



Wingspread Conference Center Racine, WI  
Sunday, March 6, 2011 - Tuesday, March 8, 2011

**BUILDING A NATIONAL AGENDA FOR SUPPORTING  
FAMILIES WITH A MEMBER WITH INTELLECTUAL AND  
DEVELOPMENTAL DISABILITIES**







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**The Johnson Foundation at Wingspread** is dedicated to serving as a catalyst for innovative public and private solutions in two spheres – one global and one regional – that reflect the Johnson Family’s longstanding passions: healthy environments and healthy local communities. Over the course of 50 years the Johnson Foundation has hosted leading thinkers and helped to inspire consensus and action on a range of public policy issues, including other disability policy-related issues.

**The Administration on Developmental Disabilities (ADD)** is based in the Administration of Children and Families (ACF) in the United States Department of Health and Human Services (HHS). The mission of the ADD is to ensure that individuals with intellectual/developmental disabilities (I/DD) and their families participate in the design of and have access to culturally-competent needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life.

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# EXECUTIVE SUMMARY

**FAMILIES** are the core unit in our society, serving as a source of support for all of its members. For individuals with intellectual and developmental disabilities (I/DD), the role of family is unique and often central in the support and care provided across the lifespan. Family members play key roles in identifying and securing opportunities for their family members to participate in meaningful ways with in their community and ensuring access to self-determined lives. Parents and other family members of individuals with I/DD often provide medical, behavioral, financial, and other daily supports beyond what most families provide. Yet, the vital role of families is not fully recognized and supported in disability policy and practices.

Supporting individuals with intellectual and developmental disabilities to live and fully participate in their communities throughout their lives

has emerged as a fundamental right and consideration in disability policy and practices. Because of the role that families continue to play in the lives of their family members with intellectual and developmental disabilities, future policies and practices must reflect the family as part of the system of support. This is especially important as the demands for services that support individuals with I/DD are increasing, while at the same time both state and federal funds are diminishing. This situation makes it critical for disability policies to acknowledge the family as a vital partner in supporting the individual to live in the community and to pursue independence, integration and full participation, and that policies and programs recognize both the individual within the context of the family and the needs of all the members.

To provide direction and guidance for such policy reform, a group of diverse national and state disability leaders met and developed



recommendations on the types of supports families need to serve in this role, and made recommendations for advancing a national agenda on supporting the family at the Johnson Foundation's Wingspread Conference Center in March 2011.

This document outlines recommendations from this gathering that must occur to ensure that individuals with I/DD are fully integrated and included in our society and that recognition of their families' role in their lives is part of the equation for success. Each section is designed to build a greater understanding of supporting the family. The first highlights the immediacy of this national agenda, the second describes the details of the Wingspread event, the third describes a world with supports to families across the lifespan, the fourth provides a description of what it means to support families and suggestions, and the fifth offers recommendations for a national

agenda on supporting families. The final section highlights activities that have occurred as a direct result of the Wingspread event.

We hope that many different audiences, organizations and systems use this report to guide further discussions, to begin planning, and to develop specific steps necessary to continue moving policy and practices at the state and federal levels. ■

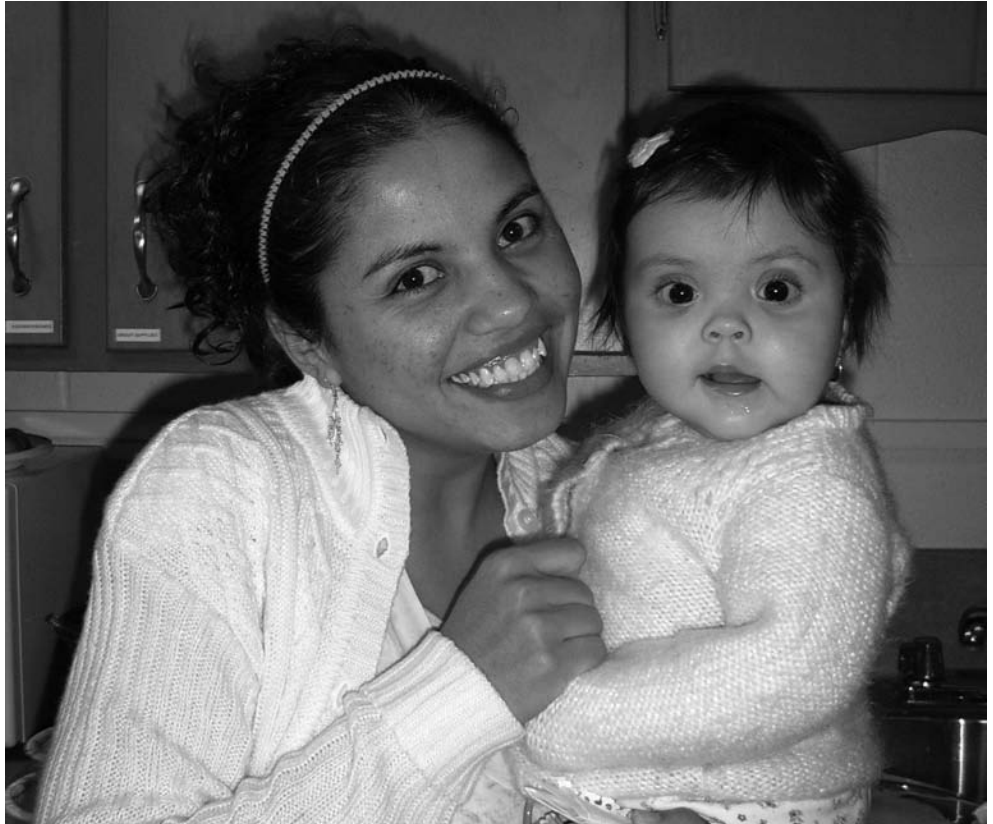


## SECTION 1:

# WHY SUPPORT FAMILIES? WHY NOW?

Disability is as a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self-determination, make choices, contribute to society and experience full integration and inclusion in the economic, political, social, cultural, and educational mainstream of American society

The Developmental Disabilities Assistance and Bill of Rights Act, 2000



**FOR** Americans with intellectual and developmental disabilities (I/DD), the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) provides for the protection and support of the fundamental rights afforded to all U.S. citizens. As a nation, it is our responsibility to not only recognize these rights but to transform our communities so that this is a reality in the everyday lives of individuals with I/DD. This requires the systems that support individuals with I/DD to transform the way they provide services and to recognize the family as a critical source of support that ensures these rights.

### **FAMILIES WITH FAMILY MEMBERS WITH DISABILITIES.**

Today there are more than 4.7 million citizens with intellectual and developmental disabilities in the United States. More than 75% of those living in their communities without formal disability services and relying on their families for varying levels of support. Of the 25% receiving services, over 56% live with their families; in some states, the figure is as high as 80%. For many families, the support provided neither is short term nor does it end when the family member turns eighteen years old.





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Families are defined as a system built upon relationships and strengths, which are called upon to adapt and accommodate to the experiences and changes of all its individual members throughout their lives. Families are resourceful and go to great lengths to support their family member with I/DD. To maintain the family as a system of support, it is important for policymakers and those in the disability field to recognize the types of on-going supports that the families themselves need to serve in this role. The following facts demonstrate where policy and practices that focus on supporting families could improve outcomes:

- Families often are faced with emotional, social, physical and economic demands that they may not have experienced had their child not been diagnosed with a disability.
- Twenty-eight percent of children with disabilities live below federal poverty levels as compared with 16% of children without disabilities.<sup>4,5,6</sup>
- Parents of children with disabilities have lower rates of, and diminished opportunities for, employment and advancement than parents of children without disabilities.<sup>2,7</sup>
- Over 58% of parents/caregivers spend more than 40 hours per week providing support for their loved one with I/DD beyond typical care. 40% spend more than 80 hours a week.<sup>2</sup>
- Long waiting lists for services and the increased lifespan of individuals with I/DD have contributed to a growing number of individuals with I/DD in households where the primary caregivers are themselves aging.

## DISABILITY SERVICE SYSTEM, ECONOMIC REALITY AND THE FAMILY

Disability service systems, through both State and Federal programs, furnish a wide array of services and supports to individuals with I/DD. These services and supports provide opportunities for individuals with I/DD to maximize their full potential and

participate in their families and community. However, these services and supports are undergoing continuous transformation and adjustments as they continue to face new social, political, and economic realities.

## A small percentage of total I/DD spending in the US is allocated to supporting families yet over half of the people receiving services live at home with their families.

The rights of people with disabilities to receive services in the most integrated settings, guaranteed by the Americans with Disabilities Act, has brought about the largest change as states close institutions and shift supports to community settings. While this change is occurring, the demand for long-term supports continues to increase and funding continues to be severely limited. This is further enhanced as the aging of the baby boom generation brings with it an increased need for public resources (Medicare, Social Security, Long Term Supports and Services).

These pressures, combined with a weak economy and large federal budget deficits require that developmental disability service systems transform the way they provide services and support. These changes include first recognizing the key role of the family as a primary source of support\* and for naming the source of day to day caregiving, and, second, supporting the capacity of the family members to provide needed assistance when necessary over time. Supports to the family unit must be a fundamental consideration in budgetary and long-term care policy as our nation moves forward. ■

(\*throughout the lifespan of a person with I/DD)



## SECTION 2:

## THE

# COMING TOGETHER

OF NATIONAL STAKEHOLDERS

A recommendation, by Wingspread participants is to use the phrase “supporting families” because the phrase “family support” is recognized by many as a specific service or program rather than an approach. Our intent is to convey the idea of supporting families using a myriad of strategies, policies and practices, which are both formal and informal.



**IN RESPONSE** to the current issues, the Wingspread Summit on Supporting Families (Wingspread) was convened. The goal of this conference was to develop comprehensive policy recommendations within new realities related to family, community, local, and state levels, as well as to inform the Congressional reauthorization of the federal Developmental Disabilities Bill of Rights Act and other relevant legislation.

Wingspread brought together nationally recognized supporting the family leaders to represent diverse experiences and relationships within the disability field. Wingspread was sponsored in part by the U.S. Department of Health and Human Services, Administration on Developmental Disabilities (ADD), a diverse national planning commit-

tee of supporting the family stakeholders, and the Johnson Foundation at Wingspread.

### The Wingspread Experience

The Johnson Foundation at Wingspread approaches issues without preconceived ideas or fixed agendas. A distinctive feature of the Wingspread approach to hosting summits is candid yet collegial conversation among those with divergent ideas and perspectives – in an environment fostering the trust and collaboration needed for innovative solutions that also can be broadly supported. The Johnson Foundation’s unique convening model, combined with a serene natural environment and gracious hospitality, contributes significantly to the authenticity of the dialogue at their conferences.





In agreement with the Wingspread philosophy, the group that was convened approached its charge using an already determined definition of supporting the family. This determination was made because for too long families and leaders in this field had discussed the “philosophy” of supporting the family, never getting to a concrete definition to build upon. As mentioned above, this conference was not about developing one more new definition of supporting the family, it was about moving forward and each invited participant had to agree to start with the same definition of supporting the family. More debate about what the term meant was not a useful or timely process. The goal was to build the discussion on one existing definition of supporting the family and move to a point of consensus as to just what “supporting the family” means in the real world and then to propose a lifespan model for providing the needed support that can be applied at the local, state and national levels.

The conversation took place over 3 days of extremely intensive work.

1. Day One was designed to *Build the Team and the Vision* and generally to set the tone for the next days of work. In fact one of

the key activities was the opportunity to have an open discussion about just what would be an innovative vision of a “Perfect World for Families with a Member with a Disability.”

2. Day Two was designed to generate solution-focused ideas and after reviewing the working definition of supporting the family and a report on the “State of the States in Developmental Disabilities,” attendees broke up into small groups. These small groups came together to share their discussion and findings as a basis for moving into a “world café” mode. After three sessions of “world café,” the day ended with a wrap-up and a preview of Day Three.
3. Day Three conversations discussed and validated the recommendations from the “world café” activity. The group worked to brainstorm and prioritize elements of a national advocacy campaign and then establish next steps and personal commitments to achieving those steps. ■



SECTION 3:

# WHAT HAPPENS WHEN FAMILIES ARE SUPPORTED?

**WINGSPREAD PARTICIPANTS** were asked to describe a world that supports families that have a family member with a disability. During the creation of this vision, there was an overwhelming recognition that although this “world” has unique features and supports specific for families

with family members with disabilities, it has the same components that would create a the perfect world for all families in the U.S. The following statements from participants describe the outcomes that would be present at the family, disability service and community levels when families are supported.



## FAMILIES WITH A MEMBER WITH A DISABILITY WOULD:

- Have a positive family identity and – if there is a family member with a disability – move beyond any diagnosis and stigma.
- Have opportunities to explore, problem-solve, plan and foster a vision for their family member with I/DD and the entire family, starting early and continuing across the lifespan.
- Have opportunities to invent a life with supports that are consistent with their vision for their entire family, including the member with a disability.
- Have access to the supports necessary to provide support and guidance to their child with a disability and to address the emotional, physical and material well being of the entire family.
- Be confident in their own ability to advocate for and achieve the life they want for their family.

## DISABILITY SERVICE SYSTEMS WOULD PROVIDE SUPPORTS TO FAMILIES THAT:

- Are based on the principle of self-determination, are timely, stable (with a variety of funding streams – generic, local, state, federal), flexible, and continuous.
- Recognize that "family" is defined broadly; it can include parents, siblings, grandparents, extended families and parents that have disabilities.
- Recognize that families have different personalities, learning styles, and issues regarding being "educated." Some families may be resistant to overtures for assistance for a variety of reasons.
- Recognize and adapt to diversity and be culturally competent reacting not only to ethnic differences but also to economic, religious, and geographic differences.
- Bridge "disability system-based" supports with generic and natural supports, responding based on the needs and wants of each family.
- Include all family members, individuals with disabilities, friends, neighbors, community entities, professionals, and providers as part of the support network.
- Recognize that while the goal is to pre-empt crisis, there are going to be times when families need immediate assistance. They need some place to call, someone to talk with, help problem-solve and provide short term assistance during crisis.
- There should be coordinated eligibility not a cumbersome process that requires multiple assessments. It must be structured around a single entry point -- a "one-stop shopping" format.

## COMMUNITIES WOULD:

- Value and support families and individuals with disabilities (realizing achievement of children, families and adults, working, living, and contributing to the community).
- Welcome, accept, and include families and persons with disabilities (feel accepted by friends and neighbors).
- Have a greater understanding of an evolving social contract/construct/obligation to create and maintain a truly inclusive community. (Inclusive here is being broad in terms of acceptance.)
- Be universally designed for physical, cognitive and social accessibility in terms of activities, environment and culture of the community.



# WORLD OF SUPPORTING FAMILIES ACROSS THE LIFESPAN

To further understand what family support looks like, basic themes from the Wingspread participants were categorized across the life-span, illustrating the need for on-going supports for the family that adjust and change as the individuals with I/DD and their family experience different stages of life. This is a sampling of ideas to stimulate discussion rather than a comprehensive list of everything to consider.



## STARTING A NEW FAMILY JOURNEY

When a child is identified with a disability, families should receive accurate information about the diagnosis if they have one and be offered the opportunity to meet with other families with a child with a disability. This is a time when the extended family may also need support understanding the implications of a child's disability. If the opportunity arises, families may want to meet youth, and adults with disabilities who can help them begin to shape a positive vision for the future filled with possibilities. This will help families articulate positive expectations of what their child can accomplish very early in his or her life. Families may also want information about advocacy and family organizations in the community that can help them along the way.



## EARLY CHILDHOOD

Beginning in early childhood, including early school-based experience, families want opportunities to continue building advocacy skills that they have been learning and practicing since their child's birth. As young children start to interact more in child care and school settings, families want more exposure to values-based information related to inclusion, self-determination and best practice. A family who has access to training and information is an empowered advocate who can express to others their hopes for the future. This can help ensure that the family member with a disability has the greatest access to experiences that build self-advocacy skills and promotes high expectations.



## SCHOOL YEARS

Navigating health care, community, education and transitions accompanying the school years requires coordination and cooperation with multiple partners and agencies, both non-disability and disability-specific. This includes laws such as the Individuals with Disabilities Education Act (IDEA), partnerships with medical providers, school districts, vocational rehabilitation, employment providers and state disability systems. This can be a daunting task with many families doing this with little or no assistance. Understanding and advocating for what is needed requires skills and relationships with others inside and outside of the disability world. Access to timely information and assistance is critical to family efficacy as they navigate this maze. The more contacts families have with their community, the more opportunities they have for relationships and networks that provide natural supports – not disability system driven supports. These contacts and supports play an increasingly important role as the child's experiences extend beyond the family.



### TRANSITION TO ADULthood

**Transition from school age to adult life** is always in the back of a family's mind. It is never too early to address planning for the future, including financial savings, post-secondary education plans and employment with many of the experiences that serve as building blocks to the future supported while children are still in school. The transition from high school can be one of the most complex times in the life of the individual and the family. Families want to draw upon all community and generic resources available to help their now adult child plan a life that is community-based, where he or she has a job, home, and relationships just like their peers without disabilities with access to the necessary supports needed to make this a reality.



### ADULT LIFE

**The adult family member moves toward a self-determined life on his or her own, that includes** beginning to search for work, find a place to call home, choose friends, including sexual partners, and maybe decide to start his or her own family. The individual, based on their needs, may continue to interact with both formal and natural support systems. Family members, including siblings, still have a critical role in ensuring access and coordination of the supports needed whether the individual is living with them or in their own home. Educated and empowered families will have learned and taught their children how to live a life based on self-determination and community participation while recognizing that both the family and individual may need appropriate supports across the life-span.



### GOLDEN YEARS

**The time comes when aging caregivers are beginning to have care-giving needs of their own** and it is more difficult for them to play an active role in the lives of their grown children. This is a time of life many parents and families dread as they think of what could happen to their adult child with a disability if they or siblings are no longer around. When life-span education and supports to families are in place – and when that education includes future planning, including financial planning and planning for the life and supports the person needs – these fears can be lessened and planful rather than crisis driven transition can happen. ■

## SECTION 4:

## STRATEGIES FOR SUPPORTING FAMILIES



One of the focuses of the Wingspread event was to gain consensus on a definition of “supporting the family.”

*The overall goal of supporting families, with all of their complexity and diversity, is to maximize their capacity, strengths, and unique abilities so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.*

**THE OVERALL GOAL OF SUPPORTING FAMILIES**, with all of their complexity and diversity, is to maximize their capacity, strengths, and unique abilities so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.

Supporting the family is defined as a set of strategies targeting the family unit but that ultimately benefit the individual with I/DD. Supporting the family strategies are intended to assist family members who have a key role in the provision of support and guidance of their family member with I/DD to address the emotional, physical and material well-being of the entire family. Strategies must be designed, implemented and funded in a manner directed by the family unit. They should be flexible, comprehensive, coordinated and include the following:

- **Information, education, and training on best practices within and outside of disability services, accessing and coordinating community supports, and advocacy and leadership skills.**
- **Connecting and networking a family with other families, including parents with disabilities, self-advocates and siblings, grandparents and other guardians for mutual support.**
- **Services and goods that are specific to the daily support and/or care-giving role for the person with I/DD, such as planning for current and future needs, respite, crisis prevention and intervention, systems navigation, home modifications, and health/wellness management.**

The design of these supports and strategies recognizes the complexity of families in terms of their diversity, experiences, resources and memberships. Members may include parents, some with disabilities themselves, siblings, aunts and uncles, grandparents and others considered to be family. They may live in the same home or within the community in their own homes.

For each family, these supports are unique in terms of the type and intensity, and are often not supports that will decrease overtime as the child becomes an adult, but rather supports that will need to continue across the lifespan. These strategies will assist families as they adjust and accommodate to their new responsibilities throughout the lifespan of the individual with a disability.



### **Information, education, and training on best practices within and outside of disability services, accessing and coordinating community supports, and advocacy and leadership skills.**

Wingspread participants recognized the importance of providing information, education and training for families to enhance their ability to access needed supports and to advocate for new policies that will assist them in supporting their family member with a disability to achieve the life they want. Families need access to educational opportunities very early on in life on possibilities for the future so that they will have “great expectations” for their family member. This will assist families in supporting their family member with I/DD to have access to living, working and advocating in the community throughout the entire lifespan.

Particularly important is access to information and practical application of self-determination, inclusion, integration, the meaning of social capital and the importance of using best practices. Training and information, however must be culturally competent and must be built on the strengths, resources and relationship of that family. Families must also have opportunities for expanding their capacity and applying their skills as leaders and advocates in systems and policies change.

#### **SUGGESTIONS FOR IMPLEMENTATION:**

- Identify family education and training as a billable service under state Medicaid Waiver plans.
- Require DD Act partners to have an individualized mandate in their five-year plans for providing statewide training and education to families.
- Urge Congress to fund Title II of the DD Act to fund education training and systems change efforts programs specifically for families.
- Seek non-traditional funding, such as foundations to fund educational and training initiatives.
- Work together to identify on-going strategies for funding and sustaining supporting the family organizations that are providing education and training to families.

### **Connecting and networking families with other families, including parents with disabilities, self-advocates and siblings, grandparents and other family members for mutual support.**

Wingspread participants realized that if the goal of a new agenda for supporting the family is going to be achieved, one of the key components is the integration of families with a member with a disability into the community. Connections with other families, connections with family groups, and connections with self-advocates help to empower families and the individual with a disability can increase their social capital. These types of connections increase the likelihood that families will have the opportunity to think about a vision for the future, “an enviable” life.

To maintain and expand these connections, it is important to support existing parent, family, and other disability organizations. Family organizations are underfunded and often are the doorway into systems. Sustainability of family organizations is a critical issue, but one must focus on the fact that these family groups play a major role in matching families with services or solutions in a culturally competent and family-specific approach. However, they themselves are in constant need of training and technical assistance.

#### **SUGGESTIONS FOR IMPLEMENTATION:**

- Ensure that organizations focused on supporting families are included as key stakeholders at all levels, especially within the DD service system and DD Act network partners.
- Identify strategies for supporting family organizations to receive on-going technical assistance that supports the infusion of evidenced-based practices and on-going capacity building to meet the changing needs of the families they serve.
- Fund parent-to-parent organizations which have been in place for 40 years and have a proven, cost effective, evidenced-based framework for supporting families.
- Model after other service systems that fund statewide information and training centers that are family-driven and run, such as the Integrate Community Parent Resource Centers (CPRCs) and Family to Family Health Information Centers (F2Fs).
- Support siblings with peer-to-peer efforts. Sibling support is different than parental support. One good example is the Sibling Leadership Network and some states have sibling support groups.

**Services and goods that are specific to the daily support and/or care giving role for the family (as opposed to primarily targeting the individual with I/DD), such as planning for current and future needs, crisis prevention and intervention, systems navigation, home modifications, and health/wellness management.**



Wingspread participants recognize the important role that families play in providing the day-to-day support to their family member with I/DD across the entire lifespan. It is important that the family has the necessary supports to continue in this role. By supporting families in this role, the goal is that the family and the member with I/DD will have an increased quality of life and the demand for long-term or crisis supports will lessen. The type of supports for families varies depending on their individual needs.



*Planning for a future for their family member with I/DD and the entire family system, starts early and continues across the lifespan. Wingspread participants recognized the importance of starting early to develop a strong vision of the future that is continuously updated and expanded across the life span of the family member with a disability. Families must have access to family/person centered thinking tools that can assist them in preventing crisis, increasing self-determination, accessing natural supports and developing a vision for the future. In fact, having this “vision” and helping others to see it was one of the over-arching principles of the conference.*

#### **Reliable crisis prevention/intervention system for families and other caregivers.**

Participants at the Wingspread conference made it very clear on numerous occasions that a system or infrastructure that is built on crisis response not crisis prevention is not serving families well. Participants recognized that crises could be medical, behavioral or caregiving issues, all requiring urgent or immediate attention. An infrastructure would be available to all families and would provide education, training and planning to prevent a crisis. There was also the recognition of the need

to not only prevent crisis but to also have a system that assists families if a crisis cannot be prevented, such as counseling, training and respite supports. In all situations, families should have supports before any crisis so they know they are not alone and that there are supports out there.

#### **Consistent support to navigate and access services within and outside of disability service systems.**

It was the consensus of the participants that the families need supports and services that are seamless, individualized for each family and utilize the disability system and generic supports. Participants proposed a lead go-to person that would be available to help the family navigate across service systems (medical, educational and disability) and community resources and through the many transitions into new systems would increase access to services and supports. Navigation support would integrate all three of the family support strategies. Looked at together these various strategies, when coordinated and individualized across the lifespan can enhance a family’s capacity to provide day-to-day care, coordination of supports and services, decrease their feelings of isolation, and increase all family members’ ability to live full lives in the community.

#### **Health and wellness management supports and services specific to the family member providing daily support and/or care giving.**

Many people define supporting the family in the disability field as concrete services to support the family or caregiver to provide day-to-day supports until the family member is eighteen, such as respite, home modifications and cash assistance. Wingspread participants agreed with this and acknowledged that the general under-



standing must expand the scope of services offered, who receives supports, and possibilities of funding. Family members must have access to supports that assist them in their caregiving and support role throughout the entire lifespan of the individual with I/DD. Health and wellness management and service supports must support the everyday needs of caregiving and support to the family member with I/DD, as well as the health and wellness of the family members to serve in that role.

#### **SUGGESTIONS FOR IMPLEMENTATION:**

##### • Planning Mechanisms for Current and Future needs

- Develop and fund “mechanisms for planning” within current disability service systems that includes a focus on the family unit.
- Hire or connect families to facilitators that understand innovative options within the disability field and think broader than the available disability services in order to connect to community resources.
- Train and develop a cadre of family leaders as facilitators for planning with other families.
- Fund family organizations to facilitate planning with families and/or serve as support brokers.

##### • Crisis Prevention/Intervention System

- Develop and fund “crisis prevention/intervention infrastructure” within the community.
- Ensure that infrastructure develops a system for pre-crisis services, as well as access to 24-hour intervention services for all types of crises: urgent vs. emergency, medical, behavioral or caregiving issues.
- Extend the services of a crisis prevention/intervention infrastructure to all family members and caregivers (i.e. counseling, training, planning, and respite services).

##### • Navigation System

- Develop a recognized role or discipline, “navigator,” that could help families work within and across public systems (disability, education, aging, social services) and community resources.
- Fund a “navigator” using targeted case-management funds to support families in community-based problem-solving. This is a similar but very different function from current case-manager roles as defined by CMS.

- Fund family organizations to provide the navigation function for families across the lifespan.

##### • Health and Wellness Management Services and Supports

- Incorporate person/family thinking into policies and practices, similar to systems change work occurring in several other states with Michael Smull.
- Fund services that support the family caregiver to fulfill their role in providing supports to the Medicaid/Medicare recipient.
- Develop specific mechanisms within Medicaid waivers or tax incentive programs that enable family caregivers to be compensated for providing supports to their adult family member with I/DD.
- Create mechanisms for families to “buy” family support services within self-directed programs.
- Identify strategies outside of Medicaid funding for assisting with caregiving/support needs of a family member with I/DD, such as Human Co-op, Exchange Networks, etc. ■





## SECTION 5:

# RECOMMENDATIONS TO ADVANCE A NATIONAL AGENDA ON SUPPORTING FAMILIES

**TO ENSURE** the rights of individuals with I/DD to be fully integrated and included in our society it is imperative that the role of families is recognized as part of the equation for success. The following recommendations provide direction and guidance for such policy reform that will better support the family's role in services for individuals with I/DD. While these recommendations are interrelated, they are not sequential, nor does the order imply priority.

## RECOMMENDATION 1

**Design the structure and functions of state service systems to include a focus on supporting families reflective of the fact that most people with I/DD are living with their families in the community.**

Wingspread participants felt that both the service system and families needed to recognize the vital role that each can play and the expectations and contributions that each can offer. To do this, the service system must be flexible to the ever-changing demands, needs and resources of families and at the same time families must utilize and have support to access non-traditional, natural and community services.

**The following are specific details for redefining the current service system to be more reflective of a system where families are providing a majority of the care in the system:**

- Identify strategies for collaboration and support with local and statewide family-focused organizations or networks that can assist in the development, implementation and evaluation of strategies for supporting families.
- Establish mechanisms to maintain ongoing dialogue with families, services system representatives and other key stakeholders involved in supporting families.
- Increase opportunities for self/family directed service options.
- Build the capacity of service coordinators/case managers to support and plan with persons with I/DD within the family unit.
- Identify and fund strategies for assisting individuals with I/DD and their families to navigate both disability and community services and supports, including informal or natural supports.
- Provide training to all stakeholders on supporting persons with I/DD within their natural homes and communities, accessing community services along with disability supports as needed.

**RECOMMENDATION 2**

**Develop and fund National Supporting the Family Initiatives that explore principles, practices, and data indicators that will inform practice and policy related to supporting families across the lifespan.**

Wingspread participants propose the development of a national initiative to support families. The purpose is to gain consensus on issues related to supporting families at both the national and state levels that would inform practices and identify policies for advancing family supports. These initiatives would also focus on working together to further define and build collaborations within and outside of the disability system for supporting families across the lifespan, ensuring that community integration is the standard of all the work.

**The following are specific details for developing and funding National Supporting the family initiatives that explore principles, practices, and data indicators that will inform practice and policy related to supporting families across the lifespan:**

- Consider Administration on Developmental Disabilities (ADD) and National Association of State Directors of Developmental Disabilities Services as possible lead conveners and/or funders of these initiatives, along with support from other national organizations.
- Ensure key family-driven organizations, self-advocacy organizations, and the three network partners of ADD (University Centers for Excellence in Developmental Disabilities, State Protection and Advocacy agencies, and State Councils on Developmental Disabilities) serve in lead roles.
- Achieve the following outcomes:
  - Explore and expand promising family support practices, including collaboration with non-traditional partners and efforts.
  - Create a repository for practitioners, researchers, policymakers and family organizations to capture practices, provide models, and connect to products, publications, research and other organizations.
  - Identify strategies to infuse or disseminate family support educational materials and training curricula to a diverse array of target audiences across the nation.
  - Assist in the development of a national data set with indicators to evaluate and research the impact and cost-effectiveness of family support services, practices and initiatives.
  - Provide a feedback loop to state service agencies that redesign the structure and functions of their systems to include a focus on supporting families.

**RECOMMENDATION 3**

**Develop a National Data Collection Initiative with consistent and uniform data to identify the impact on families and people with I/DD, and cost-effectiveness of supporting families across local, state and federal systems.**

As Wingspread participants discussed the issues of supporting families, there was strong consensus around the need for consistent and uniform data to support the investment and cost-effectiveness in supporting family strategies. The discussion at and proceeding Wingspread focused on building consensus on the definition of family support for the intellectual and developmental disability field as the first step in developing a uniform definition that can be put into practice and that has concrete strategies and activities for which data can be collected.

**The following are specific details for developing a national data collection initiative:**

- Develop and fund a national data set with indicators of effective family supports based on outcomes defined within these recommendations.
- Collect data that would evaluate and research the impact and cost-effectiveness of supporting the family services, practices and initiatives.
- Correlate data collection efforts and work in unison with the national family support initiative mentioned above.

**RECOMMENDATION 4****Elevate the recognition of the role of families and the need for supporting families within key Federal policies and national programs.****Key Federal Policy.**

There are several important federal policies that directly impact families who have family members with a developmental disability. The most obvious is the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which assures that individuals with developmental disabilities and their families participate in the design of, and have access to, culturally competent services, supports, and other assistance and opportunities that promote independence, productivity, integration, and inclusion into the community. The DD Act has an important function since it specifically focuses on individuals with I/DD however it is imperative that all federal legislation have language that specifically recognizes and supports families who have members with I/DD as they are reauthorized and/or passed.

The following are specific details to elevate the recognition of the Role of Families and the need for Supporting Families within the DD Act and the Other Key Federal Policies:

- **Reauthorize the Developmental Disabilities and Bill of Rights Act (DD Act):**

- Change the language and focus of the entire DD Act to address building an infrastructure within the community and supports to families so that individuals with intellectual and developmental disabilities are autonomous, resilient and interdependent citizens, as opposed to only focusing on the direct service infrastructure.
- Reauthorize and strengthen supporting families under Title II of the DD act – including funding for each state and accountability to measure outcomes.
- Link the language of the DD Act to the state DD service agency.
- Require the three DD Network Partners to collaborate in developing and funding family support initiatives in their state, similar to the self-advocacy mandate.

- **Reauthorize the Individuals with Disabilities Education Act (IDEA)**

- Increase funding and Amend Part C of IDEA to move away from a medical model and instead focus on helping families develop a vision and expectations for their child and support the entire family.

- Amend Part D to require more accountability requirements on Parent Training Information Centers, place increased accountability requirements on schools related to transition and strengthen language related to Parent Involvement.
- Strengthen transition provisions in Elementary and Secondary Education Act (ESER), IDEA, Higher Education Act and the reauthorization of the Rehabilitation Act.
- Increase funding for Parent to Parent (evidence-based model) program and include Person-Centered Planning (PCP) as part of Parent to Parent so that PCP is provided by peers.
- Amend language in ESEA so that Impact Aid, which goes to the states and school districts with high poverty levels includes disability rates as a variable.

- Add a new provision to IDEA to fund Protection and Advocacy systems to focus even more attention on compliance re Part C and Part D of IDEA and the the Rehabilitation Act.

- **Reauthorize the Older Americans Act**

- Amend the language in the National Family Caregivers Program to ensure that it meets the original Congressional intent of covering aging caregivers of adults with I/DD.
- Strengthen the language related to Aging and Disability Resource Centers (ADRC) so that they address the particular needs of individuals with I/DD and their families and facilities and materials.

- **Reauthorize the Family and Medical Leave Act**

- Ensure that the language covers families with members with I/DD and covers the needed time for leave for necessary care.
- FMLA should define family broadly, covering siblings and other family members who are primary caregivers for family member with I/DD

- **Reauthorize the Lifespan Respite Act**

- Increase funding for the Lifespan Respite Act and ensure that it is inclusive of families with members with I/DD across the lifespan.



### Key National Programs.

Knowing that collaboration between the local, state, and national level is key to accomplishing outcomes, Wingspread participants came up with the number of recommendations for collaborative efforts, while at the same time pointing out the key role of families and self-advocates. It is important to elevate the “critical issues of supporting families with members with I/DD across the lifespan” within organizations, systems and initiatives which may result in the development of both future legislative and non-legislative recommendations.

Specifically the Administration on Developmental Disabilities, as the federal agency that oversees the DD Acts implementation, should serve in a key role in the development of collaborations at the federal and state levels. This should be accomplished through the DD Acts four distinct but integrated entities in almost every state and territory known as the DD Network Partners, Councils on Developmental Disabilities, Protection and Advocacy Services, University Centers for Excellence in Developmental Disabilities, and Projects of National Significance. However, the responsibility does not stop there, it must be the responsibility and the role of all organizations at the state and federal levels whose focus is on developmental disabilities to initiate and collaborate with other organizations both inside and outside of the disability field to advance this national agenda.

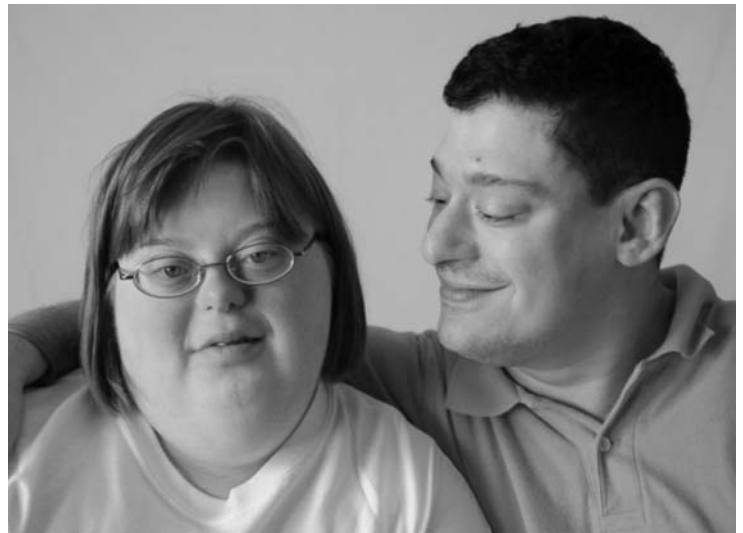
The following are specific details to elevate the recognition of the role of families and the need for supporting families through **collaboration of key national programs**:

- Designate the Administration on Developmental Disabilities as one of the lead organizations to advance this national agenda and establish key collaborations with other national and federal entities.
- Initiate collaborative efforts starting with the following key national programs or initiatives:
  - Department of Defense and ADD to develop a cooperative agreement to work together to develop and coordinate supporting the family programs.
  - Maternal Child Health/HRSA to integrate Community Parent Resource Centers and Family-to-Family Health Information Centers with efforts related to supporting families.
  - Department of Education and vocational rehabilitation to work to increase expectations and outcomes for employment and community living throughout school years.
  - Social Security Administration identify a tax credit or benefit that can be given to family caregivers for supporting a family member with I/DD.
  - Centers for Medicaid services that support families:
    - a. Make Medicaid work to support families and be more efficient; right now only the individual recipient is eligible for services.
    - b. Build in portability of Medicaid from state to state.
    - c. Federalize through Medicaid to pay family members for services provided to individuals; now a state by state decision.
  - American Pediatrics and American Association of Family Physicians collaborate on initiatives to inform families early of expectations and a vision for the future and care coordination through the medical home model.
  - Ensure that the effort of the middle class task force focuses broadly on all families, including families with members with developmental disabilities and parents with developmental disabilities.
  - Parent Training and Information Centers work to ensure families have information and training to assist in developing expectations and hope across the future. ■

SECTION 6:

# ACTION STEPS FOR THE NATIONAL AGENDA ON SUPPORTING FAMILIES





**ONE OF THE** most important components of a conference such as Wingspread, is the commitment from participants to continue to pursue the goals of the meeting. Wingspread participants committed to be more involved; they filled out a card and identified what they would do and a target date. In addition, participants who chose to make a commitment to carrying the message forward agreed to identify others in their networks and work to develop an environment which would allow this broad group of individuals to be involved in next steps.

Some of the major components of this future commitment process are to:

- Identify how the work accomplished at Wingspread fits into other stakeholders' priorities, for example, can the DD Network and the National Association of State Directors of Developmental Disability Services (NASDDS) share information with their networks? Embed the priorities leaving here in sync with the priorities of relevant federal agencies, and with national disability groups such as The Arc, United Cerebral Palsy (UCP), AUCD, and with the national Consortium for Citizens with Disabilities? In addition, priorities identified here must be on the agenda of national aging organizations.
- Identify a method to acquire long term stable funding to keep this initiative moving forward with staffing. This could include federal funding, asking specific organizations to make a monetary commitment or, working with foundations that support these outcomes.
- Develop grassroots efforts with a base of families (such as existing family networks) and other stakeholders.
- Form an email group and “build it” with other stakeholders using social media and marketing to build a movement.
- Develop materials that other organizations and stakeholders can use to promote the national agenda for supporting families.
- Finish white papers and supporting documents.
- Develop a plan for disseminating and advancing the national agenda.
- Design a state/local application of conference recommendations and work to move it forward at different levels (legislative, executive, state, and non-governmental organizations) with follow-through strategy and follow-up plan.



## SECTION 7:

# ACCOMPLISHMENTS OF THE NATIONAL AGENDA ON SUPPORTING FAMILIES

**SINCE** the conclusion of the Wingspread Conference, participants have continued to actively move the National Agenda on Supporting Families forward. The following provides an overview of the different types of activities that have occurred:

## Information on the National Agenda on Supporting the Family was shared with the following:

- Staff of Administration on Aging and state Lifespan Respite grantees and partners at the ARCH National Respite Network conference.
- Board of Directors for the Arc of Racine
- College Students at University of Kansas
- National Sibling Leadership Network
- Supporting Illinois Brothers and Sisters
- Arc of Illinois Board of Directors
- IL UCEDD staff and Consumer Advisory Committee
- National Youth Leadership Network, shared information with the National Youth Leadership Network Governing Board and state partners.
- Wisconsin Division of Long Term Care
- Attendees at AUCD 2011 Annual Conference Poster Session and Roundtable Breakout Session
- Parent to Parent USA Directors' Leadership Meeting in Denver

## Federal Policies and Initiatives

- The Administration on Developmental Disabilities issued and awarded grant funding focused on the collection and analysis of national data on supporting the family.
- The National Association of State Directors of Developmental Disability Services (NASDDDS), since attending Wingspread, has now focused its efforts on assisting disability service systems to recognize and support the role of families in its policies and practices, such as:
  - NASDDDS mid-year conference in May 2011 emphasized the need for state Wingspread participants, Sharon Lewis the Commissioner of the Administration on Developmental Disabilities and Michelle Reynolds of the University of Missouri Kansas City, Institute for Human Development provided keynote presentations utilizing the framework and information from the Wingspread meeting. For program and presentations link to <http://www.nasddds.org/Meetings/2011MidYearConference/2011MYCPresentations.shtml>.
  - NASDDDS state directors participated in a 1.5 day facilitated meeting focused on developing strategies and outcomes that assist state systems to transform to better support families.



- NASDDDS *Community Service Reporter*, June 2011, featured Sharon's Lewis' conference keynote on *Supporting Families: Where Do We Go From Here?* and the July 2011 issue featured an article by Sheli Reynolds entitled *Uncharted Waters: Moving Beyond What We Know as Family Support*.

- NASDDDS Research Committee is focusing on improving the data on supporting the family gathered by the Coleman Institute at the University of Colorado and the Research and Training Center on Community Living at the University of Minnesota Institute on Community Integration.

- The Beach Center at the University of Kansas analyzed and drafted a report focusing on Supporting the family for Military Families with Children with Disabilities and presented it to the Department of Defense and its branches, the Army, Air Force, Navy, Marine Corps and Coast Guard.
- ARCH National Respite Network drafted a funding letter signed by 45 national organizations, including the National Council on Aging, Association of University Centers on Disability and Arc of

U.S. which were represented at Wingspread, requesting funding for supporting the family and other caregiver support programs and sent it to House and Senate appropriations subcommittees

- The Leadership Council of Aging Organizations (LCAO), a coalition of 65 major national aging organizations, included language in their consensus document developed for Congress for the Reauthorization of the Older Americans Act to include aging family caregivers of adults with disabilities in the National Family Caregiver Support Program (NFCSP) and promote the practice of caregiver assessments. [http://www.lcao.org/docs/consensus\\_document\\_oaa.pdf](http://www.lcao.org/docs/consensus_document_oaa.pdf)

## GET INVOLVED IN THE MOVEMENT!

Everyone can be involved in moving forward the National Agenda for Supporting Families with a member with Intellectual and Developmental Disabilities. To tell share your accomplishments or to stay connected to the movement to go to [www.familysupportagenda.org](http://www.familysupportagenda.org) to find out what is happening or sign up for the listserv. ■

## SECTION 8:

# ATTENDEES

**John Agosta, Professional**  
Vice President  
Human Services Research Institute  
Oregon

**Katie Arnold, Sibling**  
Director of Community Education  
Institute on Disability and Human Development  
Sibling Leadership Network  
Illinois

**Joe Caldwell, Parent**  
Director Long-Term Services and Supports Policy  
National Council on Aging  
Washington, D.C.

**Sandra Engle, Professional**  
Executive Director  
The Arc of Racine County  
Wisconsin

**Tonia Ferguson, Parent**  
Director National Initiatives  
The Arc  
Washington, D.C.

**Kathryn Fialkowski, Sibling**  
Joseph P. Kennedy Jr. Public Policy Fellow  
Administration on Developmental Disabilities  
Washington, D.C.

**Marty Ford, Sibling**  
Acting Director  
The Arc and UCP Disability Policy Collaboration  
Washington, D.C.

**Elizabeth Hecht, Parent**  
Coordinator  
Waisman Center, UCEDD  
Wisconsin

**Isabel Hodge, Parent**  
Program Analyst  
Department of Defense Office of Community  
Support for Military Families with Special Needs  
Virginia

**Jill Kagan, Professional**  
Program Director  
ARCH National Respite Network and  
Resource Center  
Virginia

**Barbara Katz, Parent**  
Co-Director  
Family Voices of Wisconsin  
Wisconsin

**Sharon Lewis, Parent**  
Commissioner  
Administration on Developmental Disabilities  
Washington, D.C.

**Vyonda Martin, Professional**  
Associate Director  
Oklahoma UCEDD  
Oklahoma

**Sally Mather, Professional**  
Owner/Consultant  
Mather and Associates  
Wisconsin

**Chas Moseley, Professional**  
Associate Executive Director  
National Association of State Directors of  
Developmental Disabilities Services  
Virginia

**Kim Musheno, Professional**  
Director of Legislative Affairs  
Association of University Centers on Disabilities  
Washington, D.C.

**Tia Nelis, Self-Advocate**  
Self-Advocacy Specialist  
Institute on Disability and Human Development  
Self-Advocates Becoming Empowered  
Illinois

**Julie Petty, Self-Advocate**  
Project Trainer and Research Assistant  
Partners for Inclusive Communities/UAMS  
Self-Advocates Becoming Empowered  
Arkansas

**Lisa Pugh, Parent**  
Public Policy Coordinator  
Disability Rights  
Wisconsin

**Susana Ramirez, Parent**  
Special Education Advocate  
Disability Rights Oregon  
Oregon

**Michelle Reynolds, Sibling**  
Director of Individual Advocacy and Family Support  
UMKC-Institute for Human Development (UCEDD)  
Missouri

**Martha Roherty, Parent**  
Executive Director  
National Association of States United for  
Aging and Disabilities  
Washington, D.C.

**Beth Swedeen, Parent**  
Parent Leader  
Wisconsin Board for People with  
Developmental Disabilities  
Wisconsin

**Cathy Ficker-Terrill, Parent**  
Chief Executive Office  
Institute on Public Policy for People with Disabilities  
Illinois

**Nancy Thaler, Parent**  
Executive Director  
National Association of State Directors of  
Developmental Disabilities Services  
Virginia

**Trish Thomas, Parent**  
National Partnership/TA Coordinator  
National Family Voices  
New Mexico

**Rud Turnbull, Parent**  
Co-Director  
Beach Center on Disability  
University of Kansas  
Kansas

**Betsy Valnes, Self-Advocate**  
Executive Director  
National Youth Leadership Network  
Maryland

**Kathryn Weit, Parent**  
Executive Director and Policy Analyst.  
Oregon Council on Developmental Disabilities  
Oregon

**Dana Yarbrough, Parent**  
President  
Parent to Parent USA  
Virginia









**BUILDING A NATIONAL AGENDA FOR SUPPORTING FAMILIES WITH A MEMBER WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES  
WINGSPREAD FAMILY SUPPORT SUMMIT • WINGSPREAD CONFERENCE CENTER • 3/6/11 - 3/8/11 • RACINE, WI  
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