



Supporting Family Caregivers: The Changing Policy and Practice Landscape

June 2024

TODAY'S EXPERTS



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AGENDA

- A Word About Words
- Emerging Landscape
- RAISE Strategies and Implementation
- 2022 National Strategy for Supporting Families of a Member with I/DD
- Discussion: Evolving Opportunities

RESPECTFUL LANGUAGE

Different words used to describe unpaid family providing support:

- Aging networks/RAISE: **“family caregiver”**
(Not to be confused with “caregiver,” often used for paid direct service worker)
- Intellectual and developmental disabilities(I/DD) communities: **“family member providing support”**; **“supporting families”**
- Some organizations for chronic illnesses: **“care partner”**
- International: **“carer”**

The distinctions reflect differences in histories, cultures, expectations and evolving roles



Family Caregiving in America

- 53 M Americans engage in some form of caregiving activity in a year (NAC/AARP, 2020)
- 40 M for adults over 50; 9 M for children
- Prevalence: 21.3% (18.2% in 2015)

People with I/DD:

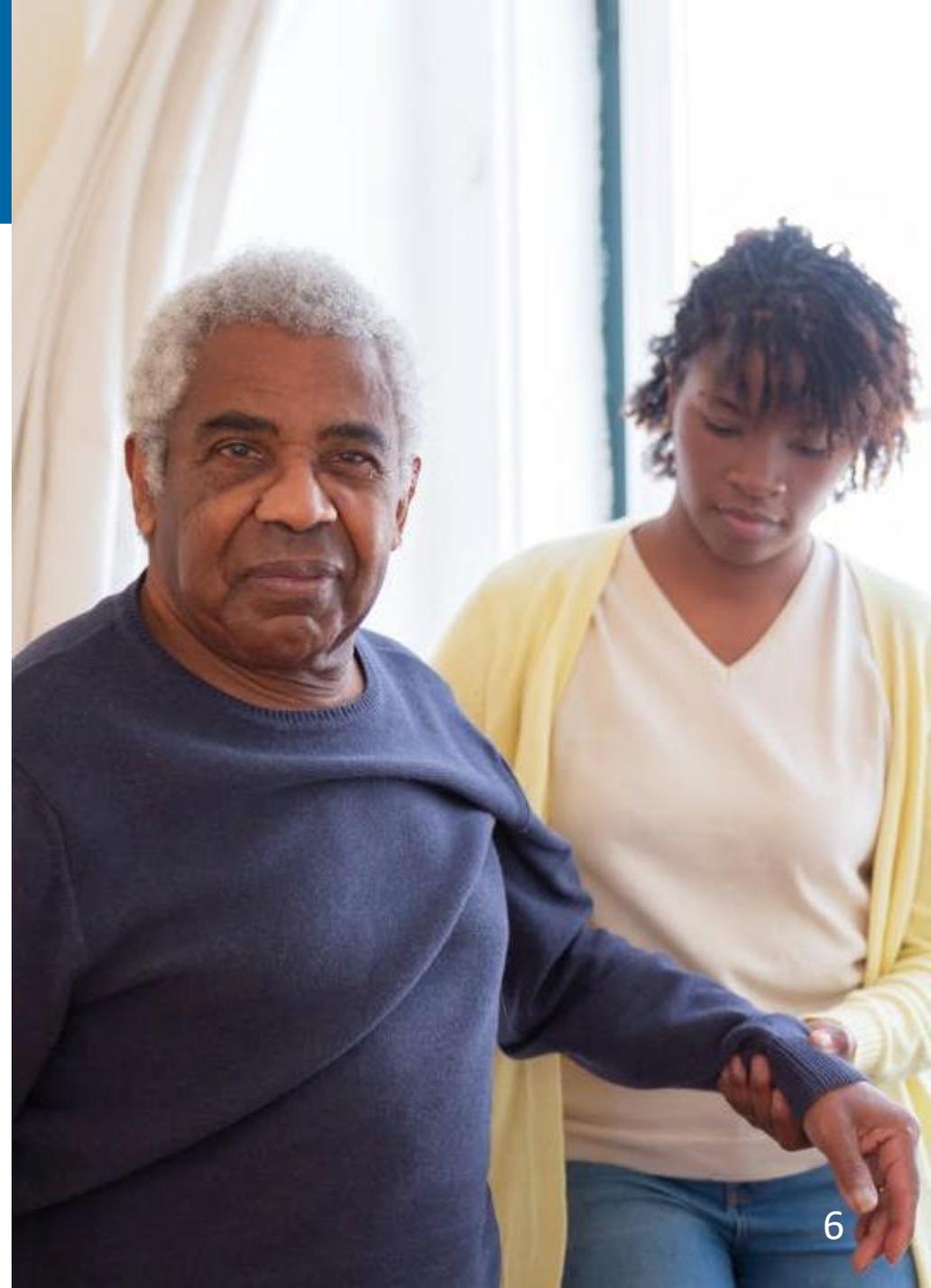
- About 80% live with family members
- Families often provide housing, financial, social, transportation and day-to-day support throughout people's lives



A CAREGIVER'S PLEA

“I don't think anyone can understand the intense, crushing isolation and loneliness of caregiving unless they have ‘walked a mile in our shoes.’ I miss the intimacy we've had for more than 50 years, and I'm not talking about physical intimacy, although I miss that, too. I miss having someone to talk to or share a chuckle or one of our little ‘inside’ jokes. It's all gone! I'm not ready to ditch my marriage vows and dash out and have an affair, but I long to have a companion again--even someone to just stand and hold me while I cry the tears I've had to squelch and swallow for so long.”

-The wife of a man with Alzheimer's Dementia





SUPPORTING FAMILIES OF PEOPLE WITH I/DD ACROSS THE LIFE SPAN

“The overall goal of supporting families, with all of their complexity, strengths and unique abilities, is 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 Community of Practice for Supporting Families

EMERGING LANDSCAPE

Federal: CMS initiatives to support home-based care (e.g., Acute Hospital Care at Home) and family-oriented care (e.g., GUIDE Model); Community integration policy (CMS Access Rule, recently updated 504 regulations, Olmstead enforcement)

States: Medicaid agencies increased requirements for family assessment and supports (e.g., Indiana MLTSS); Multi-Sector Plans for Aging; increased reliance on self-direction (e.g., paid family members) to meet gaps in direct care workforce; Cross-system initiatives to support families and individuals engaged in multiple systems of support; growth of Medicaid HCBS intended to support the individual in the context of family and culture

Medicaid/Medicare Advantage Health Plans: Increased caregiver benefits; increased use of vendors' digitally based caregiver support programs (e.g., TCARE, Careforth, Trualta, Carallel, Homethrive, Givers Health)

Private Sector: Greater numbers of vendors fueled by private equity and venture capital; technology as a key component of supporting individuals and families

Advancing Supports for Family Caregivers: The National Strategy as a Catalyst for Change

Greg Link, MA

Director, Office of Supportive and Caregiver Services
Administration on Aging, Administration for Community Living

June 27, 2024



“How do we create a world where caregiving is central to who we are, as opposed to something that diverts us or is a sideline of our real lives?”

–Carol Zernial, RAISE Council Co-Chair

THE RAISE ACT & THE NATIONAL STRATEGY TO SUPPORT FAMILY CAREGIVERS

The RAISE Act: Nuts & Bolts

- Became law: Jan 22, 2018
- Three key components:
 - Family Caregiving Advisory Council
 - Initial Report to Congress
 - National Family Caregiving Strategy

Public Engagement at Every Step

For Starters:

- ACL RFI (2019)
 - 1613 responses
 - 75% from caregivers
- Caregiver Focus Groups
 - 13 sessions/80 individuals
 - All populations, including teens
 - Delved into RFI findings
- Stakeholder Listening Sessions
 - Aging and disability organizations
 - 60 invited/42 participated
 - 6 sessions focused on operationalizing the recommendations
- Public input during council meetings

From 12/2020 - 12/2021:

- Interviews & Listening Sessions
 - 17 key informant interviews
 - 22 listening sessions
 - 145 stakeholder organizations
- Stakeholders included
 - State entities
 - Counties
 - Employers (large and small)
 - LTSS and healthcare providers
 - Respite providers
 - CBOs/faith-based organizations

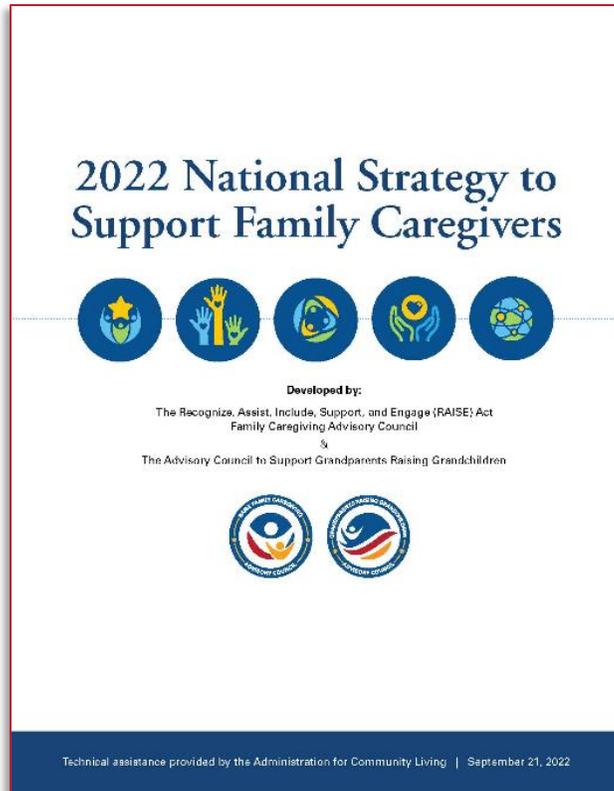
One Strategy – Four Components

[2022 National Strategy to Support Family Caregivers](#) - An overview and description of the strategy's goals and intended outcomes

[First Principles: Cross-Cutting Considerations for Family Caregiver Support](#) - Describes the four key principles that must be reflected in all efforts to improve support to family caregivers

[Federal Actions](#) - Nearly 350 actions that 15 federal agencies will take in the near term to begin to implement the strategy.

[Actions for States, Communities, and Others](#) - More than 150 actions others can take.



What the Strategy is...and is Not

The Strategy is...

- A vision and roadmap for change
- A baseline for action and progress
- A framework for all caregiving situations and experiences
- Intended for use by many stakeholder groups

The Strategy is not...

- A timeline or how-to document
- A list of requirements or “musts”
- Specific to any particular caregiving situation, topic or condition
- Exhaustive of all the possibilities

Most Importantly...It's the first...Not the last

A “Whole of Society” Approach

- States, tribes, county governments, and communities
- Community-based providers of long-term services and supports
- Child welfare agencies
- Kinship support systems
- Health care systems
- Business leaders and employers
- Communities of faith/faith-based organizations
- National, state, regional and local philanthropic organizations and funders
- Academic institutions and researchers
- Advocates, family caregivers, care recipients, you, me, anyone!

THE NATIONAL STRATEGY AS A DRIVER OF CHANGE FOR STATES, COMMUNITIES & OTHER SECTORS

A Catalyst for Change at the Federal Level

- Approximately 40 additional Federal actions added
- The President's Care Executive Order
- ACL's new National Caregiver Support Collaborative
- Updated Older Americans Act Regulations
- CMS' new Guiding and Improved Dementia Experience (GUIDE) Model
- International attention and focus

ACL Initiatives to Support Implementation

- National Caregiver Support Collaborative
 - Five grantees/one goal each
 - TA Coordinating Center
- New Initiatives/Notices of Funding Opportunity (NOFOs)
 - Caregiver navigator demonstration
 - Advancing State Implementation of the Strategy
- The Strategy as Framework for Other NOFOs

The Strategy as Change Agent

- Provide a unifying structure for working together
- Framework for state and community planning efforts
- A rallying point for enhancing collaboration
- Ideas for new service delivery modalities
- Expansion of outreach and awareness campaigns
- Employer engagement
- See state examples on the [NASHP's State Policy Roadmap](#)

Examples from States and Other Sectors

- Catalyst for counties to increase participation in programs and services for family caregivers
- States are using the Strategy to...
 - Inform state and multi-sector plans on aging
 - Inform policy and program development
 - Further legislative advocacy
 - Promote cross-agency collaboration (similar to federal)

Resources for Implementation

Funded by: The John A. Hartford Foundation, National Academy for State Health Policy (NASHP)

- National Alliance for Caregiving
- UMass Boston
- Community Catalyst

The RAISE Family Caregiver Resource and Dissemination Center
(<https://www.nashp.org/the-raise-family-caregiver-resource-and-dissemination-center/>)

Support Caregiving (<https://supportcaregiving.org/>)

Looking Ahead

- 2024 Joint RAISE/SGRG Council Update Report to Congress
- Federal agencies will meet regularly to more closely collaborate
- Meeting in subcommittees and working groups to...
 - Gather information and ideas for updating the national strategy
 - Review research and data
 - Begin crafting ideas for non-federal sector updates to the Strategy in 2025

We now have an unprecedented opportunity to achieve – and go far beyond – the goals Congress established in the RAISE Family Caregivers Act

-Alison Barkoff, 2021



National Agenda on Supporting Families with Members with DD

Sheli Reynolds, PhD

Sr. Associate Director, UMKC Institute for Human Development, UCEDD



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

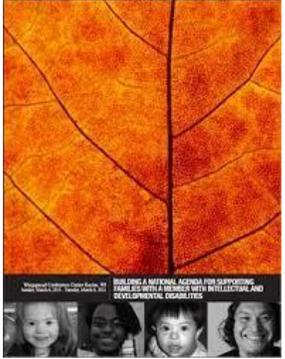
 **NASDDDS**
National Association of State Directors
of
Developmental Disabilities Services

 **ACL**
Administration for Community Living



History of National Agenda on Supporting Families

2011 “Wingspread Conference”



30 representatives of diverse national and state disability leaders met and developed recommendations to advance a national agenda on supporting the family, with four priorities:

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

2022 Supporting Families Summit



Over 65 key national and state stakeholders, representing 54 different organizations, came together to

- share in their commitment to elevating the on-going needs and important role of families who are supporting members with developmental disabilities.
- Celebrate the accomplishments of the Supporting Families Movement over the past 10 years
- Understand the “state of the states” for families of people with I/DD
- Identify the needs of families – from their perspective – in the years to come
- Develop collective priorities and a collaborative agenda for supporting families to guide the next “phase” of the movement
- Determine how to best weave the Supporting Families agenda and movement with key national initiatives and opportunities



Moving to Supporting Families



Family Support	Supporting Families
Defined by eligibility, services or programs available, or funding	Not a program or based on eligibility, it is needs defined by the families across the lifespan regardless of service provision
Caregiver or parent	Family is defined functionally; inclusive of siblings, parents with disabilities, grandparents, spouses, children
Tension between self-advocacy and family support	Enhances opportunities for self-advocacy and self-determination of all its members
Crisis, immediate response	Preventative, long-term planning
Supporting caregiver in order to decrease demand on long-term services	Supports a quality of life for person with DD and their family by supporting their many roles



Why the Urgency for a National Agenda on Supporting Families?

- **Supporting individuals with intellectual and developmental disabilities** to live and fully participate in their communities throughout their lives is a fundamental right and must be considered in all disability policy and practices.
- **Families** need supports across the lifespan because more than half of the people receiving services live at home with their families and many more aren't receiving any formal services.
- **Disability policies, funding and systems** must acknowledge and support the vital role and partnership of families in supporting the individual to live in the community and to pursue independence, integration and full participation.



National Agenda 2022 | Vision for Families

- Hope and a sense of possibility that leads to high expectations
- Focus on quality of life, not just services
- Belonging and connection
- Inclusive, educated communities that are universally designed and welcoming for all
- Access to integrated supports and resources for a quality of life
- Confidence and competence to support each family member in their unique role and to ensure reciprocation of support
- Seamless systems of support and the knowledge/skills to navigate
- Valued and empowered as leaders, driving all legal and policy development and changes
- Quality, innovative, person-centered supports
- Peer support and role modeling at all life stages
- Facilitators of self-determination for all family members



National Agenda 2022 | Supporting Families

- **Goal: Recognizing that individuals exist within a family system**

National Agenda on Family Support at Wingspread Conference Center (2011)

Individual	Families	
Will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life	Will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support the individual to achieve their goal	
DISCOVERY AND NAVIGATION Knowledge & Skills	CONNECTING AND NETWORKING Mental Health & Self-Efficacy	GOODS AND SERVICES Day-to-Day & Caregiving/Supports



National Agenda 2022 | Needs Across the Life Span

Discovery and Navigation	Connections and Partnership	Goods and Services
<ul style="list-style-type: none"> - Timely information (in plain, accessible language and more non-English languages) - 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 (esp. for parents/siblings) - Father support groups - Mental health supports - Parent support groups - Networking and connection opportunities - Peer supports and mentoring (role models) - Assistance developing social capital/community integration 	<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 - Navigational supports to access services and support systems - Funding for adaptations and accommodations to facilitate life experiences

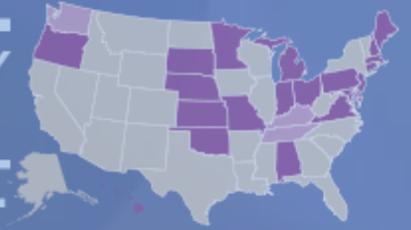


National Agenda Recommendations for Supporting Families

1. Adopt a **fluid, expansive (yet universal) definition of family**
2. **Operationalize “family support practices”**
3. **Design and fund peer support as a critical service**
4. **Redesign waiver services and supports** (quality-of-life outcomes, flexibilities, access and navigation, self-determination while also balancing support for the family)
5. Develop **more effective “front doors”** that provide lifespan support
6. Ensure **meaningful leadership roles of people with disabilities and families** at all levels of the system
7. Fund and support a **National Training, Research, and Resource Center for Family Support focused on Persons with I/DD**
8. Create a **national, interagency task force on supporting families of people with I/DD** for research, funding, and advocacy

[2022 National Agenda details are available here \(supportstofamilies.org\)](https://supportstofamilies.org)

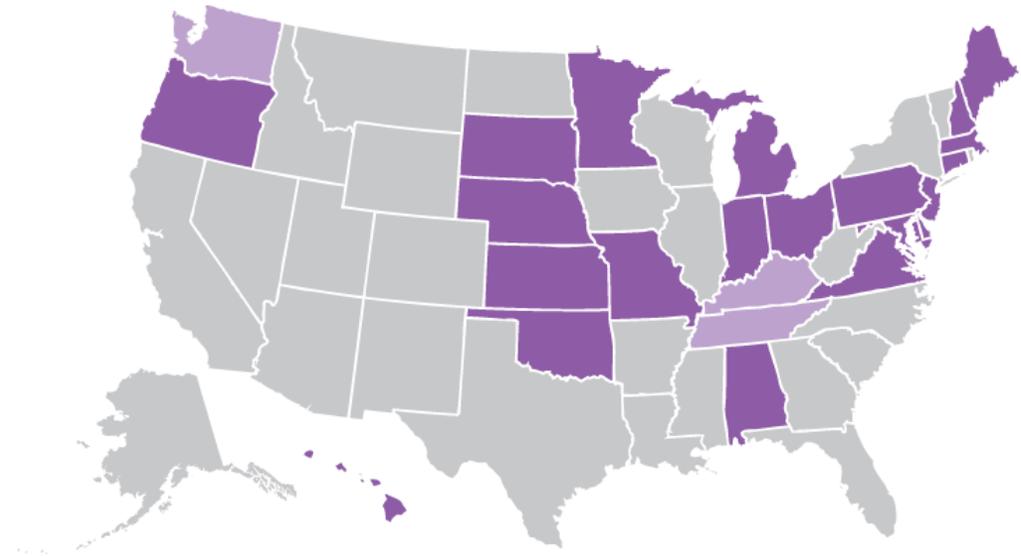
THE
NATIONAL
COMMUNITY
OF PRACTICE
FOR SUPPORTING FAMILIES



The Community of Practice on Supporting Families of Individuals with Intellectual and Developmental Disabilities

National Community of Practice for Supporting Families

2012-2016: ACL Grant Funded for 6 states
2016 -2019: 11 membership states
2019 – 2022: 13 membership states
2022 – 2024: 22 membership states



Collaboration between



Goal of National CoP on Supporting Families



Support state CoP teams to develop strategies to enhance and drive policy, practice, system and community-wide transformation to **support the person with I/DD within the context of their family and their community**



Type of Change that is Needed

Transitional Change	Transformational Change
<ul style="list-style-type: none">• “Retooling” the system and its practices to fit the new model• Mergers, consolidations, reorganizations, revising systematic payment structures,• Creating new services, processes, systems and products to replace the traditional one	<ul style="list-style-type: none">• Fundamental reordering of thinking, beliefs, culture, relationships, and behavior• Turns assumptions inside out and disrupts familiar rituals and structures• Rejects command and control relationships in favor of co-creative partnerships

Creating Blue Space, Hanns Meissner, 2013

Strategies & Supports Targeting Families



- Information and Education
- Navigation Support
- Formal Peer to Peer Services
- Support Groups
- Professional Counseling
- Crisis Prevention and Intervention
- Respite
- Home Modifications
- Health and Wellness of Caregivers



Enhancing HCBS Services and Supports that focus on Person in Context of Family



- Enhancing front doors (intake, eligibility, navigation)
- Person-centered planning process to include families and to also identify families needs
- Service Options: Self-Directed Services, Paid Family Caregivers, Technology Supports, Shared Living Models
- HCBS Waivers: wait lists, services for family members, self-directed options
- Engaging with families at all levels

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Focus on Family Initiatives in Other Systems



- **Self-Advocacy Organizations**
- **Early Childhood and School Age Education and Care**
- **Transition to Adulthood and Employment**
 - Community Integrated Employment
 - Meaningful Days
- **Access to Technology for Everyday Life**
- **Aging Systems and No Wrong Door Systems**
 - Futures Planning for Person and/or Family
 - Aging Caregivers and Grandparents
- **Housing and Transportation**
- **Supported Decision-Making, Guardianships, and Alternatives**





<https://supportstofamilies.org>

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WHAT CAN WE DO FOR YOU?

Our depth and breadth of experience has helped an incredibly diverse range of healthcare industry leaders.

Questions?

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