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
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

<table>
<thead>
<tr>
<th>Family Support</th>
<th>Supporting Families</th>
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<tbody>
<tr>
<td>Defined by eligibility, services or programs available, or funding</td>
<td>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</td>
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<tr>
<td>Caregiver or parent</td>
<td>Family is defined functionally by the person; inclusive of siblings, parents with disabilities, grandparents, friends who provide supports</td>
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<tr>
<td>Tension between self-advocacy and family support</td>
<td>Enhances opportunities for self-advocacy and self-determination</td>
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<tr>
<td>Crisis, immediate response</td>
<td>Preventative, long-term planning</td>
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<tr>
<td>Supporting caregiver in order to decrease demand on long-term services</td>
<td>Creates a quality of life for person with DD and their family by supporting their many reciprocal roles</td>
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Outcome | Goal of Supporting Families

**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

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

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
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 than 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
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 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

2022 National Agenda
A Summary of the Current State and Future Vision for Supporting 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
• 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
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

<table>
<thead>
<tr>
<th>Discovery and Navigation</th>
<th>Connections and Partnership</th>
<th>Goods and Services</th>
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<tbody>
<tr>
<td>- Timely information (in plain, accessible language – and more languages)</td>
<td>- Trauma supports (esp. for parents/siblings)</td>
<td>- Basic needs (housing, food, healthcare, financial supports)</td>
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<td>- Advocacy skill training</td>
<td>- Father support groups</td>
<td>- Technology</td>
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<tr>
<td>- Anticipatory guidance (related to life experiences at each life stage, transitions, etc.)</td>
<td>- Mental health supports</td>
<td>- Home modifications</td>
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<tr>
<td>- Supported decision making supports</td>
<td>- Parent support groups</td>
<td>- Respite/short breaks</td>
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<tr>
<td>- Education and training around parenting skills</td>
<td>- Networking and connection opportunities</td>
<td>- Childcare</td>
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<tr>
<td>- Information, education, and resources for navigating systems, supports, services, etc.</td>
<td>- Peer supports and mentoring (role models)</td>
<td>- Everyday life and future planning/problem-solving supports</td>
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<td></td>
<td>- Assistance developing social capital/community integration</td>
<td>- Navigational supports to access services and support systems</td>
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<td>- Funding for adaptations and accommodations to facilitate life experiences</td>
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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
National Supporting Families Best Practice Series

Join the ListServ

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

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

Scan the QR Code to Sign up for the ListServ
National Activities

• ACL RAISE Report
  • https://acl.gov/CaregiverStrategy
• National Family Caregivers Month
  • #NationalCaregiverStrategy
Sheli Reynolds
reynolds@umkc.edu
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](http://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
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
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).
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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theller@uic.edu

Funded by National Institute on Disability, Independent Living and Rehabilitation Research, Administration on Community Living, grant # 90IFRE0051 to the University of Illinois Chicago.
Family Support 101: Understanding Policies that Support Family and Family Caregivers for Trainees

*Respite: Policy, Practices and Innovation*

AUCD
November 14, 2023
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
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!
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
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

Lifespan Respite Voucher Programs:
- Orange: Lifespan Respite State with Self-Directed Respite Voucher Program
- Blue: Lifespan Respite Emergency Respite Vouchers only
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
Respite and Caregiving Policy
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 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
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

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)
Join us!

RAISE the Bar for Respite

Strategies to strengthen family caregivers

2024 National Lifespan Respite Conference • May 21-23, 2024 • Albany, NY
Lifespan Respite
Technical Assistance Center

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Thank you!
Please share feedback on today’s webinar!

https://www.surveymonkey.com/r/FamilySupport101