



CONTINUING THE CONVERSATION:

A National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities



THE COMMUNITY OF PRACTICE
for Supporting Families of
Individuals with Intellectual &
Developmental Disabilities

UMKC Institute for
Human Development
A University Center for Excellence in Developmental Disabilities

 **NASDDDS**
National Association of State Directors
of
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supportstofamilies.org/national-agenda/



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Click or scan the QR Code above to download a PDF of the *2011 Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities*.



BACKGROUND

In 2011, a group of diverse national and state disability leaders gathered to discuss supporting families that have members with intellectual and developmental disabilities(I/DD). The impact of this event has driven the Supporting Families movement for over ten years.

The leaders in attendance at the Johnson Foundation’s Wingspread Family Support Summit recognized that families play a vital role in supporting people with I/DD to live in an integrated community. At the time, disability policies and programs did not acknowledge the family as a vital partner, therefore not recognizing the individual within the context of the family or the needs of all family members. The Wingspread Family Support Summit was held to make recommendations on the types of supports families needed, provide direction and guidance for policy and program reform, and advance a national agenda on supporting families. The result was *Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities*, which remains the foundation and vision for supporting families nationwide.

At the time of the Wingspread Family Support Summit, more than 4.7 million people with I/DD lived in the United States. More than 75% of those individuals were living in their communities without formal disability services. Of the 25% receiving formal services, over 56% were living with their families. Today, there are more than 7.39 million people with intellectual and developmental disabilities living in the United States. Of these 7.39 million individuals only 22% are known to or served by state I/DD agencies, meaning the other 78% live in their communities without formal services. Of those receiving Long-Term Services and Supports (LTSS), 60% live with their families. The increase in these numbers since the 2011 National Agenda demonstrates the continued need for supporting families efforts.

To celebrate the accomplishments and continue the efforts of the Wingspread Family Support Summit and the 2011 National Agenda for Supporting Families, two events were held as a collaboration between the Community of Practice for Supporting Families—led by the University of Missouri Kansas City Institute for Human Development (UMKC-IHD) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS)—and supported by the Administration for Community Living (ACL).

The Virtual 10-Year Celebration was held in December 2021, followed by the in-person Supporting Families Summit in May 2022.



SECTION 1:

REFLECTING ON THE 2011 FAMILY SUPPORT SUMMIT





Introduction

In March of 2011, The Johnson Foundation’s Wingspread Family Support Summit brought together 30 National and state disability leaders to develop recommendations for policy reform to ensure families of people with I/DD receive the recognition and supports they need. In December 2021, a Virtual Celebration was held to commemorate the 10th anniversary of the Wingspread Family Support Summit. The virtual gathering brought together 222 participants; a diverse cohort of family members, self-advocates, research, government professionals, and case managers representing many states, sovereign nations, and territories to celebrate the impact of the Wingspread Family Support Summit and reflect on the successes and challenges faced by the supporting families movement over the last decade.

Much of the work of supporting families since the Wingspread Family Support Summit has been driven by the key priorities established in the *2011 National Agenda for Supporting Families*, elements of which have been adopted into state and national policy, funding, and practices.

Revisiting the Outcomes from the 2011 National Agenda for Supporting Families

Priority 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.

One of the notable contributions of the Wingspread Family Support Summit was the formation of the National Community of Practice (CoP) on Supporting Families, which was funded through a five-year grant by the Administration for Community Living (ACL) in 2012 and led by the National Association of States Directors of Developmental Disabilities Services (NASDDDS), the University of Missouri Kansas City-Institute for Human Development (UMKC-IHD) and the Humans Services Research Institute (HSRI). A community of practice is a collective learning environment devoted to the development and cultivation of community knowledge as a force for change.

The primary goal of the CoP on Supporting Families was to increase capacity for system-wide change by building a network of states dedicated to creating better policies and practices that seamlessly support people with I/DD and their families across the lifespan.

Following the completion of the grant cycle, several more states expressed interest in joining the CoP. NASDDDS and UMKC-IHD agreed to co-lead an expanded Community of Practice for Supporting Families to support the adoption and implementation of the principles of supporting families through policy, procedure and practice changes. As of 2023, the CoP has 22 member states committed to ongoing learning, collaboration and change efforts to ensure families receive the supports they need.

In the decade since its founding, the CoP on Supporting Families developed national consensus on a framework for improving support for people with I/DD and their families, elevated the voices and perspectives of self-advocates and family members in policy and systems change efforts, increased access to community-based services, enhanced national and state policies and practices and increased capacity of state systems to replicate and sustain exemplary practices to support families.



The CoP continues to serve as a vital space for innovation in the development of replicable policies, services, and capacity-building strategies, while also ensuring the voice of people and families is elevated in systemic decision-making and championing leadership opportunities for people with disabilities and their families.

Charting the LifeCourse:

Another vital force for change throughout impact levels—from family networks and grassroots advocacy to federal policy—has been the Charting the LifeCourse (CtLC) framework, created with elements of the 2011 National Agenda for Supporting Families embedded into its principles. The CtLC framework was created to help individuals and families of all abilities and all ages develop a vision for their “good life,” explore their needs, goals, and strengths, identify how to discover and develop supports, and determine what it takes to accomplish their life aspirations. The framework is the keystone for supporting a community of learning that champions transformational change through knowledge exchange, capacity building, and collaborative engagement. The Charting the LifeCourse framework and tools provide a powerful lens for understanding the process of change through establishing a vision and exploring existing and needed resources are used by people, families, professionals, and organizations throughout the world.

Priority 2:

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

The University of Illinois at Chicago Family Support Research and Training Center (FSRTC) was highlighted as a fundamental national initiative devoted to enhancing practice and policy for supporting families. The FSRTC is dedicated to engaging and centering families in the generation of new knowledge in critical areas such as self-direction and managed care, the development of culturally responsive peer-to-peer family interventions, and the formation of a national family support resource center. The University of Pittsburgh Rehabilitation Research and Training Center (RRTC) on Family Support was also noted as a vital contributor to enhancing policies and practices to support families. The outcomes of the research projects at RRTC on Family Support include the development of a strategic research plan, the identification of practices to enhance collaboration and information sharing across the aging and disability fields, increased research on managed care, self-directed supports, and family support across various life stages. The findings of these research projects were infused and disseminated through training and technical assistance programs.

Priority 3:

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

The HSRI Families Information Systems Project (FISP) was highlighted as a key initiative in developing consistent and uniform data collection to understand the impact of services and systems for people with I/DD and their families. This project collected, reported, and disseminated essential information on in-home supports and services provided to people with I/DD (including self-directed services) and those designed to support their families. A family advisory group guided the project to identify significant data needs and initiated several studies around waiver services. This project also developed a taxonomy of waiver services categorized to collect data according to age.

Participants also emphasized the impact of the Residential Information Systems Project (RISP), which is one of the three Longitudinal Data Projects of National Significance funded by ACL and is led by the Institute on Community Integration (ICI) at the University of Minnesota in collaboration with NASDDDS. The RISP is an integral source of information and statistics on Medicaid and state-funded residential and in-home supports, providing vital insight into data trends around Long-Term Supports and Services.

Priority 4:

Elevate the recognition of the role of families and the need for supporting families within key Federal policies and national programs.

The RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregiver Advisory Council was noted as a major contributor to the federal policies and programs that have elevated the need for recognizing and supporting families. Its initial Report to Congress identified challenges to family caregivers and necessary efforts to address them. Building upon the report, the council adopted 26 recommendations, which provide the framework for the 2022 National Strategy to Support Family Caregivers. Members of the supporting families movement honor the crucial importance of the National Strategy in elevating the needs of a broad group of family caregivers at a federal level and note the ongoing necessity to address the unique context and challenges faced by families supporting a member with Intellectual and Developmental Disabilities.

As part of the national push to address the needs of aging caregivers, The National Association of Councils on Developmental Disabilities (NACDD) has been awarded funding through ACL to



develop a national Community of Practice for Bridging the Aging and Disability Networks. The Community of Practice will strengthen collaborations across the aging and disability fields to create culturally responsive systems that enhance supports to families across the lifespan.

Within this recommendation, participants of the 2011 Wingspread Family Support Summit listed Key Federal Policies requiring reauthorization to support people with I/DD and their families. Among these recommendations was the reauthorization of the Older Americans Act (OAA) and the amendment of the language in the National Family Caregivers Program to ensure it aligns with original Congressional intent to cover aging caregivers of adults with I/DD. Since the *2011 National Agenda for Supporting Families*, there have been two reauthorizations of the Older Americans Act. The 2020 Reauthorization provides states and localities with flexibility when deciding the allocation of National Family Caregiver Services between populations served, as well as extending the authorization of the RAISE Family Caregiver Act and the Supporting Grandparents Raising Grandchildren Act for an additional year.

In addition to the OAA, the following Federal Policy recommendations from the 2011 National Agenda for Supporting Families are ongoing priorities of the Supporting Families movement:

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 transition provisions in the 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) programs 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 regarding Part C and Part D of IDEA and the Rehabilitation Act.

Reauthorize the Family and Medical Leave Act (FMLA)

- 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 a 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.



SECTION 2:

SUPPORTING FAMILIES SUMMIT: 10 YEARS LATER





Introduction

In May of 2022, the National Community of Practice for Supporting Families (CoP), supported by the Administration on Community Living (ACL), hosted an in-person Supporting Families Summit in Washington, D.C. to build on the momentum and continue the efforts of the Virtual Celebration.

The Summit brought together key partners in the supporting families movement to explore the current landscape of supporting families initiatives, develop common definitions and vision for the work, and identify existing and needed policies and practices for enhancing supports to families across the lifespan.

Representatives were selected based on their lived experience and their ability to represent others with lived experience and/or a local, state, or national initiative for supporting families. Representatives include those with knowledge about grassroots efforts, promising and best practices, state and federal policies, and key research considerations for supporting families. In total, 69 attendees from 49 different organizations and 29 different states participated in the Summit.

Specific objectives of the 2022 Supporting Families Summit included:

- Understanding the “state of the states” for families of people with Intellectual and Developmental Disabilities (I/DD).
- Identifying the needs of families—from their perspective—now and in the in the years to come.
- Developing collective priorities and a collaborative agenda for supporting families to guide the next “phase” of the movement.
- Determining how to best imbed the Supporting Families agenda and movement within key national initiatives and opportunities.

Summit Summary

The Summit reestablished the emphasis of intellectual and developmental disabilities as invaluable parts of the human experience that contribute to the richness of our communities.

Key principles of the supporting families movement were revisited, including the importance of high expectations and the need to assist people with I/DD and their families in developing and furthering self-determination and advocacy skills. Discussion also highlighted the importance of ongoing dedication to ensure that all families are supported through systems, policies, services, and communities that center cultural humility and value diversity and promote equity, inclusion and belonging. Panelists with lived experience as a person with I/DD or a family member shared perspectives on the role and impact of family, emphasizing the importance of reciprocal relationships, knowledge and education, choice and risk, community connections, peers, and unconditional support. The need to adopt a fluid, expansive definition of family that can evolve alongside the needs of the family and include a broad, interactive network of support was emphasized, and panelists noted that it is critical to spend time understanding the diversity and complexity of families to ensure that policies and practices aren't excluding families due to cultural norms.

A Vision for All Families

As the panelists underscored, developing a common understanding of the definition of family is critical to the discussion of supporting families.

It was agreed among participants that family is more than a legal or biological/genetic construct and should be defined by the person. Family should be understood as those with mutual and reciprocal connections and that are marked by such characteristics as:

- **Commitment and trust**—the ability to rely on, count on, and/or depend on each other.
- **Unconditional love**—"fiercely care about each other."
- **Support**—believing in each other and supporting each other's goals and dreams.
- **Sense of safety**—ability to be authentically oneself, to tell the truth.
- **Sense of teamwork**—problem-solving and working together.
- **Respect**—listening to and honoring each other and encouraging self-determination.
- **History and shared experience**—being a part of each other's lives.



It was noted that families are complex and “messy,” and that there are different roles that family members may play that evolve and change over time. As people grow and experience new things, connections and relationships may also change. This constant evolution, as well as the important consideration of cultural values, experiences, and definitions; highlight the need for terminology and policies that respect the vast uniqueness of what “family” can mean.

Developing a vision for families includes recognizing the complexities and honoring the experiences of each individual family unit as they define themselves. Respect for the different ways that families can look and an appreciation for the intersectional identities of all family members, including the person with the disability were noted as foundational beliefs that underscore other aspects of a vision for families. Participants emphasized the need to move away from any systems that are overly complex and full of unnecessary barriers and any practices or services that contribute to exclusion, isolation, judgment or a lack of choice or options for families.

Additional, high-level themes and priorities that were noted include:

- Hope and a sense of possibility that leads to high expectations and opportunities to dream, with information on what’s possible beyond traditional services.
- Focus on quality of life-not just services-and being valued as a person able to have life experiences that lead to a life that is wanted without barriers or added “hoops.”
- Belonging and connection—social capital and networks of support with knowledge and skills for how to develop community.
- Inclusive, educated communities that are universally designed and welcoming for all—education, experience, and exposure that creates openness among community members.
- Access to integrated supports and resources for a quality of life, including for basic needs, health care, mental health, community supports, housing, employment, transportation, etc.
- Training for families and professionals to establish confidence and competence in appreciating and supporting each family member in their unique role.
- Autonomy and choice—right to risk.
- Seamless systems of support with plain, easy-to-understand, common language that families have the knowledge and skills to navigate.

- Service Systems have transparent and flexible policies, and are inclusive of supporting families and individuals across the lifespan with “back-up” plans to mitigate reliance on one “system.”
- Valued and empowered as leaders, driving all legal and policy development and changes where they are presumed competent, included, respected, engaged, and considered partners.
- Quality, innovative, person-centered supports utilizing best and promising practices through accessible and available quality providers.
- Peer support and role modeling at all life stages—connections with self-advocates who can teach parents/family members, peer to peer mentoring, focused efforts in early childhood and/or at diagnosis.
- Training, skill-building, services, and supports on self-determination for all family members, with particular emphasis on how to shift autonomy to adult children with I/DD to foster decision making and support dignity of risk.






Identifying the Needs of Families Across the Lifespan

In moving toward this vision for families, it is vital to take a perspective that responds to both the needs that are consistent across the lifespan and those specific to a particular lifestage.

The 2011 *National Agenda for Supporting Families* identified and categorized the key support needs of families into three areas:

- 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.

These three strategies became the Three Buckets: Discovery and Navigation, Connecting and Networking, and Goods and Services. The three buckets are a fundamental part of the Charting the LifeCourse Framework. The 2022 Summit explored the needs of families through the lifespan in each of these categories.

 DISCOVERY AND NAVIGATION	 CONNECTIONS & PARTNERSHIP	 GOODS AND SERVICES
<ul style="list-style-type: none"> • Timely information (in plain, accessible language and translations) • Advocacy skill training • Anticipatory guidance (related to life experiences at each life stage, transitions, etc.) • Supported decision making supports • Education and training around parenting skills • Information, education, and resources for navigating systems, supports, services, etc. 	<ul style="list-style-type: none"> • Trauma supports • Parent support groups that support all family roles, including fathers • Mental health supports • Networking and connection opportunities • Peer supports and mentoring (role models) • Community integration and assistance developing social capital 	<ul style="list-style-type: none"> • Basic needs (housing, food, healthcare, financial supports) • Technology • Home modifications • Respite/short breaks • Childcare • Everyday life and future planning/problem-solving supports • Professional navigational supports to access services and support systems • Funding for adaptations and accommodations to facilitate life experiences

Needs of Families across the Lifespan | Table 1



Following the identification of general needs of families across the lifespan, summit attendees explored the experiences of each life stage for all families and added additional considerations that may exist for people with I/DD and their families.

PRENATAL/INFANCY

For all families in the *prenatal/infancy stage*, caregivers are making decisions about how to raise a child. They are learning about parenthood and may be experiencing excitement or fear. At this stage, families may need support to learn parenting skills and to identify their “circle of supports” for themselves and their child(ren). They likely will need supplies, such as bottles, diapers, and clothes. They may also need emotional support related to life changes, post-partum challenges, and decision-making. Additional considerations for people and families experiencing disability may include emotional supports and guidance, such as peer support, help to access and navigate resources and services—including health systems, and advocacy support to maintain their parental rights, especially for parents with I/DD.

EARLY CHILDHOOD

Experiences in *early-childhood* often include ongoing adjustments to life changes, such as changes in job or childcare situations as well as new routines and responsibilities. Families may need support to make these adjustments and access the resources or services required, such as childcare. Accessing childcare can be especially challenging for families experiencing I/DD, as options may be limited. They may need additional support as they adjust to the demands of a young toddler, navigate new services, and/or learn to advocate for themselves—possibly as a parent with I/DD—or for their child to ensure their needs are met.



SCHOOL AGE

For families of *school-age children*, there is often a focus on education and other activities, such as playdates, team activities, or other sports. At this life stage, the child may be taking on more responsibilities, such as chores. The family as a unit continues to adjust to the priorities and roles of each family member related to their interests and abilities, which may create challenges for families of multiple children as they try to balance competing schedules, activities, and interests. Children need to try new things, learn from mistakes, and develop decision-making skills at this stage. Families may need support navigating multiple systems and developing or maintaining connections with peers. This is especially true for those experiencing disability, who may have additional system involvement beyond education. For all family members, it is important to have role models and peer support, autonomy and identity development, and encouragement to take healthy risks and make choices. Families of children with disabilities may also need access to integrated and inclusive extracurricular activities and after-school programs.



TRANSITION TO ADULTHOOD

Much occurs in the life of a person and their family as they *transition to adulthood*. For many, this tumultuous time can feel like being on the edge of a “cliff.” Many decisions are made with a potential loss of support from changes in peer groups and resources or services, such as schools, pediatricians, etc., that are no longer available. During this phase, transition is happening in all life domains and there is a need for all families to have information and guidance on “what’s next.” Planning and problem-solving in all life domains is important for all individual and families, as is emotional support for navigating changing roles and experiences. Peer support becomes critical for all families in transition. It is especially vital for those who experience disability. Networking with other families encourages the intentional development of high expectations, dignity of risk, and self-determination.



ADULTHOOD

Adulthood is a broad life stage encompassing a long time period with many possible experiences, such as jobs or careers, marriage or partnership, social and civic engagement, social and leisure activities, and community living. This period is marked by increased self-reliance but may also include providing care and support for others, including children, aging parents, other family members, or friends. During this stage of life, people and families need support in the various roles they may play—whether they involve pursuing individual goals or caring for or supporting others. Resources to ensure basic needs are met, maintain health, access healthcare, and plan for the future are important for all families. For families experiencing I/DD, peer connections continue to be a priority and families may need support in developing connections and fostering or maintaining relationships. Financial and future planning and support to access and navigate services may also be necessary. As families balancing the many roles and responsibilities of adulthood alongside supporting a family member with I/DD, caregiver supports such as respite are critical.



AGING

In *older adulthood*, people and families may be considering retirement and a schedule change. Their body may also be changing, and they may be experiencing real or perceived limitations in their activities. Some families in this stage could be downsizing their home, experiencing loss of family and/or friends, loss of skills or freedom, and re-defining their sense of self and purpose. Financial and housing considerations are considered, and legal aspects of decision-making could become a conversation. Supports for all families may include end-of-life planning and support for making difficult decisions such as advanced directives. Caregivers or other supporters may become more active and necessary in the older adult's life, so families may need access to additional resources, such as training and respite opportunities. It is especially important that the choices and decisions of older adults with I/DD and their families are respected and that there are options available specifically for the living arrangements a person may prefer. Ongoing supports for people with I/DD and intentional planning that includes the person may need to be considered for those with aging parents or family supporters.



Key Areas for Supporting Families

Having established a vision for families and explored the needs of families across the lifespan, attendees discussed priorities for ensuring systems and services support this vision. Building upon the recommendations from the *2011 National Agenda for Supporting Families*, the *(RAISE) Act Family Caregiving Advisory Council Report*, and the *Issue Brief: Supporting Families of People with I/DD from the National Goals Conference (2015)*, discussion was grouped into five key areas to organize existing or needed efforts related to supporting families. These areas were:

- Grassroots Movements for Supporting Families
- Best and Promising Practices for Supporting Families
- State DD Systems and Supporting Families
- Federal Policy for Supporting Families
- Research and Data for Supporting Families

Key Themes

Across all areas, and all discussions throughout the Summit, several themes consistently emerged. These ideas are critical elements for all of the resulting recommendations, and any strategies must consider and be responsive to the following assertions:

- All transformation efforts must move beyond understanding and acceptance towards a foundation of appreciation for the many intersectional identities of all family members and an intentional, ongoing focus on diversity, equity, inclusion, justice, and belonging.
- Families play a critical role in ensuring self-determination for the person with I/DD, and need supports to foster choice, control, and decision-making.
- Supports must be balanced intentionally and flexibly to ensure the person is directing their plan and life while also supporting families in their multi-faceted role(s).
- High expectations and opportunities to explore possibilities are essential, and are often developed through role models and peer support opportunities.
- Similarly, community connections and networks for people with I/DD and their family are essential, and a specific focus on strategies to ensure community capacity building to support social networks are needed.
- There is significant value in lived experience, and people with I/DD and their families should have the support and training needed to hold meaningful, leadership roles in state, local, and federal efforts.
- Eligibility specific service systems are overly complex and lack flexibility, so even if and when supports are available, they are difficult or cumbersome to access which necessitates the enhancement of navigational and community supports for families.



Grassroots Movements for Supporting Families

Grassroots Movements for Supporting Families share the key elements of being historically informal and rallied around causes, such as de-institutionalization, transportation, or education. In recent years, these movements have been more splintered, without a unifying “cause or message.” Self-advocacy has been reliant on projects with no structured funding, and in many instances, self-advocates and family advocates (and related organizations or networks) are competing for funding opportunities against bigger organizations, some of which do not see the value in family roles.

Recommendations for “what needs to happen” in this area centered on: uniting around common ground, including strategic calls to action and developing coalitions, and increasing the involvement of, support for, and professionalization of the role of people with lived experience, such as increasing the participation and leadership of self-advocates and family members on boards in major roles and otherwise valuing the skill set of lived experience. Highlights and suggested next steps included:

- Developing partnerships between organizations providing support for families, self-advocacy and family networks, and working together—rather than competing to affect change.
- Reaching a common definition of family support to create consistent expectations and clear messaging.
- Local involvement and advocacy with education and training around what’s happening in individual states and how to create community buy-in.
- Strengthen family and professional support of the self-advocacy movement. Create partnerships and ensure significant representation from self-advocates within the family support movement, especially self-advocates who are parents or family members.

Best and Promising Practices for Supporting Families

Best and Promising Practices for Supporting Families are innovative practices working to “fill the buckets,” meeting the informational, connection, and material needs of people and families. They are the holistic, replicable, flexible practices—sometimes developed for and by families themselves—that are implemented and adopted by systems. This process often involves capacity building or certification to ensure replicability and scalability. Several examples of best practices were shared, including active parent center networks with various funding sources, parent centers with peer-to-peer support and mentorship programs, family leadership training and youth leadership development, respite and respite networks, the use of cultural brokers, and navigation supports, especially at key life transitions. Current gaps in best practices emphasized lack of mental health supports and lack of education, training, and anticipatory guidance around key topics, such as healthy sexuality and cybersecurity and safety. Discussion also underscored the need for staff who represent diverse lived-experiences and cultural and linguistic backgrounds as well as education for communities and organizations to ensure meaningful family inclusion and leadership. Highlights and suggestions for next steps included:

- Education and Training for self-advocates and families ensuring these are offered from various cultural perspectives, in various languages, and through various strategies (i.e. virtual, in person, etc.) on topics such as:
 - Healthy sexuality
 - Building social capital and connectedness and community
 - Internet/cyber security
 - How to start a 501c3 to “fill in the gaps”
 - Self-care and stress management
 - Supported decision-making, and
 - Emergency preparedness
- Pre-professional and professional education through partnerships with universities and family organizations that includes:
 - Education and training for mental health professionals-particularly for dual-diagnosis and providing trauma supports to people and families.
 - Required curriculum and education in post-secondary programs for educators, doctors, etc.
- Developing common and/or similar language in states across the lifespan and across the state agencies for breaking down silos and streamlining processes.



- Developing core competencies and certification for parent to parent and peer support models to enhance funding and improve service delivery.
- Infrastructure for sharing resources and best practices across parent organization/family organization networks.
- University partnerships, including connection with UCEDDS, to support research that develops an evidence base of programs and best practices that meet the cultural and linguistic needs of families across the lifespan.
- Ability to “buy” family support services, including but not limited to mental health supports for caregivers, family navigation and long-term planning supports, parenting classes for parents of children with I/DD and for parents with I/DD, home modifications and assistive technology.
- Partner with legal corporations who have a set aside for pro bono work to “specialize” in special needs trusts to enhance opportunities for futures planning.
- Expand the definition of family, especially when delivering family support services, and think about ways to specifically include and support other family roles, such as dads, siblings, in-laws, etc.
- Increase knowledge, access, and use of technology as a means of engaging with and supporting people and families.

State Systems and Supporting Families

State Systems and Supporting Families encompass elements of the State I/DD agency, such as support coordination/case management, waivers and waived services including paid family caregivers and self-direction services, and “front door” access to paid services. The group noted that the state DD systems are “too complex” and that it is difficult to access waiver supports and services. There is a need to be thoughtful about flexibility in supports and services and the parameters that will ensure the person with the disability is leading and driving their plans and supports while also balancing the needs to support the family in their multi-faceted role(s). Shifting messaging, communication, and practices that position the waiver as the “golden ticket” to focus on a “whole life” and “integrated supports” are key considerations related to state I/DD systems requiring shifts in communication and messaging strategies as well as capacity building for staff at all levels and positions. Other needed changes included consideration—and possible transformation—of the case management or support coordination role to make it more effective and feasible related to core competencies and expectations, as well as a focus on timely and user-friendly communication with all team members. Increasing the fluidity between waivers and the portability between them—within and between states—as well as expansion of peer supports and services were also noted as needed changes, as was increasing self-direction, both in use and in accessibility, creating more effective front doors that include life exploration and a focus on outcomes rather than systems. Highlights and next steps included:

- Enhancing communication by ensuring the information available to individuals and families is linguistically appropriate, simple to understand, and presented using multiple different communication methods and tools.
- Increasing and improving self-directed services and paying family caregivers. This also requires investing in roles such as a support broker to help families navigate these service options, and enhancing opportunities for the development of self-determination.
- Continuing efforts to ensure individuals have integrated, self-directed living options in their communities rather than being placed in institutions.
- Exploring quality metrics and improvement strategies and ensuring a path for people to express their satisfaction with services and supports.
- Transforming and defining the role of case management, including (in the short term) elevating their specific role as “family helper, family coach or family navigator.”
- Enhancing IT systems to create real and meaningful opportunities for portal designs for individuals and families so that they have access to as much information as a state agency.
- Enhancing and streamlining service provision processes and practices to minimize the administrative burden placed on families and enhance access.



Federal Policies for Supporting Families

The area of *Federal Policies for Supporting Families* relates to the federal agencies and their policies and funding structures, such as ACL and Centers for Medicare and Medicaid Services (CMS), and to the broader legislative, political, and social landscape. It was noted that though the federal agencies may have a willingness and invested resources in moving policies and practices forward to better support families, changes in federal funding associated with the social and political climate have created obstacles for the movement that must be overcome. Current challenges and opportunities for innovation and advocacy include the stress on the Home and Community-Based Service (HCBS) system that was exacerbated by the pandemic, the Direct Support Professional (DSP) crisis and the lack of a qualified workforce, massive wait lists, and gaps in funding. Specifically, it was noted that communication of the outcomes of demonstration projects and other grants must be widely shared with people, families, and legislators to create high expectations and prioritize funding for essential supports, such as family-to-family information centers and Aging and Disability Resource Centers (ADRCs). Utilizing the data that is available, such as National Core Indicators (NCI), the President's Committee for People with Intellectual Disabilities (PCIDD) report, and the National Council on Disabilities (NCD) Inclusion report to develop a compelling message about the needs of families is a critical component to creating an environment where innovation can thrive. Simultaneously, ongoing efforts for scaling best practices, establishing and overseeing quality measures and expectations at the state level, and ensuring a specific focus on supporting families through task forces and coalitions should remain a priority of federal agencies, including ACL, CMS, and others. Highlights and next steps include:

- Expand technical assistance and capacity building in the states, to ensure states have the information they need and that all stakeholders are aware of their roles, responsibilities, and rights within the system of support.
- Require states to collect data on specific quality measures related to supporting families.
- Explore funding of key family support and family capacity building, such as Partners in Policymaking and/or other family leadership and advocacy opportunities, respite, technology supports, long-term and future planning, including end of life support.
- Create an interagency task force on family support, inclusive of ACL, CMS, Housing and Urban Development (HUD), Departments of Education and Labor, etc. to encourage partnership and alignment with the President's Committee on People with I/DD for a unified message/agenda.
- Develop a national resource on family support, modeled on Self-Advocacy Resource and Technical Assistance Center (SARTAC).
- Gather data on the DSP crisis and craft a complete and compelling message with related requests/action steps.

Research and Data for Supporting Families

Research and Data for Supporting Families was defined as gathering information to better understand families and their circumstances to support best practices and effective policies. Data must be collected, interpreted, analyzed, and presented in culturally responsive ways that help to answer questions that are relevant to families. Although current research initiatives such as the Supporting Individuals and Families Information Systems Project (FISP), Family and Individual Needs for Disability Supports (FINDS), and the National Core Indicators (NCI) are doing vital work, there is still a lack of data, particularly comparative data, specific to supporting families. It was also noted that other enhancements to research methodologies are needed, including greater diversity in researchers, funding of family research and reimbursement for participants, partnerships with champion organizations and cultural brokers, and the development of culturally and linguistically responsive research methods and materials available in plain and accessible language. It will also be important to create research agendas specifically focused on implementation research and study current efforts in family supports, rather than just demographic or service acquisition information. Finally, data findings must be conveyed in accessible, engaging ways that use multiple communication methods and emphasize storytelling. Specific recommendations and next steps include:

- Support states in identifying research questions—and data collection strategies—that support advocacy efforts at the state level, helping to build a case for legislative funding.
- Collect information about strategies that are effective and use that data to promote best practices through widespread communication.
- Enhance diversity and equity practices in research, including people with lived experience and diverse backgrounds from the beginning in framing the questions being asked and the methods that are used to gather information.
- Review the national data and research efforts to identify what is available and how it can be used, as well as to determine gaps and needs for additional strategies. Research priorities should also focus on families not involved in the service system.



Discussion Takeaways

Throughout the discussion, it was evident that all areas must work together to achieve these recommendations and affect significant, lasting change for people and families. Best practices require research to become evidence-based practices, states require changes in federal policies to enhance flexibilities, and grassroots advocacy is vital in influencing the federal and political landscape. Recognizing the connection between areas is essential to establishing priorities and creating a comprehensive action plan and agenda.







SECTION 3:
RECOMMENDATIONS



SECTION 3: **RECOMMENDATIONS**

The following recommendations emerged from the priorities, themes, vision and next steps established by attendees of the 2021 Virtual Celebration and 2022 Supporting Families Summit. These recommendations will provide a framework for the efforts of the National Collaborative for Supporting Families and will guide the ongoing systems change efforts of the Supporting Families movement.

Recommendation 1

Establish a fluid, expansive—yet universal—definition of family that is driven by the person and can incorporate the many complex, unique iterations of the networks of mutual and reciprocal supports we call “family.”

Formalized recognition of “family” as more than a legal or biological/genetic construct, but rather inclusive of mutual/reciprocal connections marked by elements of trust, respect, shared experiences/values/beliefs, and unconditional love and caring is critical to ensure policies and practices are responsive to the many expressions of family. A shared definition creates common expectations for expanding supports for family members chosen by the person, respecting the vast individuality, the changing roles and relationships, and the important consideration of cultural values, experiences, and definitions.

Recommendation 2

Operationalize “family support,” with a common understanding of what that entails, to create consistent, clear and funded services that are responsive to the needs of all family members and their (potentially multi-faceted) role(s).

Consistent expectations for family support services are necessary to develop training on best practices, ensure competent implementation of supports for families, and expand community-based networks of belonging and connection to offer comprehensive, natural, integrated supports outside the service system. Developing research and demonstration projects and creating avenues for scaling effective universal strategies are necessary to ensure ongoing innovation in family supports that are responsive to the expressed needs of all family members. Potential services or supports that may be prioritized include, but are not limited to: peer support and mentoring, intentional, long-term, holistic life planning, community relationships and community capacity building, navigational supports, respite, home modification, mental health supports, training and education, and assistive technology.

Recommendation 3

Design and fund peer support as a critical service, including state specific funding for Family Support Programs.

The need for parent-to-parent and peer-to-peer programs cannot be overstated. Strong research and evidence exist to validate the important role that peer mentorship plays in enhancing resiliency and positive outcomes. Peer-to-peer programs provide mentorship and emotional support for developing high expectations, encouraging autonomy, responding to various life circumstances through problem-solving, navigating integrated support and service systems, and developing advocacy skills.

Many family support programs exist, such as Health Resources and Services Administration (HRSA) Family-to-Family Health Information Centers (F2F HIC), IDEA Parent Training and Information Centers (PTI), and Substance Abuse and Mental Health Services Administration (SAMHSA) Family Networks; however, funding for these programs is limited-if existent at all-and family organizations are burdened with continuously seeking funding through grants and philanthropic organizations to sustain their critical services. These services and the programs that provide them must be elevated through the identification of core competencies and development of certification for peer support services. Additionally, it is necessary to develop a research bank of evidence-based practices for peer support of families experiencing I/DD. These strategies will provide a foundation for substantial, sustainable funding for peer support services and programs and will continue to professionalize the role of peer mentors and enhance mechanisms for continual quality improvement of services and programs.



Recommendation 4

Redesign waiver services and supports to focus on quality-of-life outcomes, increase flexibilities, improve access and navigation, and ensure self-determination and self-direction while also balancing the need to support the family.

Waivers or other eligibility-specific services are often messaged as the “golden ticket,” which may result in a focus on the services themselves rather than the quality of life an integrated array of supports can facilitate. Furthermore, accessing services is cumbersome, complex, and often requires significant effort on the part of the individual or family. A lack of flexibility and portability may create limitations and restrictions for the person, and result in a lack of support or resources for their family members. Transformation of waived services is necessary, beginning with increased flexibility and portability of services that allow for responsiveness to the needs of all family members including the person with I/DD, which may change over time. Exploring quality metrics around life outcomes—rather than service compliance—and building on demonstration projects and other research to better define indicators related to self-determination and choice are also needed.

Transformation of the case management role, inclusive of efforts to ensure a competent and skilled workforce, is another critical element of this recommendation. Case managers are often the mainstay in the service system, but many times lack necessary resources and are burdened with extensive administrative duties from complex systems, preventing them from focusing on supporting the person to lead and drive their plans while also considering the person in the context of their family. Recognition and consistency in the role and expectations of case managers are important elements in improving access and furthering self-determination for people and their families.

Increasing self-direction and use of support brokers or other professionals to facilitate choice and control over budgets and services is an essential consideration in transforming eligibility-specific supports. Strategies to increase and simplify self-directed services related not only to personal care but also other needed family support services, such as home modification, mental health supports, education and training opportunities, assistive technology, etc. must be explored, with careful consideration of the mechanisms of paying family caregivers while safeguarding the choice and control of the person.

Recommendation 5

Develop more effective “front doors” that provide lifespan support, include life exploration and focus on outcomes.

The need for intentional, long-term planning and problem-solving has been well-established, as has the difficulty many families experience in attempting to access, navigate, and integrate complex service and support systems. Intentional focus on “front door” supports that provide opportunities to explore possibilities, identify strengths and needs for life experiences, and facilitate connection to a variety of integrated supports and services are needed. Leveraging existing structures and opportunities—such as re-emphasizing ADRCs as a lifespan agency and ensuring a focus on people with I/DD and their families in existing No Wrong Door initiatives—is essential and must be emphasized to support the other recommendations of this report, specifically refocusing waiver services, centering peer supports and ensuring representation of people with lived experience in critical roles.

Recommendation 6

Ensure meaningful leadership roles of people and families with lived experience by professionalizing family and self-advocate roles and increasing mechanisms for capacity building and preparing organizations and systems to appreciate family leadership.

People with I/DD and their families must be recognized and compensated for their contributions. They must also receive training and support as competent professionals in that valued role. Funding self-advocate and family networks to provide capacity building for self-advocate and family leaders—as well as education and support to organizations and systems in best practices for including people and families beyond tokenism—is one important aspect of raising expectations for people in professional roles and the organizations to which they contribute. The exploration and implementation of strategies to elevate the role of people and families with lived experience throughout the system underpin all of the recommendations, emphasizing the necessity of representation as the driver of lasting change.



Recommendation 7

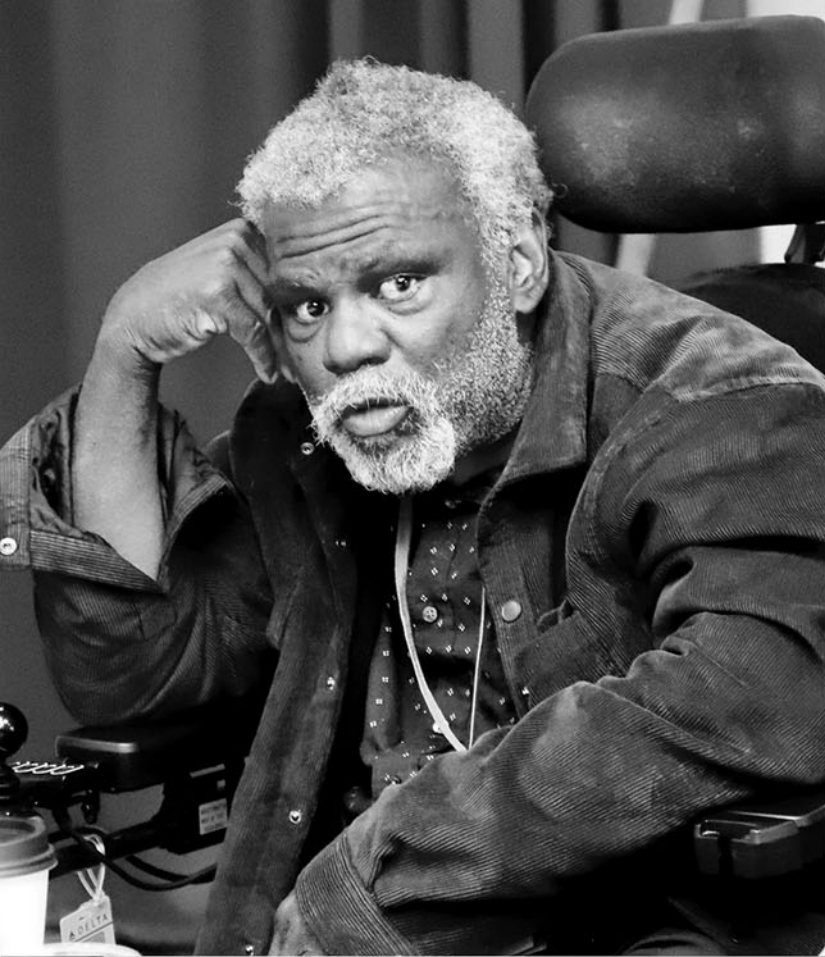
Fund and support a National Training, Research, and Resource Center for Family Support, to serve as an infrastructure for sharing resources and best practices, and to provide ongoing technical assistance and support for family organizations, state systems, and federal programs.

A national infrastructure for family supports is needed to disseminate research and resources related to best practices, serve as a clearinghouse of resources especially for parent and family organizations and networks, provide technical assistance, and train the family support workforce. Similar to the Self Advocacy Resource and Training Center (SARTAC), a national center would provide a central location for information and training, connection and networking, and tangible resources and materials to ensure implementation and integration of best practices for supporting families at local, state, and federal levels, with a focus on supporting diverse and underserved families.

Recommendation 8

Create a national, interagency task force on supporting families of people with ID/DD for research, funding, and advocacy.

Ongoing work is necessary to better understand the landscape of supporting families of people with I/DD and to develop strategic and thoughtful strategies to respond to identified needs. An interagency task force to identify a unified research agenda and data collection strategy inclusive of opportunities for comparative data across states to further prioritize family support is required. Specific areas of ongoing research recommended include: understanding the strength, needs, and resources of those not accessing formal supports focusing on diversity and equity, understanding the DSP workforce and impact on families, understanding the impact of disability services or lack thereof on families, focusing on disparities and equity, and implementation research of family support services documenting existing family support efforts and impact to develop and scale best practices. Developing the expectation that the DD network must prioritize family support as an area of emphasis and ensure that people with lived experience must be included at every stage of research and information dissemination are also recommended actions of the task force to ensure the ongoing elevation of families of people with I/DD in research and policy decisions.





SECTION 4:
MOVING FORWARD

In the years that have passed since the Wingspread Family Support Summit and the development of the *2011 National Agenda for Supporting Families*, the ongoing challenges to ensuring that all people and families are truly supported and valued have been confronted by many vital initiatives and efforts from advocates with lived experience, professionals, researchers, local and state organizations, and federal policy-makers.

Although there is still considerable work to be done to ensure that the needs of all families are proactively, effectively addressed, the work of the last decade provides a powerful foundation for ongoing innovation. As attendees of both the 2021 Virtual Celebration and the 2022 Supporting Families Summit continuously emphasized, collaboration across disciplines, key areas, experiences and systems are instrumental to implementing the significant and sustainable changes needed to truly support families. It is vital for leaders at every level of the supporting families movement to not only advocate for change within their sphere of influence but to enhance partnerships across efforts-whether between aging and disability fields or self-advocate and family organizations-to leverage collective power and unite around the common goal of a “good life for all.”

Continued Efforts Since the Supporting Families Summit

In response to the ongoing need to focus on supporting families, the Community of Practice for Supporting Families with the support of the University of Missouri Kansas City Institute for Human Development (UMKC-IHD) UCEDD and the National Association of State Directors of Developmental Disabilities Services (NASDDDS) continued hosting Supporting Families Summit Regroup Meetings. Supporting Families partners met virtually in September 2022 to reflect and debrief from the Summit and in November 2022 to explore strategies for leveraging collective work and discuss the National Strategy for Family Caregivers. The third virtual reconvening took place in April 2023 and served as a kickoff for the National Collaborative for Supporting Families. The National Collaborative is an outgrowth of the interest and momentum for continued, shared efforts following the Summit. A Steering Committee will serve as a space for connection and information dissemination for systems change agents dedicated to enhancing supports for people with I/DD and their families. The Supporting Families Best Practices Series will introduce and elevate best practices related to supporting families. Each session will feature a panel of individuals and entities who will address the key recommendations from the 2023 National Agenda for Supporting Families.

More information about the National Collaborative for Supporting Families, the Best Practice series and other events can be found at supportstofamilies.org/national-agenda/.



SECTION 5:
CONTRIBUTORS



The Virtual Celebration of 10 Years, Supporting Families Summit and Regroup Meetings were convened and facilitated by the National Community of Practice for Supporting Families—a partnership between the National Association of State Directors of Developmental Disabilities Services and the University of Missouri Kansas City-Institute for Human Development, UCEDD—with support from the Administration on Community Living. Additional planning support and guidance was provided by a team of national leaders in the family support movement, including Max Burrows from Green Mountain Self-Advocates/SABE, Julie Petty from SABE/SARTAC, Katie Arnold from the Sibling Leadership Network, Tawara Goode from the National Center on Cultural and Linguistic Competence, Donna Meltzer from the National Association of Councils on Developmental Disabilities, and Joe Caldwell from the National RAISE Family Caregiving Advisory Council.





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