RECOMMENDATIONS

- Survival Coalition recommends **Wisconsin Department of Health Services (DHS) make the Direct Care Workforce Crisis a priority**. This priority would support people who rely on the direct care workforce to remain independent and would recognize personal care agency's growing difficulty to recruit and retain a quality direct care workforce. A proactive approach is necessary to address the current workforce crisis and to meet the anticipated growth for these services in the future.

Strategies to address the crisis recommended by the Centers for Medicare and Medicaid include: establishing an open registry of workers for public use; supporting home care worker training and development; analyzing the relationship between wage sufficiency, workforce health, and access to care; developing tiered rate structures that provide enhanced reimbursement for services rendered by workers who are able to serve beneficiaries with more complex needs or have other advanced skills.

- Survival Coalition recommends **DHS not recreate the prolonged lapse in rate adjustments** so Personal Care Agencies (PCA's) can offer competitive wages and benefits and to keep pace with the cost of doing business. Reimbursement must also account for additional costs to agencies associated with Federal and State mandates such as the 2019 implementation of Electronic Visit Verification (EVV).
- Survival Coalition recommends **DHS Re-invest the projected \$60 million Medicaid Surplus** by addressing the direct care workforce crisis. Increasing the Medicaid personal care reimbursement rate by \$2.50 would cost \$26 million GPR per year. This increase would bring reimbursement rates in line with provider costs and allow agencies to increase direct care worker wages.

This would also alleviate public assistance costs—it is estimated that 51% of the current direct care workforce is utilizing various forms of public assistance¹, increasing the wages of direct care workers will result in decreasing workforce utilization of public assistance. Additionally, the surplus funds could be reinvested to support family caregiver tax credit initiatives and expand benefits of the Medicaid Purchase Plan (MAPP) to further support working individuals with disabilities. There is also opportunity for an enhanced rate to cover costs associated with supportive employment and job coaching for people with disabilities.

- Survival Coalition recommends additional funding to support an increase in wages for all direct care workers in the long-term care system including CLTS, Family Care, Partnership

and IRIS. This infusion of funds must be sustainable and address wages for all workers to include: personal care, supportive home care, home health aides, therapy aides, job coaches, peer mentors and respite workers.

- Survival Coalition recommends **training and “network adequacy” quality measures for Family Care, IRIS and Children’s Long-Term Support.** These measures would uncover the current and future growth of workforce needs and would capture the impact of unmet care needs as a result of the workforce shortage. This data would be helpful to address any health and safety concerns and capture preventable costs associated with hospitalizations, ER visits, nursing home and other facility based costs when community / in-home services are not available.

Additional support from Managed Care Organizations, IRIS Consulting Agencies, and other stakeholders to partner with personal care providers to identify shared responsibilities related to recruitment and retention of the direct care workforce. A concerted effort must be made by all to recognize the value of direct care workers and the complex nature of the work. Such a collaboration is needed to address challenging behaviors and environmental barriers which often lead to workforce turn over.

A stronger collaboration between DHS and DWD to invest in training and education opportunities identified by stakeholder groups that will continuously develop a quality direct care workforce and offer career pathways. Effective training is linked to retention and greater job satisfaction and reduced turnover costs. Specific training opportunities include accessing resources available through apprenticeship, Fast Forward Grants, and Health Care Assistance Training. Measurements must be monitored to provide evidence that additional funds and training positively impact Wisconsin’s direct care workforce crisis and reduce long term care recipient’s health and safety risks and utilization of higher cost services.

- Survival Coalition recommend **DHS to work with Personal Care Agencies (PCAs) to eliminate rules that add burden and cost but no value.** There is opportunity to reduce costs and administrative burden for PCAs by eliminating the red tape. An example is the growing concern for the CMS mandate for Personal Care Workers to obtain Medicaid provider numbers and registration will negatively impact recruitment and retention. This initiative must consider the barriers facing many direct care workers such as language, access to technology, and other necessary resources to meet the expectations of the rule.
- Survival Coalition recommends **DHS create a Medicaid Buy-In waver for direct care workers and unpaid caregivers.** Many direct-care workers are also Medicaid BadgerCare recipients. A Medicaid Buy-In model would allow workers to earn and save more in exchange for paying a premium, may encourage worker retention, and may encourage workers to contribute more hours to Wisconsin’s caregiving needs.

¹<https://phinational.org/resource/state-of-care-wisconsins-home-care-landscape/>

²Survival Coalition 2016 Survey

³PHI State Facts: Wisconsin's Direct-Care Workforce fact sheet, issued by PHI in December 2017. More information is available at <http://phinational.org/policy/states/wisconsin>

⁴Wisconsin Department of Administration, Demographic Services Center, Wisconsin's Future Population, Projections for the State, Its Counties and Municipalities, 2010 - 2040, December, 2013

EDUCATION BUDGET PRIORITIES

STATEMENT

Improving Education for Wisconsin Students with Disabilities. Survival Coalition supports high expectations for all students with disabilities. This means students must be fully included in their general education curriculum and classroom, learning alongside their peers and are supported to be career and workforce ready. An investment in quality public education for every child with a disability should result in access to postsecondary education or competitive employment in the community and the skills to live independently with necessary supports. Wisconsin parents of children with disabilities are reporting significant dissatisfaction with special education supports and sometimes reporting critical concerns due to lack of funding in special education.

BACKGROUND

Wisconsin public schools educate 867,800 students; approximately 14% of those children have disabilities and qualify for special education services through an Individualized Education Plan (IEP). These services may include education related therapies, classroom accommodations, modified curriculum, or one-on-one support. Research shows us even students with the most significant disabilities can make progress in grade level content when provided with appropriate supports. Unfortunately, academic performance for Wisconsin students with disabilities is poor. The 2017 4th grade reading scores recently released by the National Assessment of Educational Progress show Wisconsin students with disabilities scoring nearly 10 points below the national average (177 to 184). Approximately 76% of Wisconsin 4th graders with disabilities scored "below basic" in reading.

Special education categorical aid in Wisconsin has remained flat for a decade while special education costs have increased over 60% since 2000 and the rate of reimbursement has fallen from 35.8% to 25.7%. The current special education reimbursement rate for Wisconsin public schools forces Districts to make tough choices to make up the difference. At the same time, funding for the special needs scholarship program will balloon this year to 90% of the cost to educate a student with a disability. This shows unfair state funding support for the great majority of students who receive their special education in public schools. In many areas of Wisconsin students with disabilities have no choice school options, or these schools indicate they cannot meet a child's needs.

574 parents of students with disabilities responded to a recent Survival Coalition survey about the quality of special education in Wisconsin. Families shared significant concerns around loss of staff, poor implementation of services, increases in disciplinary measures and concerns for their children's future.

RECOMMENDATIONS

Invest in Students with Disabilities in our Wisconsin Public Schools

- Increase state special education categorical aid funding to keep pace with local costs. Support an additional \$600 million in special education categorical aid. Fund 60% of costs up from 26%, addressing a decade-long funding freeze by the 2nd year of the biennium.
- Even out the reimbursement rate for the special needs scholarship program to more closely match the reimbursement rate for students with disabilities in public schools.

Support Families to Advocate for Results and Quality Special Education

- Initiate a meaningful audit of special education quality and outcomes, including the preparation of students with disabilities for college and the workforce.
- Direct DPI to develop an internal special education quality improvement plan to address achievement gaps for students with disabilities. Direct DPI to set benchmarks for targeted areas (i.e. academic, disciplinary, least restrictive environment and college/workforce readiness indicators and report annually to the legislature.
- Require a review of the quality of education provided to students with the most significant disabilities and outcomes in state-funded County Children with Disability Education Boards. Require CCDEBs to be placed within the state's school accountability system to provide parents with information on student academic, post-school and other outcomes before their children are placed in these settings.
- Support enhancement of the current school accountability system to ensure that schools of all kinds – public, voucher, charter, County Children with Disability Education Boards (CCDEBs) report similar data and that allows for informed choice and comparison between options for parents.

Support Students with Behavioral Needs to Succeed

- Increase the state investment in statewide implementation of Positive Behavioral Intervention and Supports. (PBIS) is an evidence-based strategy that gives teachers critical tools to increase academic performance of all students while managing a positive environment and contributing to school safety. School safety proposals must include funding for increased PBIS in Wisconsin schools.
- Support legislation to limit the use of restraint and seclusion in schools.
- Expand categorical aid funding for school mental health staff. Increase categorical aid funding to \$44 million and expand to include more pupil services staff extend including school counselors, psychologists, and nurses.

- Increase community and school collaborative mental health grants. Increase grant funding to \$10 million to support integration and co-location of community mental health services in schools.
- Provide \$5 million in statewide training and support to include the creation of a new state program to fund parent peer specialist to help assist families in overcoming emotional and mental health challenges.
- Expand statewide training for school staff and community partners around mental health screening and interventions. Increase funding to \$1.42 million for statewide training in Youth Mental Health First Aid, Trauma Sensitive Schools, and SBIRT (Screening, Brief Intervention, Referral and Treatment).

Focus on Youth Outcomes in Transition

- Increase the Transition Readiness grants from the current \$1.5 million up to \$5 million annually to better prepare students with disabilities for community employment and independence after high school by meeting their transition goals.

TRANSPORTATION BUDGET PRIORITIES

STATEMENT

Transportation is critical to maintaining the independence of people with disabilities. Many people with disabilities do not drive or own a vehicle because of their disability and/or limited income. Access to transportation is consistently the top concern for people with disabilities in Wisconsin. When people with disabilities cannot access transportation or the transportation network does not get them where they need to go when they need to, they are unable to work, spend money at local businesses, attend worship, or visit family and friends.

BACKGROUND

Transportation is the number one concern identified by people with disabilities. People with disabilities are not able to get where they need to go on their schedule. Community employment, staying healthy, and independently taking care of personal business depends on reliable and routine access to transportation. If rides don't come or are late, it can cause other disruptions in an individual's life. Increased costs can result when more transportation must be scheduled, appointments are missed, or jobs are lost because unreliable transportation makes commuting impossible.

Barriers to transportation for people with disabilities include; limited transportation on weekends and evenings, transportation options or routes not going where people need to go, rides being cancelled or not arriving on time, and lack of accessible transportation. Other barriers to transportation include high fares or unaffordable rates, one-ride one purpose

programs that do not allow people to use the same ride to accomplish multiple tasks, fragmented transportation systems that fail to connect to each other (between towns, across county lines etc.).

RECOMMENDATIONS

- Survival Coalition recommends **DHS reform the Non-Emergency Medical Transportation (NEMT) brokerage** to ensure pay for performance billing for all NEMT rides, establish additional criteria for the NEMT broker, and establish independent oversight and quality assurance of NEMT services.
- Survival Coalition recommends **DWD request additional \$1.8M appropriations each year of the biennium for the Wisconsin Employment Transportation Assistance Program (WETAP)** to expand the funding available to help low income people commute to work.
- Survival Coalition recommends **DOT request an additional \$2.5M in state appropriations** for each year of the biennium to enhance existing federal funding **for rural and regional mobility management**.
- Survival Coalition recommends **DOT request a 10% increase each year** of the biennium for specialized and public transit as well as **18M in continuing appropriations** to restore previous cuts to transit funding.
- Survival Coalition recommends **DOT request creation of state-funded continuing appropriation lines for coordinating, operating, improving, and developing public transportation options**, available to counties and transit commissions that are pooling funding for the purpose of regional transportation across and throughout their service area.
- Survival Coalition recommends **DHS require inclusion of transportation as a component of employment outcomes for LTC participants** working in community integrated employment or receiving community integrated employment services. Transportation must be directly connected to employment goals in care plan development.

EMPLOYMENT BUDGET PRIORITIES

STATEMENT

Wisconsin's economy depends on all workers being in the game. In 2016, Wisconsin's unemployment rate was only 4.2%, and since then, employers report a desperate shortage of workers, particularly entry-level employees. Nationally, studies consistently show that managers positively view people with disabilities, regarding them as easy to supervise and producing as much work, or more than co-workers without disabilities. Yet nationwide, the

employment rate for people with disabilities is only 17.9%, compared with 65.3% for the general population.

BACKGROUND

Wisconsin is having success in getting people with disabilities to work, but there is more to be done. Project SEARCH trains students with significant disabilities for a variety of jobs and has a nearly 90% employment success rate. The Division of Vocational Rehabilitation (DVR) is serving more clients than ever before. Wisconsin PROMISE moving youth with disabilities and their families from reliance on public benefits to work and increased economic independence. Still, some populations of people with disabilities and some areas of Wisconsin are being left behind. Currently, working-age adults in Wisconsin's long-term care system are still only employed at levels of 4% to 10%. Many people with disabilities say they want to work in the community and are not connected to employment supports.

RECOMMENDATIONS

- Survival Coalition recommends that Department of Health Services (DHS) develop a One-Time Provider Transformation Fund to support employment service providers in the state's long-term care system. Providers would be selected through a competitive process and must meet sustainable, measurable outcomes that move people who have shown an interest in working in integrated employment into competitive-wage community jobs. The Fund could operate similarly to the 2017-2019 Biennial budget direct care and services fund increase.
- Survival Coalition recommends that DHS implement a tiered rate system across long-term care programs that takes into consideration a person's individual employment support needs, differentiates between unique services and prioritizes competitive integrated employment.
- Survival Coalition recommends that Department of Workforce Development (DWD) develop a Transportation-to-Work Fund that matches employer contributions with state funds to provide transportation to a competitive integrated employment job.
- Survival Coalition recommends that Department of Children and Families (DCF) support creation of an Individual Development Account (IDA) program, modeled after success in the PROMISE Youth Supplemental Security Income pilot project that matches youth earnings to purchase work-related expenses.
- Survival Coalition recommends that DWD increase access to high-quality benefits counseling to all workers with disabilities using strategies identified through the PROMISE project. Effective strategies identified in PROMISE have led to better outcomes at lower costs.

- Survival Coalition recommends that DWD continue support for the PROMISE Family Advocacy network system which has shown success in supporting families to reduce reliance on public benefits by connecting them with appropriate resources and supports that lead to employment.
- Survival Coalition recommends that (Department of Public Instruction (DPI) propose an increase in the incentive payments to \$1,500/youth (currently \$1000/youth) for competitive integrated employment (CIE) outcomes and ensure that payments are targeted specifically toward youth directly engaged in CIE or post-secondary education.
- Survival Coalition recommends that DPI create a \$100,000 incentive fund for schools to engage in Community Conversations related to employment for youth in their communities. Funds would be awarded with an expectation that a defined number of youth with disabilities achieve competitive integrated employment in the following year demonstrating an increase from the prior period. Schools could apply for \$1000 grants to conduct these conversations with required participation from area employers, community leaders and other stakeholders. The fund should account for necessary support to ensure implementation with fidelity. [Community conversations](#) have proven to be an extremely successful strategy for raising community and employer expectations for youth with disabilities, cultivating local commitment and getting youth jobs.
- Survival Coalition recommends that Wisconsin state agencies become “model employers, (Barnett, S., & Krepcio, K. (2011), In Brief.) developing strategies for moving people with disabilities into careers in state government. Recently, a number of governors have recognized the importance of increasing employment and work opportunities for people with disabilities within state, county and municipal government in addition to efforts to increase employment rates in the private sector.
- Continue funding of successful Partners with Business employment pilot to increase employment opportunities for people with significant disabilities and equip businesses to hire and retain workers with disabilities.

MENTAL HEALTH BUDGET PRIORITIES

STATEMENT

Mental health is crucial to so much of life and ill health can result in serious repercussions for individuals, families and society as a whole. One in 5 Wisconsinites experience diagnosable symptoms in a year and more than 230,000 adults have a psychiatric disability, also called "serious mental illness."

- In Wisconsin over 700 people die by suicide each year – 60% of them had a depressed mood but only 52% of those who died had received mental health treatment at some point.

- Children with mental health conditions are less likely to graduate from high school than youth with other disabilities.
- These conditions tax criminal justice systems – 30% of men in prisons and upwards of 60% of those in county jails have diagnosable conditions.
- Over 50% of individuals in the long-term care system need services to address mental health or substance use conditions in addition to services for their other disabilities.
- Conditions cause more days of work loss and work impairment than many other chronic conditions such as diabetes, asthma, and arthritis.
- Mental Health conditions often co-occur with other chronic health conditions, resulting in more sickness and death.
- Adults living with psychiatric disability die on average 25 years earlier than other Americans.

People do recover, even from the most serious conditions, when treatment and services are available.

BACKGROUND

The Governor and Legislature made significant investments in mental health in the 2013-2105 biennium, recognizing the urgent need to expand access to community services and supports. While progress has been made, children and adults in Wisconsin still face many barriers to accessing community services and supports that promote recovery, and far more needs to be done to increase access and quality. It is a smart investment to fund a continuum of services including psycho social rehabilitation, housing, benefits counseling, and employment supports, because these help people maintain their independence and limit reliance on more costly and traumatizing crisis and inpatient services. This includes program models which support employment, peer-run respite services, reducing incarceration and improving the reintegration back to the community of adults and juveniles who are incarcerated. In addition, the Legislature has yet to significantly address the prejudice, discrimination and isolation that prevents recovery.

RECOMMENDATIONS

- Survival Coalition recommends that DHS work with peers, advocates, providers, educators, and other stakeholders to develop a plan to address the shortage of mental health and substance use disorder professionals in Wisconsin. People with mental illness face significant challenges to receiving the mental health services they need because there are too few of mental health professionals in the state. **49** of Wisconsin's **72** counties are designated as "Mental Health Professional Shortage Areas".
- Survival Coalition recommends that DHS enhance the effectiveness of the Individualized Placement and Support (IPS) employment training programs by funding technical assistance and support to the counties running these programs. Increase the responsiveness of IPS programs to the employment training needs of individuals moving to work under the Medical Assistance Purchase Program (MAPP).

- Survival Coalition recommends to the Interagency Council on Homelessness (?) funding two Housing First pilots; one in South East Wisconsin and one in a less populated area of the state to encourage capacity-building of affordable, accessible housing for low-income individuals, many of whom are people with mental illness.
- Survival Coalition recommends that DHS create a state funded program to ensure access to mental health and substance use services in the language of Deaf Wisconsinites and which includes a statewide mental health coordinator, peer specialist program and clinical training and supervision.
- Survival Coalition recommends that DHS increase opportunities for paid in-home respite for families who have a child with a serious emotional condition.
- Survival Coalition recommends continued expansion of Opening Avenues to Reentry Success (OARS) to additional regions of the state. OARS has been an effective means of reintegrating inmates needing services back into the community and reducing recidivism.

MEDICAID BUDGET PRIORITIES

STATEMENT

Wisconsin's strong Medicaid program is essential to the health and independence of people with disabilities. Adults with a disability are more likely to be: low-income, have less access to health care, and report higher health risk factors and chronic conditions. The Medicaid budget should not be balanced in a way that harms individuals with disabilities. People with disabilities rely on specific supports only available to them through Medicaid.

BACKGROUND

Medicaid provides affordable, quality health coverage to individuals with disabilities. Many people with disabilities do not have access to private health insurance or cannot have all their needs met through private insurance plans – this is especially true for people who rely on non-emergency medical transportation, home care services, or need comprehensive mental health and substance abuse services. Medicaid helps people with disabilities see primary care doctors, receive personal care services, go to the dentist, see therapists and obtain other needed medical services and equipment. In Wisconsin, adults and children may use a specialized long-term care program such as Family Care or IRIS while others use a more general program like BadgerCare. There are also programs designed to help children with significant disabilities (i.e. Katie Beckett) and working adults with disabilities gain access to Medicaid (e.g. Medicaid Purchase Plan).

RECOMMENDATIONS

- Increase reimbursement rates of all Medicaid home and community-based providers, including Medicaid personal care services, private duty nurses, mental health and

substance abuse providers;

- Change DHS policy interpretation to allow funding for Medical Assistance Personal Care (MAPC) to be provided to individuals with disabilities in community settings, not just within the confine of their homes. The change will allow more people with disabilities to pursue work and volunteering in the community and will provide more flexibility to families with young children with significant disabilities who may otherwise be homebound. DHS recently eliminated the settings restriction for home health services, which will allow people with disabilities to receive these needed supports anywhere — not just in their homes. Rules and funding policies should be consistent for people who receive MAPC to ensure equal access to community.
- Improve access to Medicaid allowable services that are subject to prior authorization by reducing repetitive administrative review, increasing the number of visits, providing a timely response to requests and streamlining the prior authorization (PA) process (reduced administrative costs);
- Prioritize development of a culturally competent and adequate network of providers for all Medicaid programs, including SSI Managed Care and BadgerCare;
- Expand Medicaid to adults between 100% and 133% of the Federal Poverty Level;
- Fund at least 3 DHS positions for implementation for MAPP changes created by the 2017-19 state budget;
- Address lack of dental care accessibility for people with disabilities, including increase in dental care provider reimbursement rates and incentives for more providers to accept Medicaid;
- Maintain current eligibility criteria, authorized services and supports, and do not reduce reimbursement rates;
- Fund pilot programs that address the social determinants of health for Medicaid enrollees with a particular emphasis on access to housing.

LONG-TERM CARE BUDGET PRIORITIES

STATEMENT

Survival Coalition advocates for a community-based support system that allows people with disabilities and the elderly to live inclusive lives in the community with individualized and appropriate services to meet their needs.

BACKGROUND

Wisconsin's system of Long Term Services and Supports helps people with disabilities and older adults maintain better health and independence through support/services in individual homes, and other community-based settings. Nursing homes and other institutional settings are a more costly way to provide care. The State, Counties, Managed Care Organizations, Self-Direction (IRIS) Consulting Agencies and direct care workers provide assistance for people with daily living tasks—like dressing, bathing, meals, household chores and tasks, getting ready for work, transportation—and management of chronic health conditions. The Department of Health Services (DHS) oversees Wisconsin's Long Term Care programs including Family Care, IRIS, PACE/Partnership, and Aging and Disability Resource Centers.

RECOMMENDATIONS

- Survival Coalition recommends **DHS request an appropriation line for continuous outcome improvement initiatives** for the improvement of employment, transportation, and community living outcomes for people with disabilities, and analysis of innovation project outcomes.
- Survival Coalition recommends **DHS create a Medicaid waiver for “pre-Medicaid” individuals**. Wisconsin could use its waiver authority to grant access to a limited package of HCBS services for low income older adults, family caregivers, and people with disabilities who are financially eligible for Medicaid and need supports to remain independently in their homes, but do not yet meet the functional criteria (nursing home level of care) required by Family Care/IRIS.
- Survival Coalition recommends **DHS establish one or more county mental health crisis pilot projects** between based on the existing Mobile Crises Centers (Milwaukee) and Community Ties (Dane County) models, an MCO, a county CLTS program, and county mental health department to keep people with I/DD in the community and out of mental health institutions.
- Survival Coalition recommends **DHS have robust stakeholder involvement before proposing changes to LTC system design or specific long-term care programs**, and continue stakeholder engagement throughout any change or transition process.

CHILDREN WITH DISABILITIES BUDGET PRIORITIES

STATEMENT

Children and youth with significant disabilities can need unique supports to fully participate and benefit from community experiences that benefit all children. Added responsibilities beyond typical parenting for families include critical roles as advocates, care coordinators, benefits navigators and 24/7 caregivers. They must leverage supports, services, community connections,

and employment opportunities for their children. Supporting families in these roles and ensuring full community inclusion is cost effective and needs to become a major focus in our system of supports and services.

BACKGROUND

Families play key roles in identifying and securing opportunities for their children to participate in meaningful ways within their community increasing the likelihood of having self-determined lives. A modest investment in families, so they have the support, skills, information and training necessary to be effective in their roles, results in the most efficient use of both formal and informal supports. Such an investment will help both families and children with disabilities live healthier lives. Historically we have invested more resources into designing systems and delivering services than in ensuring the best outcomes for families.

An investment in supporting families as they navigate school, health, community and disability resources ensures the right amount of support at the right time. This support reduces family stress and maximizes community connections for children with disabilities. Not all families need the same roadmap to be successful. The right support at the right time is critical.

Recent analysis by the Department of Health Services reveals that despite efforts to reach all eligible families, only 25% of children potentially eligible for long-term supports or other programs are actually connected to services. While not all families may need publicly funded supports, most benefit from information about resources and connection to other families.

- Thank you for championing an end to the wait list for children and families needing long-term supports and services. Survival Coalition recommends DHS make this commitment to all newly eligible children by **including CLTS funding in the base Medicaid budget.**
- Survival Coalition recommends **DHS request an appropriation to plan and implement Family Support and Disability Resource Centers (FSDRCs) to supporting families and children with disabilities** FSDRCs will provide a central point of contact for:
 - Comprehensive Information and assistance for children with disabilities;
 - Family Navigators to help families access resources already available in their health, community and school systems;
 - Family Education to help families effectively work with schools, medical and community resources;
- Family-to-Family connection for mutual support and community engagement
 - Eligibility Determination for public and private programs
- Survival Coalition recommends **DHS monitor elimination of the waiting list** and initial enrollment in CLTS waiver to insure that all eligible children have access to the waiver regardless of county capacity to enroll new children from the wait list. The budget should reflect funding and staffing for this initiative as necessary.

- Survival Coalition recommends **DHS provide funding and staff to address the lack of access to Medicaid allowable services, particularly HealthCheck Other Services, to reduce delays, denials and cost shifting to the waiver for Medicaid services that are currently allowable but hard to access.** This includes developing an internal process and substantive outreach with guidance and tools for providers; provider education; service coordinator education and; family education on the use of the benefit. The budget should reflect funding and staffing for this initiative as necessary
- Survival Coalition recommends **DHS support a state and county infrastructure and needed staff to eliminate disparities to access and utilization of long-term supports** for children served in the children’s waiver. We believe all families, regardless of race, ethnicity or geography should have equal access to supports and services. Counties must provide uniform program implementation and assure that staff have the skills necessary to support families and children. The budget should reflect funding and staffing for this initiative as necessary.

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