



Association of University Centers On Disabilities

Family Support 101: Understanding Policies that Support Family and Family Caregivers for Trainees

Tuesday, November 14, 2023

2:30 PM-4:00 PM

Zoom Housekeeping

- Ensure your name is displayed correctly in the participant list. You may also include the program name and state and preferred pronouns.
 - Example: Cindy Smith, AUCD, she/her
 - Hover over your name in the “Participants” box and select “More” → “Rename”
- Use the chat box to introduce yourself!
 - Name, Role, Program
 - If you had an extra hour in your day, how would you spend it?
- Remain muted unless speaking
- State your name prior to speaking
- Captioning is available
- Recording will be available

Agenda

- 2:30 PM Welcome
- 2:40 PM Overview and History of Family Support, National Agenda on Supporting Families and State DD CoP on SF – Sheli Reynolds
- 3:00 PM Current Needs of Families and Family Caregivers - Understanding context, data, etc., of families and family members (Aging and DD CoP, etc.-aging, older parents, parents with disabilities, siblings, etc.; Sibling Leadership Network, family policy, etc.). – Tamar Heller
- 3:20 PM Respite - Policy, Practices and Innovations – Jill Kagan
- 3:45 PM Q & A
- 4:00 PM The End

Public Policy Staff



Cindy Smith



Liz Weintraub



Kevin Ryle

Presenters



Sheli Reynolds,
Key Developer
Charting the LifeCourse
LifeCourse Nexus



Tamar Heller
Professor &
Department Head
Disability and Human
Development
University of Illinois Chicago.



Jill Kagan
Program Director
ARCH National Respite Network
and Resource Center



History of the Supporting Families Movement in the USA

Sheli Reynolds, PhD

University of Missouri- Kansas City, Institute for Human Development



About Sheli Reynolds

- Mother of two teenage sons and a sibling of three brothers, one who is 41 years old with developmental disability with 24 hour support needs
- Senior Associate Director, UMKC Institute for Human Development
 - *Director and Founder, LifeCourse Nexus*
 - *Director, National CoP on Supports to Families*
 - *Former Director, Mo Family-to-Family Health Info Center*
 - *Statewide Advisor, People First of Missouri Self-Advocacy Movement for 12 years in Missouri*
- Leadership Team, National Agenda on Supporting Families (2011 and 2023)
- Former Member, Presidents Committee for Persons with Intellectual Disabilities Appointed by President Obama





History and Evolution of Supporting Families



Evolution of Person-Centered and Family-Centered Services and Supports

1800s Exclusion---Segregation---Specialized---Inclusion---Self-Determination



1800s Blame---Damaged---Over-Burdened---Coping---Supported---Resilient





Disability Movements and Key Policies

1950s Veterans and Mom-----Parent-----Fathers---Family Movement

1970s Civil Rights: Self-Advocacy/Independent Living Movements

2010s Siblings, Fathers, Grandparents, and Parents with Disabilities

2020s Access, Inclusion, Diversity and Equity for All

1960s Medicaid and Medicare Established

1980s Medicaid Waiver (Community Supports) and Family Support

2010s Olmstead Act, Affordable Care Act, CMS Guidance-Settings

1970s Rehab Act: 504 Plans

1975s Education for All Children

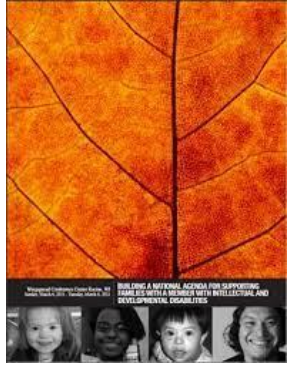
1990s IDEA, ADA, Family Support

2010s Ticket to Work, Workforce Investment Act



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 ongoing 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 ID/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



Outcome | Moving from Family Support 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 an approach to supporting families across the lifespan regardless of service provision and where a person lives
Caregiver or parent	Family is defined functionally by the person; inclusive of siblings, parents with disabilities, grandparents, friends who provide supports
Tension between self-advocacy and family support	Enhances opportunities for self-advocacy and self-determination
Crisis, immediate response	Preventative, long-term planning
Supporting caregiver in order to decrease demand on long-term services	Creates a quality of life for person with DD and their family by supporting their many reciprocal roles



Outcome | Goal of Supporting Families

GOAL



Individual

Will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life

Families

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



Recognizing that individuals exist within a family system



Defining Supporting Family Strategies



**DISCOVERY
AND NAVIGATION**
Knowledge & Skills

**CONNECTING
AND NETWORKING**
Mental Health
& Self-Efficacy

**GOODS AND
SERVICES**
Day-to-Day
Supports

Set of strategies targeting the family unit but that ultimately benefit the individual with I/DD.

Intended to assist family members who have a key role in the provision of support and guidance to their family member with I/DD to address the emotional, physical and material well-being of the entire family.

Must be designed, implemented and funded in a manner directed by the family unit. They should be flexible, comprehensive, and coordinated



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



Original Project Dates: 2012-2016

Funded by the United States Department of Health and Human Services, Administration for Community Living (ACL), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Grant# 90RT50320-01-00



National Community of Practice on Supporting Families

Goal

To build capacity through a community of practice across and within States to create policies, practices and systems to better assist and support families that include a member with intellectual and developmental disability across the lifespan.

Outcomes

- State and national consensus on a national framework and agenda for improving support for families with members with I/DD
- Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families
- Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems



Forming a National Community of Practice

A community of practice is a **learning environment** for an intensive exploration into current policy, practices, trends, and barriers. The key to a community of practice is understanding that **the sum of the community knowledge is greater than the sum of individual knowledge.**





Leveraging National Agenda to Develop Key Principles for Supporting Families

Transitional Change

- “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

Transformational Change

- 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



Charting the LifeCourse Framework | Outcomes and Impact



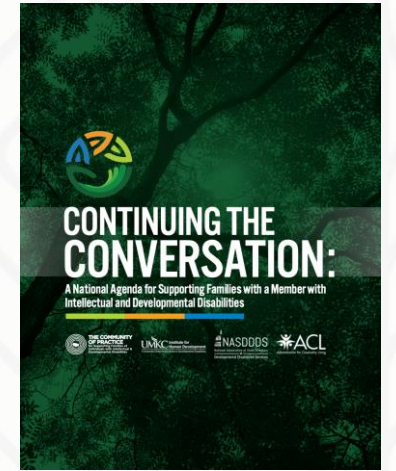
- Charting the LifeCourse framework and tools are being integrated into person-centered thinking, planning and policy change across diverse populations, age groups and systems
- National CoP membership consists of 21 States and continues to grow
- In 2017, ACL awarded an evaluation contract to New Editions and Lewin Group to evaluate the impact of the CoP and the CtLC framework

https://acl.gov/sites/default/files/programs/2019-10/ACL_CoP_Annual_Report_Final_SF_508.pdf



2022 National Agenda

A Summary of the Current State and Future Vision for Supporting Families





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 | Cross Cutting Considerations

- Beyond understanding and acceptance, an **appreciation for the many intersectional identities of all family members** must drive intentional focus on diversity, equity, inclusion and belonging as an integral foundation of all transformation efforts
 - Families play a **critical role in ensuring self-determination** for the person with ID/DD, and **need supports to foster choice, control, and decision-making**
 - Balance is needed to **ensure the person is directing their plan and life, while also supporting families in their (potentially multi-faceted) role(s)**
 - **High expectations and opportunities to explore** possibilities are essential, and often times are developed through **role models and peer support opportunities.**
 - There is significant **value in lived experience**, and people with ID/DD and their families must have **access to capacity building and should hold meaningful, leadership roles in state, local, and federal organizations, and efforts**
-



National Agenda 2022 | Definition of Family

- Family should be defined by the person, that it is **more than a legal or biological/genetic construct**. 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 :
- Should be **understood as those with mutual/reciprocal connections** and that are marked by such characteristics as:
 - Commitment and trust – the ability to rely/count on/depend on each other
 - Unconditional love – “fiercely care about each other”
 - Support – believing in each other, and supporting each others’ goals and dreams
 - Sense of safety – ability to be authentically one’s self, 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



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 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

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



National Collaborative on Supporting Families



National Collaborative for Supporting Families

- **National Collaborative for Supporting Families Steering Committee:** Meets quarterly and open to anyone who wants to guide the work, space for connection and information dissemination for systems change agents dedicated to enhancing supports for people with IDD and their families. Supporting Families Best Practices Series
- **The Supporting Families Best Practice Series:** Held quarterly in collaboration with the National Community of Practice for Supporting Families. Open to anyone who wants to learn about the best practices around recommendations from the new agenda. Each session will feature a panel of individuals or entities who will address key recommendations from the National Agenda through their lens of grassroots advocacy, “practice level” implementation, states service systems, federal policies, and research.
- **Website:** hosting National Agenda Reports and other materials and opportunities



The 2023 National Agenda for Supporting Families



CONTINUING THE CONVERSATION:

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





National Supporting Families Best Practice Series

Join the ListServ

- Updates and news that impact supports to families
- Opportunities to engage, participate and take action



Scan the QR Code to
Sign up for the ListServ

Register for Future Webinars

- **December 7, 2023:** Enhancing the Peer Support Workforce for People with I/DD and their Families
- **March 7, 2024:** The Role of HCBS Waiver Services in Supporting Families
- **June 6, 2024:** Supporting Families to Navigate Services and Supports



National Activities

- ACL RAISE Report
 - <https://acl.gov/CaregiverStrategy>
- National Family Caregivers Month
 - #NationalCaregiverStrategy

Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act **Initial Report to Congress**

Prepared by: RAISE Family Caregiving Advisory Council

With assistance from: Administration for Community Living,
an operating division of the U.S. Department of Health and Human Services



September 22, 2021



NATIONAL COLLABORATIVE FOR SUPPORTING FAMILIES



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

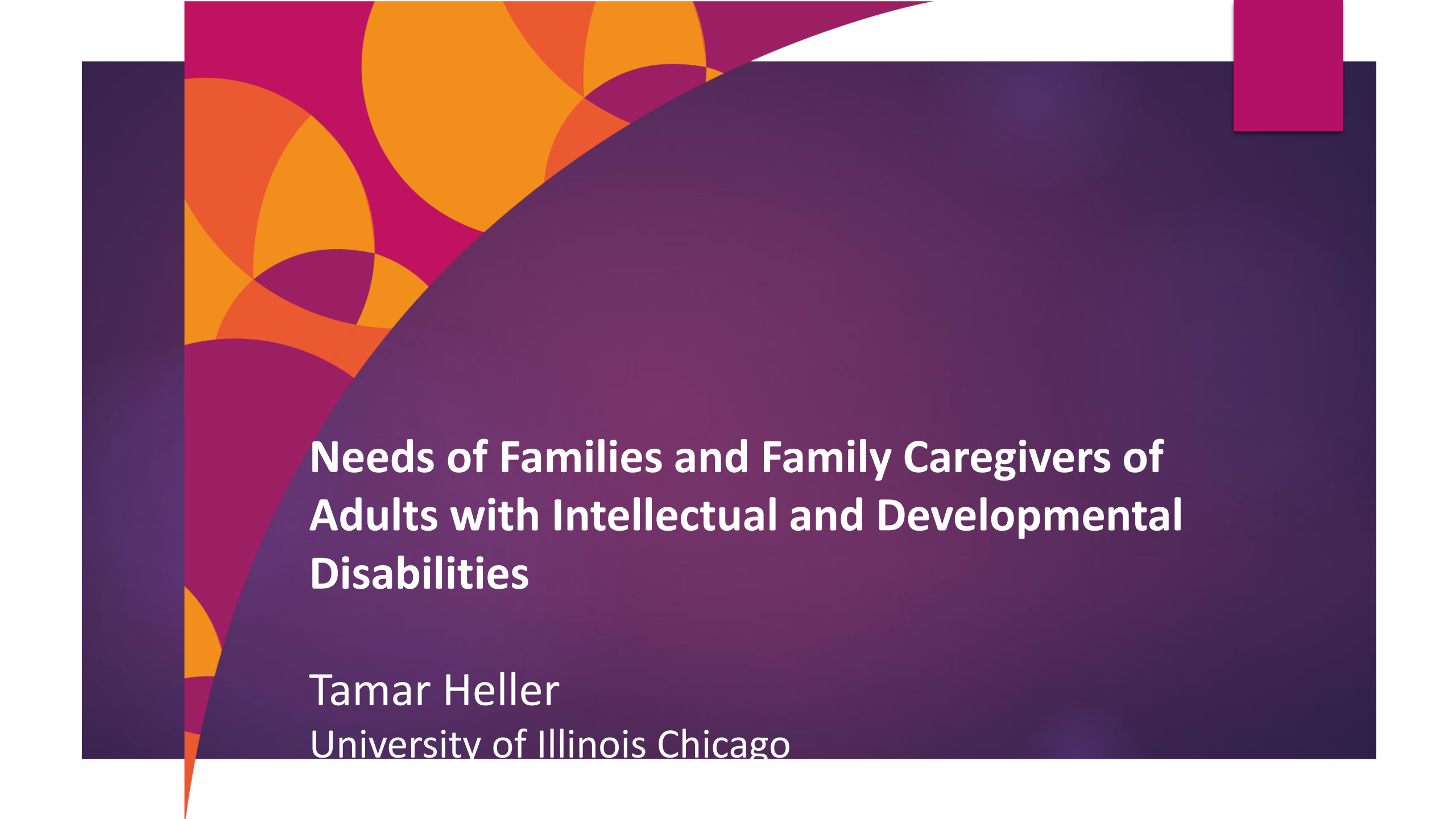
UMKC Institute for
Human Development
A University Center for Excellence in Developmental Disabilities

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

 **ACL**
Administration for Community Living



Sheli Reynolds
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Needs of Families and Family Caregivers of Adults with Intellectual and Developmental Disabilities

Tamar Heller
University of Illinois Chicago

Life Course Perspective

- ▶ View present within past, current tasks to master, future to which moving
- ▶ Examine development phase and what is different from normative
- ▶ Address stress of transitions from one stage to next
- ▶ Take into account personal, family, community, and state and national policy changes
- ▶ Consider social determinants and effect on adults and their families

Life-Long Impact for Families

- ▶ Experience chronic stress and risk of poor mental health and QOL.
- ▶ Greater risk for some underserved groups
- ▶ Difficulties as person with IDD and parents age
- ▶ Caring also has its positive aspects

Caregiving Impact: Economic

- ▶ Often results in reducing work hours, changing jobs, stopping work entirely, and taking a leave of absence (NAC, 2009)
- ▶ Caregivers of individuals with IDD less likely than non-caregivers to be employed, miss more days of work (Bronheim, Goode, & Jones, 2006), and have less income (Parish, Seltzer, Greenberg, & Floyd, 2004)
- ▶ Families of individuals with disabilities have lower savings leading to less for retirement (Metlife, 2011)
- ▶ Economic losses greater for racial/ethnic minority groups (AARP, 2013)

Impact on Families: Health and Social

- ▶ Parents of adults with disabilities have higher stress, depression, anxiety, and physical health issues (Vanegas & Abdelrahim, 2016, Lunsky et al., 2014)
- ▶ Greater impact when:
 - ▶ need for more behavioral support, complex health care needs, and difficulty getting services
 - ▶ compound caregivers (Wang et al, 2022)
 - ▶ racial/ ethnic minorities (Magana & Smith, 2006)
- ▶ Social networks more restricted (Seltzer et al., 2011)
- ▶ Impact changes over time

Positive Aspects

- ▶ Can be source of fulfillment and meaningfulness
- ▶ Some report better mental health, life satisfaction (Grossman & Webb, 2016)
- ▶ Reciprocity in caregiving, especially to aging parents; people with disabilities are also caregivers (Heller & Factor, 2008; Arnold, 2022)

Impact on Siblings

- ▶ Sisters more involved in care of adult siblings with ASD
- ▶ As get older sibs more involved in care
- ▶ Worst combination is female with ASD and typical brother
- ▶ Negative factors: family history of depression, especially mother, and stressful events
- ▶ Positive factor is family support
- ▶ Sibling well being and close relationship bi-directional
- ▶ Less positive relationship if more challenging behaviors (Orsmond & Fulford, 2018))

Sibling Supports

- ▶ Sibling Leadership Network: Advocating for and with our siblings
 - ▶ www.siblingleadership.org
 - ▶ 27 state chapters
- ▶ Sibnet
- ▶ Siblings FORWARD (Focusing on Relationships, Well-Being, and Responsibility Ahead) (Orsmond, 2022)



Interaction of Aging and IDD in Life Transitions

Development of chronic health conditions



Changes in family caregiving and supports



Retiring from employment



Receiving end of life care

Issues in Adulthood and Aging

- ▶ Many adults with IDD continue to live at home and are unemployed or underemployed with no pensions
- ▶ High rates of medical and psychiatric conditions (can stabilize, reduce, or increase)
- ▶ Difficulty finding doctors with needed expertise
- ▶ Reduction in some behavioral symptoms
- ▶ Some earlier age- related chronic conditions (due to medications, health care, and health behaviors)
- ▶ Need to address end of life issues
- ▶ Challenge for aging parents who have fewer supports
- ▶ Siblings take on greater roles

Unmet Family Support Needs: Adulthood and Aging

- ▶ The role of families more formalized in schools unlike adult systems of care
- ▶ Among families of people with disabilities who wanted a specific service over two-thirds had an unmet need for support groups (71.7%), meal services (72.4%), and respite (73.3%). Nearly half had an unmet need for assistive technology (46.8%), home healthcare (50.0%), home modifications (59.5%), and training or education for future planning (62.8%) (Crabb, Owen, & Heller, 2021).

Need to Plan for Future Needs

- ▶ Many families do not make plans and experience barriers:
 - ▶ Unaware of legal and financial options
 - ▶ Fears for the future and unknown
 - ▶ Difficulty identifying caregiving support for the future
 - ▶ Difficulty in initiating the process
 - ▶ Have little contact with and mistrust formal disability services
 - ▶ Lack of collaboration between aging and disability service system
 - ▶ Age-related needs and daily demands
- ▶ Planning is related to resources, ways of coping, and options in the community

How Can We Support Families?

- ▶ Public Policies: governmental support
 - ▶ Cash subsidies
 - ▶ Consumer-directed supports
- ▶ Psychosocial Interventions
 - ▶ Support groups
 - ▶ Future planning
 - ▶ Support coordination
- ▶ Natural community and informal supports

Family Support Makes Public Health and Financial Sense!

- ▶ Family support is associated with positive family outcomes of better family quality of life, functioning, satisfaction, and less stress (Kyzar et al., 2012), less caregiving burden, more caregiving satisfaction, and more self-efficacy in helping the family member with a disability (Crabb, Owen, & Heller, 2021)
- ▶ Unmet service needs are associated with decreased mental health for female family carers of adults with IDD (Caldwell, 2008) and institutionalization (Heller & Caldwell, 2005)
- ▶ Respite and supplemental services have been linked to lower caregiver stress, less depression, decreased caregiver burden, and improved mental health (Chen & Young, 2010)
- ▶ Psychoeducation interventions have shown positive impacts for families of individuals with IDD (Heller & Schindler, 2009).

Collaboration with Aging Network

- ▶ Joint task forces: RAISE (Recognize, Assist, Include, Support, & Engage) Family Caregiving Advisory Council)
- ▶ Cross-training
- ▶ Differences in philosophy and aims
- ▶ Commonalities in need for long term care
- ▶ Aging and Disability Resource Centers
- ▶ National Family Caregiving Support Program
- ▶ National Alzheimer's Project Act
 - ▶ National Task Group on ID and Dementia
 - ▶ *My Thinker is Not Working*

Policy Considerations

- ▶ Service providers need to:
 - ▶ assess family support needs
 - ▶ provide family supports (e.g., respite, stipends, psycho-education training, and peer supports)
- ▶ Increase support to families for behavioral supports and for help with complex health care
- ▶ Balance person-centered and family-centered support with self-determination of person with a disability

Policy Considerations

- ▶ Culturally tailor information, services, and supports to be accessible for caregivers from various racial/ethnic backgrounds
- ▶ Develop, expand and pay for the work force of personal support workers, including paying families
- ▶ Consider other family members, e.g., siblings, grandparents, others
- ▶ Bridge aging and disabilities in community education, outreach, research and supports for caregivers (e.g., for dementia care and ID)

Contact

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UNIVERSITY OF
ILLINOIS CHICAGO

Institute on Disability
and Human Development

Family Support 101: Understanding Policies that Support Family and Family Caregivers for Trainees

Respite: Policy, Practices and Innovation

AUCD

November 14, 2023



ARCH
National Respite Network
AND RESOURCE CENTER

Asking for Help

is a sign of

strength.

archrespite.org



ARCH
National Respite Network
AND RESOURCE CENTER

- **Training and Technical Assistance Division** provides support to State Respite Coalitions, service providers and families through consultation, training, evaluation, and research.
- **National Respite Locator Service (NRLS)** helps family caregivers and professionals locate respite services in their communities.
- **National Respite Coalition** is the policy and advocacy division of ARCH.
- **Lifespan Respite Technical Assistance Center**, funded by the U.S. Administration for Community Living, supports State Lifespan Respite grantees and their partners in developing state respite systems serving caregivers of persons of all ages and conditions.

What is Respite?





Respite is...

Planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

*Lifespan Respite Care Act definition
PL 109-442*



Types of Respite

- ❑ Formal Services
 - Home care agencies
 - Group Home, Adult Day Services or Childcare Centers
 - Facility-based
 - Community-based agencies
- ❑ Informal Services
 - Family and Friends
 - Volunteer or Faith-based



Public Programs

- ❑ Medicaid Waivers
- ❑ National Family Caregiver Support Program
- ❑ Other Federal Programs
- ❑ State Funded Respite Programs
- ❑ Lifespan Respite Care Program



A woman with braided hair is smiling and playing with a young boy. They are sitting at a table with a wooden toy that has colorful rings and beads. The boy is laughing and has his hand near his mouth. The background shows a living room with a white sofa and a window with green balloons.

Private Sector Options

- ❑ Disability Organizations
- ❑ Community-based Programs on sliding-fee scale
- ❑ Parent Cooperatives
- ❑ Free Volunteer or Faith-based Services
- ❑ Self-pay



Everyone Needs Respite!

- ❑ Reduces Stress
- ❑ Improves physical and emotional health
- ❑ Enhances relationships and reduces social isolation
- ❑ Care recipients benefit, too!





Respite: Too Little, Too Late

- ❑ Yet, 86% of family caregivers of adults are not receiving respite services at all
- ❑ A significant percentage of caregivers of children with an unmet need do not receive respite (63% to 75%).
- ❑ Of those who use respite, they often receive too little, too late.
- ❑ Barriers to Respite



Enhancing Respite Practice





Innovative & Exemplary Respite Services



archrespite.org/innovative-and-exemplary-respite



ARCH
National Respite Network
AND RESOURCE CENTER



RCAW
Respite Care Association
of Wisconsin

Respite Provider Recruitment, Training and Retention Project

- ❑ Core Competencies
- ❑ Online Entry-level Respite Provider Training Curriculum
- ❑ Field Tested
- ❑ Find more information

<https://archrespite.org/provider-resources/provider-training-resources/#TrainingAccordion-1>



Lifespan Respite Care Program

Definition: Coordinated **SYSTEMS** of accessible, community-based respite services for all family caregivers regardless of age or special need.

Self-Directed Respite Voucher Models

Who can the families select to provide respite?

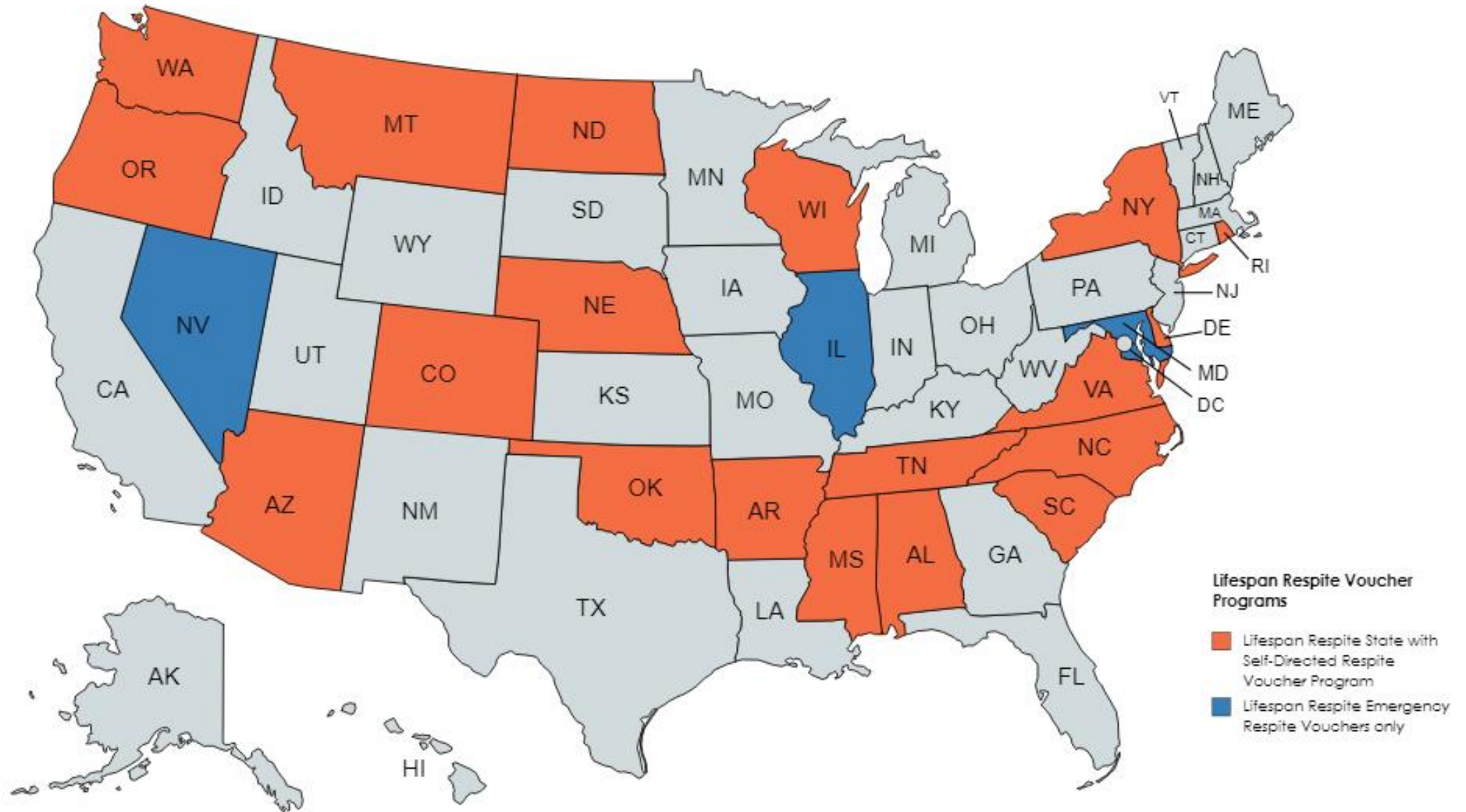
- ❑ Family, Friends, Community Members
- ❑ Vetted Agencies

Who receives payment?

- ❑ Reimburse Family Caregivers
- ❑ Reimburse Agencies/Providers



Lifespan Respite Voucher States



LifeCourse Tools for Respite

Purposes are to provide:

- ❑ information on the importance of respite;
- ❑ tools for thinking about and planning for respite; and
- ❑ additional resources for finding respite in the community.

LifeCourse Respite tools can be found at archrespite.org/caregiver-resources/planning-for-respite/#tools or www.lifecoursetools.com/lifecourse-library/exploring-the-life-domains/respite

Charting the LifeCourse

LIFE DOMAIN
ALL Life Domains

LIFE STAGE
ALL Stages

Respite:
Short Breaks for Caregivers

Being a caregiver can be one of the most rewarding and most challenging times we face. In order to continue to care for family members who require additional support, we must remember to care for ourselves as well.

This guide is meant to help caregivers and those who support them to understand the meaning and importance of respite/short breaks, see real life examples, understand the possibilities and options that exist for respite, within and outside the formal, paid service system, and create a successful plan that uses these short breaks to enhance the lives of all family members.

UMKC INSTITUTE FOR HUMAN DEVELOPMENT, UCEDD

DEVELOPED BY
MISSOURI
FAMILY TO FAMILY
UMKC INSTITUTE FOR HUMAN DEVELOPMENT | UCEDD

IN PARTNERSHIP WITH
ARCH National Respite Network
And Resource Center

Respite and Caregiving Policy

National Strategy Goals

- ❑ GOAL 1: Increase awareness of and outreach to family caregivers
- ❑ GOAL 2: Advance partnerships and engagement with family caregivers
- ❑ GOAL 3: Strengthen services and supports
- ❑ GOAL 4: Ensure financial and workplace security
- ❑ GOAL 5: Expand data, research, and evidence-based practices to support family caregivers.

2022 National Strategy to Support Family Caregivers



Developed by:

The Recognize, Assist, Include, Support, and Engage (RAISE) Act
Family Caregiving Advisory Council

&

The Advisory Council to Support Grandparents Raising Grandchildren



Technical assistance provided by the Administration for Community Living | September 21, 2022

acl.gov/CaregiverStrategy



National Strategy Content

- ❑ 2022 Strategy lays out a framework for systemic caregiver supports, and identifies caregiver needs that require new legislation
- ❑ 350+ Federal actions from 15 federal agencies
- ❑ 250+ broad actions for states, communities and stakeholders with a “roadmap” of ideas

2022 National Strategy to Support Family Caregivers: Actions for States, Communities, and Others

Developed by:

The Recognize, Assist, Include, Support, and Engage (RAISE) Act
Family Caregiving Advisory Council

&

The Advisory Council to Support Grandparents Raising Grandchildren



acl.gov/sites/default/files/RAISE_SGRG/NatlStrategyFamCaregivers_ActionsSCO.pdf



Respite Resource Guide

- ❑ Designed as an action guide for state agencies
- ❑ Produced by ARCH in collaboration with NASHP
- ❑ Examples align with 5 goals of the strategy



Respite Care Resource Guide

Respite care is a service typically delivered in the home or a community, faith, or facility-based setting that provides short-term relief for caregivers. It is one of the most desired services by caregivers who report that they need a break.

The Challenge

Despite the demand for this service, many family caregivers do not receive it. Challenges include a lack of trust of unknown providers to provide care, especially in homes; difficulty in finding and paying for quality providers; and rigid program policies that limit the types of respite providers (e.g., those that do not allow for family, friends, and known providers to provide respite).

A Historic Opportunity

The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren (SGRG) developed a [National Strategy to Support Family Caregivers](#) that is now ready for implementation. Released to Congress in September 2022, this comprehensive strategy identifies actions for the federal government to take and lays out actions for states, communities, health care systems, long-term support and service providers, researchers, employers, philanthropic organizations, and many others to support family caregivers. Respite care is a key component of this strategy.

State Action Guide

The ARCH National Respite Network and Resource Center created a Learning Collaborative of state administrators and their partners. In partnership with the National Academy for State Health Policy (NASHP), the Learning Collaborative created this roadmap for states that want to implement the respite actions identified in the National Strategy. The roadmap can support states interested in building or expanding respite care for family caregivers by offering the following policy strategies and promising practices.

<https://supportcaregiving.org/respite-care/>

Taking Congressional Action

- ❑ Urge Congress to ensure promise of **National Strategy to Support Family Caregivers** through **Act on RAISE**.
- ❑ Increase funding for the **Lifespan Respite Care Program** and the **National Family Caregiver Support Program**
- ❑ Support **Home and Community-based Services (HCBS) Relief Act (S.3118)** to strengthen the direct care workforce, decrease waiting lists for HCBS, support family caregivers.
- ❑ Advocate for **Alleviating Barriers for Caregivers Act (S.3109)**



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For More Information



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Any
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