

AN ISSUE BRIEF FROM THE FAMILY SUPPORT COUNCIL

ON BEHALF OF FAMILIES OF CHILDREN WITH DISABILITIES



SUPPORT

The following agencies and organizations fully endorse the implementation of the listed recommendations and support a statewide, comprehensive family support system.

Cerebral Palsy Association of Ohio

Easter Seals of Ohio

Federation of Families for Children's Mental Health

NAMI Ohio

Ohio Brain Injury Association

Ohio Coalition for the Education of Children with Disabilities

Ohio Developmental Disabilities Council

Ohio Governor's Council on People with Disabilities

Ohio Legal Rights Service

Ohio Olmstead Task Force

Ohio Self Determination Association

Ohio Statewide Independent Living Council

Ohio's University Centers on Excellence in Developmental Disabilities
(University of Cincinnati and Nisonger Center at The Ohio State University)

People First of Ohio

AN ISSUE BRIEF FROM THE FAMILY SUPPORT COUNCIL

ON BEHALF OF FAMILIES OF CHILDREN WITH DISABILITIES

FAMILY SUPPORT SYSTEM NEEDED AND WANTED BY FAMILIES

This issue brief calls for a cross-disability, noncategorical and comprehensive family support system for all families who provide care for children or adults with any disability. While this issue brief focuses on families as decision makers, it should, in no way, diminish the tenets and importance of self determination for people with disabilities.

“We get no support from anyone. My husband and I do all the caregiving and pay for everything ourselves, including our insurance. It has taken a toll on our health, our marriage and our family. I have tried to get help on a daily basis to help with dressing, bathing, etc. No one will do this or help us find someone to do it.”
- Lucas County parent -

Children, youth and many adults who have disabilities live with their families. Family caregivers make independence and inclusion possible. These families face challenges, sometimes extraordinary ones, that other families do not. They have additional needs - beyond a typical family's needs - for supports and services that address their child or loved one's disability and the family's stability. Family caregivers need support to meet the physical, emotional and economic demands of every day living.

Families and other informal caregivers are the backbone of care for people with disabilities and older adults. Yet their daily challenges are often ignored. Many caregivers are thrust, without information, training or support, to assume the duties of nurse, case manager, financial and benefits planner, social worker, mediator, therapist, advocate and pharmacist. Too often, the contributions of parents and other family caregivers are taken for granted and undervalued.

Supporting individuals with disabilities to live at home, and providing caregivers the support they need, is a civil rights issue. Ohio's spending of scarce resources is not well aligned with its values of community participation, productivity, and equal rights. Ohio's spending on nursing homes and other facilities far exceeds the small amounts of money used to support family caregivers.

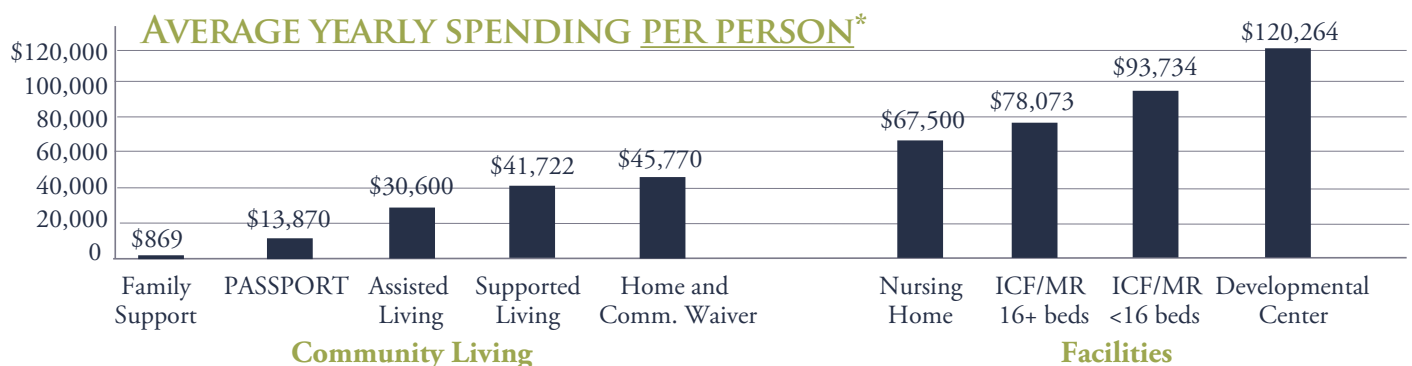
Family caregivers save Ohio millions of dollars annually - implementing the recommendations in this issue brief is good public policy and fiscally responsible government spending.

The Family Support Council (FS Council) is a group of family advocates, most who have children with disabilities. This Issue Brief, written by family members from the FS Council and endorsed by other state-wide agencies and organizations, is for policy makers to educate and inform them about Ohio's need for a family support system.

ECONOMIC IMPACT ON CAREGIVERS

For over three decades, researchers from the United States and internationally have documented the need for and the cost effectiveness of family support programs. More recently, studies have shown the economic impact of family caregiving.

- More than one in five adults, in excess of 44 million Americans, provide care to a loved one, friend or neighbor. American businesses lose between \$17.1 and \$33.6 billion annually in lost productivity costs due to family members providing informal supports.¹
- AARP conservatively estimates the national economic value of family caregiving for people with disabilities in 2007 at a stunning \$375 billion, exceeding total federal and state Medicaid contributions that year.² AARP conservatively estimates the value of Ohio family caregivers of older people and adults with physical disabilities at \$14.2 billion.³
- The financial costs of caring for children with disabilities are considerable. Families can have significant unreimbursed out-of-pocket expenses for health care, assistive technology and other necessary items. Their families' average median income is almost one quarter lower than families raising typical children (\$38,332 to \$50,098).⁴
- Families of children with disabilities - across all income levels - experience significantly greater hardship than other families, including adequate food and housing, access to health care, and paying for utilities.⁵ Many of these working, tax paying families are being driven to financial collapse.
- Families spent an additional \$6,300 per year (in 1990 dollars) in out-of-pocket expenses for their adult child with a developmental disability, compared with families who did not care for a member with a disability.⁶
- More than 1.6 million American service members have deployed to Iraq and Afghanistan. Over 30,000 returned with visible wounds and a range of permanent disabilities. An estimated 25-40% have less visible wounds psychological and neurological injuries associated with Post Traumatic Stress Disorder or Traumatic Brain Injury, which have been dubbed "signature injuries" of the Iraq War.⁷
- Taxpayers pay for unsupported caregivers in increased health care costs, less revenue from those who are underemployed or unemployed, and the high emotional and financial costs of institutionalization when care at home is not possible (see table). The Scripps Gerontology Center reports one-quarter of Ohioans with severe disabilities live in nursing homes.⁸
- Private health insurance covers the health needs of only a fraction of children with disabilities and is not considered a primary source of funding for family support services.⁹



* Data for this table were from Braddock and Scripps - see source numbers 14 and 15 on page 8.

OHIO'S SPENDING OF RESOURCES BENEFITS FACILITIES RATHER THAN FAMILIES

Historically, Ohio spends a disproportionate amount of long term care funds on services to people living in large facilities rather than funding supports needed to keep people in their home. This statistic remains constant despite the expressed wishes of people with disabilities and their families to receive services in their community homes.

- In fiscal year (FY) 2006, Ohio spent 83% of its Medicaid long-term care budget for older adults and adults with disabilities in nursing homes,¹⁰ despite an AARP study showing, an overwhelming majority of consumers prefer to remain in their home or community.¹¹
- From FY 2001 to FY 2006, Medicaid spending on home and community based services increased by \$251 million, compared to a \$342 million increase in spending for nursing homes.¹² This increased funding represents 36% more dollars for nursing homes.
- Ohio continues to reduce the funding for family support programs. The Ohio Department of Developmental Disabilities' 2009 and 2010 budget for family support is one half of one percent of the agency's total budget.¹³ Across the states, the average spending per family was about \$5,000. Ohio's average per family was \$870.¹⁴
- The Scripps Gerontology Center forecasts that the size of Ohio's population with severe disability will increase by 13% over 13 years. State Medicaid spending is currently 24% of Ohio's overall budget. Scripps projects that steady increases in numbers of people with disabilities, combined with constant increases in Medicaid long-term care expenditures, will cause Medicaid to consume half of the state budget by the year 2020. Such Medicaid expenditures are not sustainable and this forecast should compel the state to explore alternatives to long-term care services and supports.¹⁵
- The Ohio Department of Aging forecasts a 33% growth in Ohioans over the age of 60 from 2007-2020. Director Barbara Riley noted that the cost of home-based PASSPORT services is one-third the average nursing home cost, and assisted living is half the cost of a nursing home. If Ohio reached the national average of spending on home and community based services versus institutional services, a savings of \$900 million per year in Medicaid costs would be realized.¹⁶



The help we receive is a blessing, but for years we were on our own. The damage done to our family from those years is permanent! Families need to be made aware of help right away!"

-Tuscarawas County parent-

Ohio is at a crossroads with skyrocketing health care costs, particularly for long-term care, and plummeting revenues to fund services. For too long caregivers of children and adults with disabilities have been expected to shoulder unrealistic burdens that would fray any family.

It is estimated that approximately 61% of the people with a disability in the United States live with their family, who are their primary caregivers. An additional 15% live with their spouse, and another 13% live on their own.¹⁷ Over the years, families have increasingly made the choice to stay together and no longer routinely place their child/adult child in institutional care. As a result, the need for family support has increased.



Caregiving has all the features of a chronic stress experience. It creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, and can create secondary stress at work and in relationships with families and friends.¹⁸ The Institute on Community Integration reports that increased

control over respite and personal care services can result in numerous benefits including reduced stress, reduced financial worries, increased self-efficacy, increased satisfaction with services, and a decreased need for out-of-home placement.¹⁹

Families who are primary caregivers for adults with disabilities have substantial responsibilities and worries. Caregivers worry about what will happen to their loved ones if they become too sick or injured to provide care. Some caregivers have to quit their jobs or cut hours. Those who are employed worry about missing work when a provider is late or doesn't come at all, or for unexpected appointments.

Some families providing care for individuals have historically been underserved, including:

- People with brain injuries have no coordinating state or local agencies, and individuals and families often have a very difficult time finding services. Children and adults with brain injuries, and those with mental or behavioral health needs, too often face stigma and heightened discrimination.
- Ohio families with children who have challenging behaviors and mental illnesses are desperate to secure necessary treatment. They are sometimes forced to give up custody to the child welfare and juvenile justice systems. Neither system is intended to provide behavioral health care. Children are taken from those who love them and placed in settings that are often not therapeutic, and parents can no longer exercise parental rights to advocate for their children.²⁰
- Returning veterans with disabilities and their families deserve quality services. Yet, the National Council on Disability notes, "The wars in Iraq and Afghanistan are resulting in injuries that are currently disabling for many, and potentially disabling for still more. They are also putting unprecedented strain on families and relationships, strain that can contribute to the severity of the service member's disability over the course of time."²¹

Ohio needs an inclusive family support system. Families who are primary caregivers for children and adults with disabilities need varying degrees of support. Ohio must create a statewide family support system, with consistent rules and policies across all human service systems and funding streams that meets individual needs and provides meaningful choices.

"Because I work I have medical insurance, but my minimal income is just enough to exclude me from other public assistance. We struggle to survive." - Summit County parent -

FAMILY SUPPORT DEFINED

Family support is best defined as an array of practical supports that are determined by individual family needs. Ideally, family support is flexible, focuses on the entire family, changes as family needs change, encourages families to use natural community supports, and provides a convenient and central access to services. Services are based on each family's unique needs and the beliefs that all children belong with caring families, and adults with disabilities or daily functioning needs should have meaningful choices. The intent of family support is to provide or arrange for individualized, necessary supports that prevent crises and out-of-home residential placements.

Family support can include direct cash payments to families, vouchers, tax breaks, reimbursement, or direct payments to service providers that help families keep their relatives at home. Services can include

respite, family counseling, future planning, home or vehicle modifications, in-home training, sibling support programs, education and behavior management services, and assistive technology. The goals of a family support program are to help families cope with the stress associated with caregiving, and build on existing strengths and resources.²²

Many families want to raise their children at home and are only asking for help needed to make that possible. Families with older adults or adults with disabilities similarly need family support. According to Carl Dunst, a pioneer in family support research, "Research questions are no longer 'does family support work but what principles of family support provide for the best outcomes?' " The FS Council developed the following principles of a quality family support system.

*"We need people to pay attention and not give just lip service – you people should spend one long day in our shoes."
- Summit County parent-*

PRINCIPLES OF FAMILY SUPPORT

A Quality Family Support System:

- is family-directed and family-controlled and involves families in all phases of design, construction, administration, evaluation and governance.
- views families as the primary resource and decision maker for their child.
- includes individual supports, services and material items that provide "whatever it takes, whenever it is needed" to keep families together and healthy.
- builds on family strengths and based on family preference, choices and values and not on administrative expedience.
- includes resources reserved for emergencies as determined by the family.



- is proactive, fair, flexible, easily accessible, affordable and continually responsive to changing family needs, roles and ages.
- coordinates with the general service delivery system to assure maximum efficiency.

RECOMMENDATIONS

Implementing the recommendations contained in this brief is fiscally responsible. Creating a family-determined, cross-systems family support system is essential so that families stay together, and all family members have equal opportunities to participate in schools, workplaces and neighborhoods.

Develop and fund a statewide, cross-disability, comprehensive family support system that includes respite. Families consistently tell policy makers that Ohio needs a family support system that is cost-efficient, flexibly meets individual needs and includes respite as an essential component. Ohio's support system should support all primary caregivers, including foster and kinship families and for families whose children have challenging behaviors. A comprehensive system supports families and helps prevent them from relinquishing custody for their child to receive services. Family support also helps avoid institutionalization and referrals to law enforcement or the justice system.

Implement a universal assessment system to evaluate the needs of family caregivers. Ohio must identify the needs of caregivers through an automated assessment mechanism. This assessment must take into account caregiver needs, including stress, burden, and health status. Family caregivers should be reassessed annually or sooner when a significant change happens. States that have uniform assessment systems are automating them for improved efficiency.



“We need a way to get equipment that is not seen as medical but is, such as safety mats, more advanced safety latches, safety fences inside and out. We need an educational allotment for family education. Many families take time off to raise children with disabilities then re-enter the workforce. Training is often needed to re-enter.”

- Delaware County parent -

Reimburse family caregivers equitably and protect them from discrimination. Ohio's system must be modified so family caregivers are reimbursed for their services. This modification is not about shifting responsibility for family member care, rather, it is about supporting willing caregivers to maximize the value of tax dollars and to improve outcomes.

Many caregivers are called on to provide specialized services, for example, administering prescribed medications or performing health-related activities like tube feedings. They are at risk of health problems from stress, anxiety or straining to lift and carry. They have out-of-pocket costs and problems paying medical bills.

When not providing care for a family member in their home, caregivers face challenges keeping jobs, health insurance and other benefits. Ohio can follow Maine's lead and protect family caregivers from discrimination in employment, housing or access to public accommodations.²³ Ohio can provide a state tax credit to family caregivers to help lessen families' economic burden.

RECOMMENDATIONS

Adequately reimburse direct support workers and continue efforts to recruit, train and evaluate them. Disparities in pay and benefits among state-employed providers, independent providers and providers from private agencies should be addressed. Individuals and families eligible for services often go without because of the lack of qualified providers.

Implement the Unified Long-Term Care Budget based on consumer choice and need. Consumer choice and need should drive Ohio's budget allocations. Individuals should receive the right services, in the right settings at the right price. National programs have shown the benefits of implementing a consumer choice and needs plan. A simulation using Oregon's model showed that Ohio could serve 40,000 more people and save \$600 million.²⁴ Vermont created an entitlement to home and community based services for "highest need" individuals. Vermont reduced the number of Medicaid nursing facility residents by 9%, and increased home and community based case loads by 155%, including services for 1,183 "moderate need" individuals. Vermont used a global long-term care budget, allowing the elimination of the Medicaid program's institutional bias. Spending growth was less than half of what the state had projected when the program was designed.²⁵

"These families bear a work burden for the state and there needs to be compensation given with services, financial supplements and respite."

- Lucas County parent -



"Finding caregivers is difficult. Does not seem to be any agencies that can find them. We are looking for a group home for our daughter due to the fact we cannot find caregivers. We do not want to do this, we HAVE to do this."

- Summit County parent -

Develop a mechanism to assure family involvement and family control of Ohio's comprehensive family support system. The mechanism should consist of people with disabilities and family members who are caregivers of children or adults with disabilities or older adults with functional limitations. This individual and family group would be involved in all phases of the family support system including design, construction, administration, evaluation and governance.

Quotes in this Issue Brief are from a survey of nearly 2,300 Ohio families raising children with disabilities. The survey was conducted from August 2000 to May 2005 by the Family Support Council.

- 1.** How Employers Can Support Working Caregivers, AARP, July 2007, www.aarp.org/money/work/articles/how_employers_can_support_working_caregivers.html
- 2.** Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update, Research Report, A Houser, MJ Gibson, AARP Public Policy Institute, November 2008, http://assets.aarp.org/rgcenter/il/i13_caregiving.pdf
- 3.** Across the States 2009: Profiles of Long-Term Care and Independent Living, AARP Public Policy Institute, Howser, et.al., http://assets.aarp.org/rgcenter/il/d19105_2008_at.pdf
- 4.** Census 2000 Special Reports: Disability and American Families
- 5.** Material Hardship in the U.S.-Families Raising Children With Disabilities, Exceptional Children, Parish, et.al. Vol 75(1), Fall 2008
- 6.** Family Support Service in the United States, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, Vol 17(1), February 2006
- 7.** Invisible Wounds: Serving Service Members and Veterans with PTSD and TBI, National Council on Disability, March 4, 2009
- 8.** Scripps Gerontology Center Research Brief, Disability In Ohio: Current and Future Demand for Services, Shahla Mehdizadeh, April 2008
- 9.** The Arc Q&A on Family Support, August 2003
- 10.** State Long-Term Care Reform in Ohio, AARP Public Policy Institute, http://assets.aarp.org/rgcenter/il/2008_10_ltc_oh.pdf
- 11.** Taking the Long View: Investing in Medicaid and Home and Community-Based Services is Cost Effective, AARP Public Policy Institute, March 20
- 12.** State Long-Term Care Reform in Ohio, AARP Public Policy Institute, http://assets.aarp.org/rgcenter/il/2008_10_ltc_oh.pdf
- 13.** The Office of Budget and Management - Blue Book - Executive Budget for Fiscal Years 2010 and 2011
- 14.** State of the States in Developmental Disabilities, D. Braddock et al., Coleman Institute for Cognitive Disabilities and Department of Psychiatry, University of Colorado, 2008
- 15.** Scripps Gerontology Center Research Brief, Disability In Ohio: Current and Future Demand for Services, Shahla Mehdizadeh, April 2008
- 16.** Budget Testimony for the Ohio Department of Aging, Barbara Riley, Director, House Finance and Appropriations Committee, March 5, 2009
- 17.** State of the States in Developmental Disabilities, D. Braddock et al., Coleman Institute for Cognitive Disabilities and Department of Psychiatry, University of Colorado, 2008
- 18.** Physical and Mental Health Effects of Family Caregiving, R Schulz, P Sherwood, American Journal of Nursing, September 2008, www.nursingcenter.com/pdf.asp?AID=81578
- 19.** Family Support Service in the United States, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, Vol 17(1), February 2006
- 20.** Nowhere to turn: must parents relinquish custody in order to secure mental health services for their children? National Alliance for the Mentally Ill, July 2003
- 21.** Invisible Wounds: Serving Service Members and Veterans with PTSD and TBI, National Council on Disability, March 4, 2009
- 22.** Family Support Service in the United States, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, Vol 17(1), February 2006
- 23.** HP0664, LD 962, item 1, 124th Maine State Legislature, An Act To Protect Family Caregivers, www.mainelegislature.org/legis/bills/bills_124th/billpdfs/HP066401.pdf
- 24.** State Long-Term Care Reform in Ohio, AARP Public Policy Institute, http://assets.aarp.org/rgcenter/il/2008_10_ltc_oh.pdf
- 25.** Taking the Long View: Investing in Medicaid and Home and Community-Based Services is Cost Effective, AARP Public Policy Institute, March 20

FAMILY SUPPORT COUNCIL

50 West Broad Street, Suite 1400
Columbus, Ohio 43215-5923

Phone:

(614) 466-7264 • (800) 282-9181

TTY:

(614) 728-2553 • (800) 858-3542

The FS Council is funded by the Ohio Developmental Disabilities Council, under the U.S. Department of Health and Human Services, DD Assistance and Bill of Rights Act and administered by Ohio Legal Rights Service.

Published September 2009

OHIO DEVELOPMENTAL DISABILITIES COUNCIL

8 East Long Street , Suite 1200 • Columbus, OH 43215

800-766-7426 voice • 614-466-5205 voice • 614-466-0298 fax

www.ddc.ohio.gov

