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Disability and Care Across Multiple Stakeholder Groups

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Agenda

- Context: Developing a National Research Plan
- Data collection
- Analytic Methods
- Findings
- Limitations
- Implications and Next Steps

Family Support: Tell Us What We Need to Know

Family Support Research Training Center (FS-RTC)

- University of Illinois at Chicago

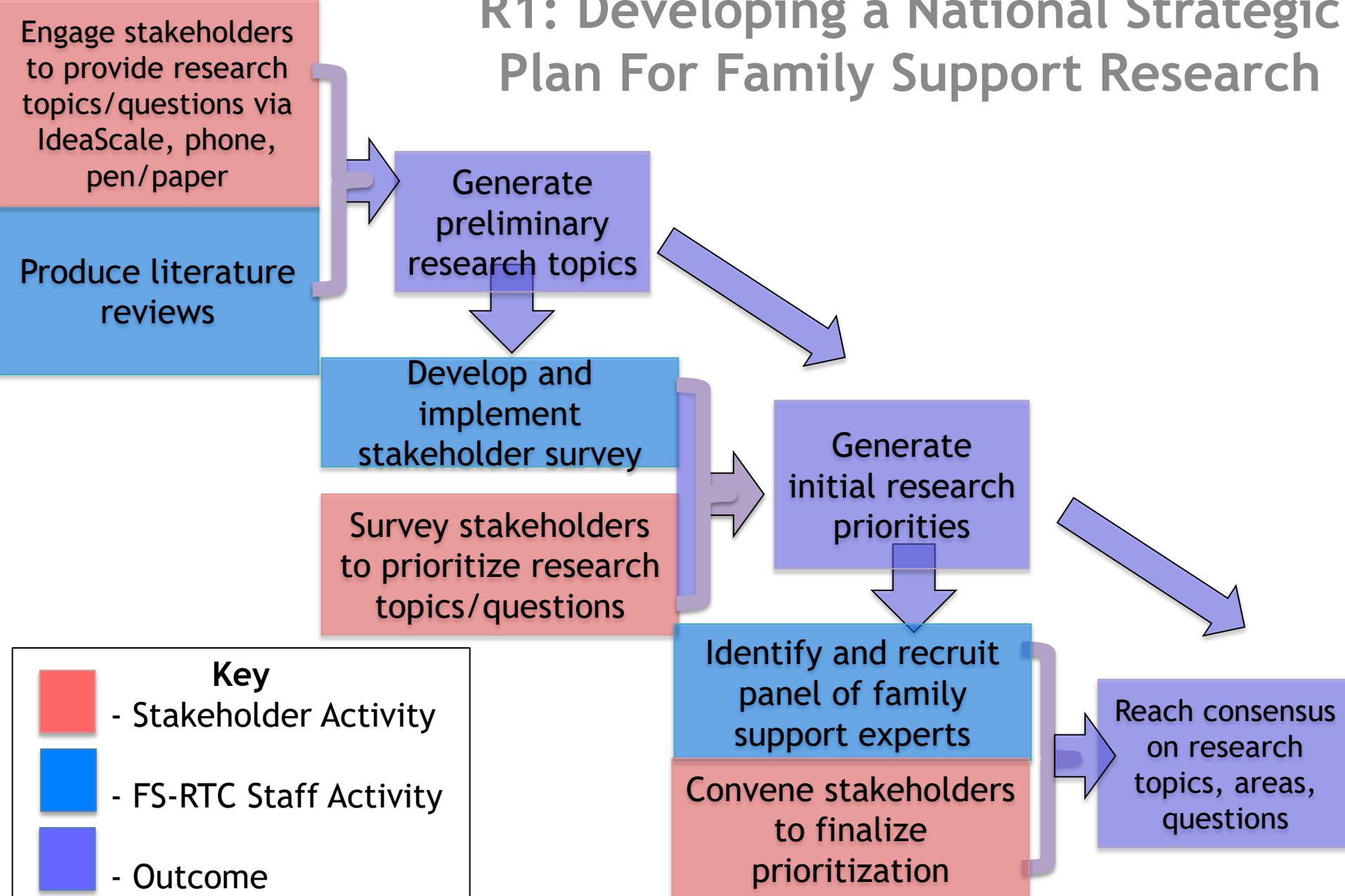
Short-term goal:

- To gather input about family support (caregiving) research topics from multiple stakeholder groups
 - Focus on different stakeholders
 - Focus on people of color, racial/ethnic diversity
 - Focus on hearing from users (consumers)
 - Family broadly defined

Long-term goal:

- To develop a national family support research agenda

R1: Developing a National Strategic Plan For Family Support Research





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Recruitment

- Large coalition of organizations
 - Across disability populations
 - Diverse: ethnic/racial and sexual minority
- Multiple modes of data collection
- Extended data collection period
 - From March to June 2015



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Data Collection - Instrument

Describe at least one topic that you think family support researchers should explore further. Explain why you think this topic is important.

Things to think about as you respond:

- practical issues with providing support to family members who need assistance
- physical, financial, spiritual, and emotional aspects of providing family support
- information you wish national and local decision makers or healthcare/social service providers know about family support.



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Modes of Data Collection

Mode of Data Collection	Timeframe	Recruitment Method	Respondents Ideas/Total
IdeaScale (online dialogue)	3/9/15 - 3/30/15	Email blasts, webinars with two large organizations	33/152
Call-in line	3/9/15 to 5/29/15	Email blasts, phone number on hard copy flyers	4/4
Pen and paper	3/9/15 to 6/30/15	Staff at partner organizations, volunteers	201/345
TOTAL			238/501

Table 1. Racial/Ethnic Identities of Respondents

Racial/Ethnic Category	Number of Respondents
White	245 (49%)
Latino/Hispanic	153 (30%)
Black/African American	58 (12%)
Asian/Asian American <i>(includes responses in Chinese)</i>	17
Arab/Arab American *	15
Bi/Multiracial	12
Native American/American Indian	2

- option to select as many as they desired
- option to select “other” and write in identity

Table 2. Respondents' self-identified relationship to family support

Relationship to Family Support	Number of Respondents	People of Color (%)
Family Support (LTSS) Provider	258	129 (50%)
Family Support (LTSS) Consumer	190	122 (64%)
Social Services Professional	57	22 (39%)
Home and Community-based Services Provider	50	18 (36%)
Healthcare Professional	45	15 (33%)
Researcher	34	11 (32%)
Policy Maker	21	6 (29%)

- option to select as many as they desired
- option to select “other” and write in identity



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Methods and Analysis

- Qualitative, inductive coding
 - (Glaser & Strauss, 1967; Charmaz, 2014)
- Translation
 - Chinese, Spanish to English
- Intercoder consensus
- Iterative process
- Theme development based on identity



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Findings

- Voice
- Suggested Research Topics
 - Distinct
 - Shared across groups



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Voice: Personal Experience

- **Parents/family members**
 - Needs assessment
 - *“I think there is a lack of support for persons like myself that in my case I’m a single mother and it is not easy to find a job that allows me to find adequate child care. It’s difficult to take them out of special care because the child need more attention and support on my part. I work during the time they are in school.”*
 - Latina woman, family support provider
- **Person with Disability/consumer**
 - Needs assessment, individual advocacy
 - *“More money to help out with things like hearing aids & glasses”*
 - Black woman, uses supports provided by family member
 - *“Self direction better use”*
 - White man, uses supports provided by family member



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Voice: Professional Expertise

- **Researchers**
 - National, outcomes focus
 - *“More research is needed to demonstrate the cost benefits of family caregiver support programs. Supporting family caregivers can reduce undesirable placements in institutional settings, prevent avoidable hospitalizations, improve care coordination, and enhance the overall health and wellbeing of individuals with disabilities.”*
 - White man, researcher
- **Service Professional**
 - Program, process, local system focus
 - *“We all know caregiving is difficult and requires a team. There are many resources available to caregivers but caregivers have challenges reaching out and asking for help. Building a care team and developing a care plan can avoid some caregiver health challenges, how do we make it okay to ask for help?”*
 - Latina woman, HCBS provider

Topics: specific to respondent type

- **Those who provide support to family members**
 - Access to linguistically/culturally appropriate services
 - Siblings - source of support, need support
 - Transitional services - to adulthood
 - Includes leisure and employment
 - Employment while providing family support
 - Spirituality
- **Those who use support from family members**
 - Unmet need - more hours, more services



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Topics: shared across groups

- Aging
- Systems navigation
- Financial support
- Respite
- Direct care workforce



Aging with limited social network

“There are many of us baby boomers who live alone and who either have no children or whose children cannot or will not provide support for an aging parent. Much is being made of “aging in place,” But I think the idea (and the ideal) of aging in place by using these resources can lull people into a false sense of security. I know several instances of people who have chosen to age in place only to have health issues require their later removal to a nursing home. several couples I know resisted the move to a CCRC only to have one partner whose health deteriorated to the point where a CCRC will no longer accept them. Some families have children or siblings who will then rally 'round to give support and care to the aging person(s), but not everyone has this support.”

-White “woman who is aging” in a rural community



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Aging “Caregivers”

“What happens when the adult with disabilities can no longer live at home because the caregiver is getting too old, has/gets physical limitations, or dies? This gives me much stress-thinking about what will happen to my son when I’m no longer around.”

– White woman, provides support to family member

“Caregivers are often elderly & taking care of a spouse can be very difficult physically as well as emotionally. Depression can be a very common ailment.”

– Latina/White woman, 65+, provides support to family member



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Future Planning

“How can my daughter support herself and become independent? I am not sure what kind of resources there are out there when I die.”

- Asian American man, provides support to family member

“Planning for the future for parents who have children with disabilities --> leading to aging parents of adult children with disabilities. How can we help parents know that their children will be cared for when they're gone?”

-White woman, Healthcare professional, HCBS provider, and provides support to family members



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Systems Navigation

“.... A lot of them need individual counseling instead of group meetings. They don't know where to turn and often don't know the process to receive needed help . . .”

- White healthcare professional

“Creating an easier way to navigate the health system for immigrants with no/limited English language knowledge. It is very difficult for me and my family to navigate health system to get the services I need due to the language barrier.”

-Arab American woman, provides support to family member

“. . . I found the Medicare/Medicaid/Social Security systems to be quite daunting to deal with. Perhaps more support in these areas would be a good topic for research.”

- White woman over 65, provides sibling with support



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Financial support

“There are many topics that family support researchers should explore, one of which includes financial support. Many families barely get by with the money that comes in and they need the money for necessities such as education, food, shelter, etc.”

-Arab American woman

“The topic of government benefits. Options for persons who did not qualify for SSI and Medicaid.”

- Latina social services professional, provider of support to family members

“Lack of income to help with needs”

- Black/African American woman 65 +, provider of support to family members and user of support of family members



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Financial support

“It is a shame that the child's check is cut when Mom works even a part-time job.”

-White woman, provider of support to family member

“Even families who are not financially stressed, still need financial support for a disabled child.”

-Black/African American transgender, provider of support to family member

He will always need assistance and education in managing money, cooking, seeking leisure activities. Paying for this out of pocket gets enormously expensive. What resources are available for families like ours . . .not poor, but on a budget?

-White man, provider of support to family member



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Respite

“Also help with respite services. Right now respite only helps care for my daughters with disabilities when need be. I am a stay at home mother of four and when my daughters need help I can't focus on one or the other.”

- Latina woman, provider of support to family member

“The most important thing for caregivers, and the family members we/they care for, is an occasional break so we can have social interaction outside the home. To take a break we need backup assistance from time-to-time that we can count on.

-White woman, provider of support to family member



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Direct Care Workforce

“No good providers and workers who can give proper care to participants”

-Black/African American user of family support

“At any rate, we need a CURRENT and regularly updated national database of skilled caring caregivers who have received some training and are willing and able to help relieve the daily grind of care giving at a reasonable cost and without all the red tape we get from home health care agencies.”

-White woman, provider of family support in rural area

“Continued problems with D[irect] S[ervice] P[rovider]. Need better trained workers.”

-Black/African American user of family support



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Implications

- Next steps
 - Connect topic analysis with literature reviews
 - Share topic analysis with expert panel
- Different voices, shared concerns
 - Families want more support



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Questions?

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<http://fsrtc.ahslabs.uic.edu>



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What We Are Learning About Siblings



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Mission

- *To provide siblings of individuals with disabilities*
 - *the information, support, and tools*
 - *to advocate with their brothers and sisters*
 - *and to promote the issues important to them*
 - *and their entire families.*



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SIBLING LEADERSHIP NETWORK

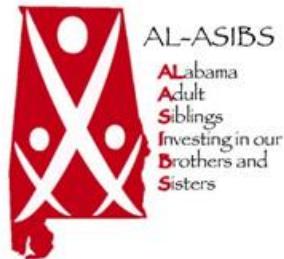


www.siblingleadership.org



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SLN Chapters



Ohio SIBS



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National Sibling Survey

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Gaps in the sibling research: Need more...

- Racially, ethnically and linguistically diverse siblings
- Non-caregiving but supportive siblings
- Siblings with multiple brothers/sisters with disabilities
- And...what about brothers?
- Perspective of individuals with disabilities, including different types of disabilities
- Longitudinal research



Development of National Sibling Survey

- Address needs and necessary supports for siblings:
 - Person with a disability perspective of sibling relationship
 - Difference in supports between parents and siblings
 - Professionals view of siblings
- Multiple siblings
- Inclusion of Spanish
- Potential for a three year follow-up
- Scales: Maladaptive behavior scale (SIB-R), Future planning scale, Advocacy scale
- Based off of previous sibling surveys (WLS, National Adult Sibling Survey) and extant literature
- Qualtrics web-based survey platform and pen/paper version



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Recruitment Methods

- Distributed nationally—had numerous national partners
- Distributed at state and local level
- Non-traditional venues
- Social Media





National Sibling Survey: Respondents

Type of Respondent	Sample
siblings of individuals with disabilities	39.1% (852)
parents of individuals with disabilities	31.4% (684)
professionals who work with individuals with disabilities	17.5% (459)
person with a disability	6.9% (182)
Total	2628



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Lessons Learned

- What about siblings of young (ages < 18) individuals with disabilities?
- What about siblings of individuals with disabilities who have passed away?
- What about other family members?
 - Siblings-in-law
 - Grandparents
- Need to build relationships over time for better outreach to diverse communities





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Voices of Self-Advocates

Video Link:

<https://www.youtube.com/watch?t=285&v=XGN3bSJZyxM>



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Thoughts?

Please raise your hand and we will call on you OR type your question into the chat box.

