Policy

Many public policies have been developed without attention to families and should be modified to be consistent with the family support framework. Current policy provides, at best, a patchwork of sometimes conflicting laws, rules and regulations that prevent or inhibit supporting families. A starting point to address these is:

- Include the family support strategies in support and service planning for individuals with IDD

- Eliminate the bias against funding goods and services that help families in their caregiving role

- Allocate funding to provide for highly flexible supports and services that best meet family needs and sustain family involvement, but may not be Medicaid allowable

Resources

Lifespan Family Research Program, Waisman Center, University of Wisconsin waisman.wisc.edu/family/
The Lifespan Family Research Program is dedicated to the advancement of knowledge about families who have a member with a developmental disability or severe mental health problem, with a special emphasis on how these families change over the lifespan.

The National Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities supportstofamilies.org
The Supporting Families project, funded by the Administration on Community Living, involves working with selected states to develop systems of support for families throughout the lifespan of their family member with intellectual and developmental disabilities.

Building a National Agenda for Supporting Families with a Member with IDD 2012
Report of the Wingspread Conference, Racine 2011. Hecht, E., Reynolds, M. The National Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities supportstofamilies.org/ The Supporting Families project, funded by the Administration on Community Living, involves working with selected states to develop systems of support for families throughout the lifespan of their family member with intellectual and developmental disabilities.

Waisman Resource Center 608.265.8610; wrc@waisman.wisc.edu
The Waisman Resource Center provides free and confidential information and assistance to families and care providers of children and youth with special health care needs. The Waisman Resource Center is staffed by a team of professionals in the fields of social work and education, and with experience in a variety of disability-related areas.

References

[1]Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends Through 2013. 2015.
[2]Wendy S. Looman, O'Conner-Von S., Ferski G., Hildenbrand D. 2009. Financial and Employment Problems in Families of Children with Special Health Care Needs: Implications for Research and Practice. Journal of Pediatric Health Care, Volume 23, Issue 2, March–April 2009, Pages 117–125.
[3]Parish, S.L., Rose, R.A., Andrews, M., Grinstein-Weiss, M., Richman, E.L., & Dababnah, S. (2009). Material hardship in US families raising children with disabilities: Research summary & policy implications. UNC School of Social Work.
[4]Seltzer, M.M., Floyd, F.J., Song, J., Greenberg, J.S., Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: Impacts of lifelong parenting. American Journal on Intellectual and Developmental Disabilities, 116(6), 479-99. doi:10.1352/1944-7558-116.6.479
[5]The National Survey of Children's Health 2007. Wisconsin Dataset.
[6]Caregivers of Younger Adults: A Focused Look at those Caring for Someone Age 18-49. 2015. Research Report. The National Alliance for Caregiving and the AARP Public Policy Institute.
[7]Swenson, S., Lakin, C. 2014. A Wicked Problem: Can Governments be Fair to Families Living with Disabilities? Family Relations. v63 Issue 1 p.185-191.
[8]Braddock, D., Hemp, R., Rizzolo, M., Tanis, E., Haffer, L., Wu, J. The State of the States in Intellectual and Developmental Disabilities 2015. University of Colorado. p. 57

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University Center for Excellence in Developmental Disabilities

Making the Case for Supporting Families in Wisconsin

In 2011 the Waisman Center and the Administration on Community Living convened a national meeting of organizations and state agencies to develop a definition and set of strategies to support families who have a family member with an intellectual or developmental disability (IDD).

Waisman staff co-authored the conference report (**Wingspread**), which set the stage for a national agenda on supporting families. Consistent with the **Wingspread Report** we propose action steps that Wisconsin can take to incorporate these recommendations into state policy and practice.

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"The hardest part of having a child with disabilities isn't taking care of him; it is the constant fight to get what he needs. It is exhausting."

Issue Statement

Families are a fundamental unit of our society, often serving as a primary source of support for all of its members. For individuals with intellectual and developmental disabilities (IDD), the role of the family is unique. In addition to all the ways typical families help each other, family members of individuals with IDD play key roles in identifying and securing opportunities for their family members to participate in meaningful ways within their communities and ensuring access to self-determined lives. For many families, the support provided does not end when the family member exits school or lives outside the family home. Yet, currently, the vital role of families is not fully recognized in disability policy and practice.

Background

Much of the national and state dialog about individuals with IDD concerns the sustainability of our public system of long-term supports. We believe that one pathway to sustainability is to invest in supporting families. Although data show that families are the primary "system" of support for individuals with IDD, the infrastructure of publically funded services and supports has been built primarily to help providers and agencies charged

Background, continued

with delivering a specific set of services, largely ignoring the family unit. It is time to refocus our efforts on supporting families to meet the complex and varied needs of family members with IDD. If we are to sustain the contributions of families across the life course, we need to reduce the challenges they can experience while providing support.

Today there are more than 4.7 million citizens with IDD in the United States–85,895 in Wisconsin–most of whom live with a family member.[1] Not surprisingly, the impact on the family system is significant. Parents and other family members often provide medical, behavioral, financial, and other daily supports beyond what is typical for most families.

Unfortunately, for many of these families, the lack of access to family supports and services can make it difficult and sometimes impossible to maintain their jobs, pay for health insurance, and keep their family intact.

Research suggests that the lifespan impact of caring for a family member with IDD can include: lower earnings; greater job instability; increased reliance on public assistance; reduced retirement savings; greater health risk factors; and for aging parents with co-residing adult children, elevated rates of depression, divorce, isolation, poorer physical health, and functional impairments. [2-6]

Nationally, uncompensated family caregiving for disabled and elderly persons is estimated to have a value of $450 billion annually.[7]

In 2013, 6.7% of total IDD spending was directed to supporting families, a decline from the 2011 spending level of 7.2 %.[8]

The Wingspread Report: A Framework for Supporting Families

The Wingspread Report proposed a set of strategies for families that, when implemented together, mitigate challenges experienced by the family, assist family members who have key roles in the provision of support, and address the emotional, physical and material well-being of the entire family.

Wingspread Report

The framework for support is designed to respond to the diverse and changing needs of individuals families and includes three primary components:

- Information, education, and training on accessing and navigating supports and services; advocacy and leadership; and best practices within and outside of disability services

- Community connections to non-disability resources, and networking families with other families, including parents, self-advocates, siblings, grandparents and guardians

- Family-directed services and goods that are specific to the daily support and/or care-giving needs of the person with IDD, such as planning for future needs, respite, crisis prevention and intervention, systems navigation, home modifications, and health/wellness management

Recommendations

Supporting the contributions and efforts of families who assist a family member with IDD is key to the financial sustainability of our long-term support system. As we commit resources to supporting families, it is critical that we have an understanding about which supports contribute to family wellbeing and how best to design and deliver those supports.

The following are a sampling of next steps to implement support to families in state policy and practice.

Programs and Practice
We know that various aspects of the family support framework are effective. We can advance our understanding of these aspects of the framework using the following:

- Invest in each of the three family support strategies. For example, offer a single point of entry to services and supports for children; increase the number of staff knowledgeable about building family networks and strategies for coping with stress such as psychoeducation and mindfulness training; and provide funding to assure timely access to services

- Incorporate the family support framework into individual support plans for state long-term supports and services for people with IDD

- Use family outcome measures to inform training and technical assistance to providers of long-term supports and services

- Provide training and technical assistance to build and support a workforce skilled in supporting families.

Quality Assurance
We need to better understand how to implement the framework, what is most effective, and who is likely to benefit. The following measures will help guide this understanding:

- Develop an evaluation tool based on a set of family outcomes and indicators that can be used to measure the impact of specific family support strategies

- Describe and measure the impact of the family support framework on family stress, health, and economic well-being

- Measure the impact of educating families on systems change efforts at the state and federal level, e.g., choices about sheltered or integrated employment