

Two States' Efforts to Strengthen their Support of Families: Supporting Individuals Living with Families is the Foundation of a Sustainable Future

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(NASDDDS)**

Today close to 60 percent of people with intellectual/developmental disabilities (I/DD) receiving services live in their families' home (National Residential Information Systems Project RISP 2010) which means that families are primary support for the majority of people enrolled in services. This percentage of people getting supports in their home has been growing as states have responded to family preferences for in-home supports and as they look for alternatives [to] too expensive and hard to staff 24-hour residential arrangements – group homes.

Waiting lists continue to grow and we know that the extraordinary funding increases of the past two decades are not likely to continue in the future. States have already come to terms with this reality as evidenced by the growth of “home-based” waivers. These waivers provide in-home and community services to people living with their family.

Supporting families is the pathway to a sustainable system and a sustainable future. The purpose of providing support to families is to strengthen their capacity to support their family member with a disability to have a good life. The more families know, the more robust their network of support and the more secure they are that they are not alone; the stronger will be their capacity to provide support.

Thinking of family in the broadest sense means including siblings, grandparents, other relatives, and sometimes friends of the person and the family. This broad approach to how we think about family multiplies the possibilities for individuals to live in the community they know and to stay close to family members. Supports that are robust, reliable, and portable can make it possible for the person and anyone they have a relationship with [such as] adult siblings, other relatives or friends, to share a life together if they wish.

Supporting families is more than delivering the standard service menu. Even as we increase the number of supports provided to families, somehow they do not feel supported. Respite care, a day program, and physical adaptations are helpful but these do not address the broader needs of families. Families want to know that they can and should do to make a good life for their family member. They want to know where to find opportunities in their community, what the possibilities are for adulthood, and how to plan for the future. Families often need help figuring out how to balance opportunity and risk. And families get strength from talking to and getting assistance from

people who have walked in their shoes – other families. **Supporting individuals and the families they live with is a multi-dimensional effort (Nancy Thaler and Sheli Reynolds):**

- **Discovery and Navigation:** Families want to know what they can do. They want to know how to access generic services in the community (e.g. a play group for a child or a community chorus an adult could join) as well as disability services and they sometimes need assistance doing so; they want knowledge about best practices so they know what to advocate for; they need training in advocacy and leadership skills so they can help their family member in all the domains of life.
- **Networks of Support:** Parent meeting parents, self-advocates meeting self-advocates, and siblings meeting siblings offer the kind of mutual support that strengthens people's spirits and empowers them to create their own solutions.
- **Services:** Individuals and families need services that are specific to daily support and care-giving, respite, crisis prevention and intervention, home modifications and health and wellness management, and planning for current future needs.

This is LIFESPAN Work: Individuals with developmental disabilities and their families generally begin the journey at birth and have needs that change across the lifespan. From birth, through early childhood and the school years, transition to being a working adult and then planning for the golden years are what families think about. And the quality of their life journey will depend on the type of life they expect and foster for their family member. However, without the supports to discover and build this life, starting early and lasting throughout the lifetime, options and possibilities become limited to the traditional services that our formal system has offered.

The Administration on Intellectual and Developmental Disabilities (AIDD) has been engaging stakeholders to facilitate the development of a national agenda and policy recommendations to further elevate the importance of family support. The following is a working definition from the 2011 ADD National Agenda on Family Support Conference:

http://www.partnership.vcu.edu/documents/ADDFamilySupportSummitReport3_2012.pdf

To support families, with all of their complexity and diversity, in ways that maximize their capacity, strengths, and unique abilities so they can best support, nurture, love and facilitate the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.

Defining, understanding, and implementing family support in new ways is a core function of state I/DD agencies.

Connecticut and Missouri's efforts to strengthen their efforts to support individuals and the families they live with in their homes and communities.

CONNECTICUT: Terrance W. Macy, Ph.D., Commissioner for the Connecticut Department of Developmental Services (DDS) has appointed Robin Wood as Director of Family Support Strategies and Advocacy.

Robin's role as the director will be a catalyst for new strategic thinking about how we convert our legacy systems to improve the way we support families to maximize their capacity and strengths so they can best support their family members. Commissioner Macy added, "We have intentionally inserted a change agent in our midst. Robin will be an integral member of our executive team and will oversee the implementation of our ambitious Five Year Plan, People and Families First. The plan has 25 goals which focus on creating a system which reflects the agency's new vision and mission."

"Not only is she a parent but she is also a very experienced professional and a well-practiced systems advocate. She understands the strengths and weaknesses of our systems, has a national perspective on current trends and issues and will provide the leadership we need to pivot our services to be much more person and family responsive," says Commissioner Macy, stating this position has been a priority of his for a long time.

MISSOURI: Bernie Simons, Director of Missouri's Division of Developmental Disabilities, has initiated a new model of supporting families by collaborating with its Missouri Family-to-Family Resource Center housed within the University of Missouri Kansas City UCEDD.

The purpose of the initiative is to connect families to other family mentors at all stages of interaction with the service system including intake, yearly planning, or anytime contact with the family is made.

When explaining the importance of the new model and collaboration, Bernie said, "Reaching out to families is pivotal in maintaining and sustaining needed supports. Family to Family support is immeasurably valuable and it should not be underestimated."

The partnership with the Family-to-Family Resource Center provides families with educational and emotional supports beyond the formal supports provided by the service system. Case managers receive training and technical assistance on supporting families and connecting families to this partnership through a newly created position. Family Support Coordinators are located in each of the 12 Regional Offices around the state. The Family Support Coordinators enhance their capacity by receiving on-going professional development and access to information and tools from the Resource Center, which is staffed by professionals who are family members. Bernie expressed enthusiasm about the partnership, stating, "Missouri is fortunate to have [UMKC staff] Sheri Reynolds working with our families and providing training and technical assistance to family support coordinators in reach region."