# Family Support Research and Training Center

## Developing a National Agenda for Family Support Research

### A report on a national campaign to involve family Support stakeholders in developing a research agenda

Prepared By:

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**Institute on Disability and Human Development**

# FSRTC

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## Acknowledgements

We are very grateful to the organizations that helped to distribute the "Need to Know" campaign to their stakeholders:

- AARP Public Policy Institute
- Age Options
- Alzheimer's Association
- ARCH National Respite Network
- AUCD's Family Support Special Interest Group
- Easterseals
- National Adult Day Services Association
- National Association of Councils on Developmental Disabilities
- National Alliance on Mental Illness (NAMI) Multicultural Action Center
- National Center for Parent Information and Resources (CPIR)
- National Council on Independent Living (NCIL)
- National Disability Rights Network (NDRN)
- National Hispanic Coalition on Aging (NHCOA)
- Parent to Parent USA (P2P)
- RRTC on Community Living Policy
- Self-Advocates Becoming Empowered (SABE)
- Services and Advocacy for Gay, Lesbian, Bisexual, and Transgender Elders (SAGE)
- Supporting Families Community of Practice
- Through the Looking Glass, The National Center for Parents with Disabilities and their Families
- Wisconsin Family Assistance Center for Education, Training & Support (WI FACETS)

We are especially grateful to the 500 stakeholders who responded to the "Need to Know" campaign. We want to give special acknowledgment to staff at Easterseals who facilitated the use of IdeaScale and those who engaged their affiliates in reaching underserved stakeholders.

# About Family Support Research and Training Center (FSRTC)

FSRTC
Family Support
Research & Training Center

UIC Institute on Disability
and Human Development

The Family Support Research and Training Center (FSRTC) is a collaboration of researchers who are focused on synthesizing and generating knowledge about the needs and experiences of families who provide support to children and adults with disabilities across the life course. We recognize that there are similarities in family support across different types of disabilities and age groups and needs that are specific to situations and individuals. Our aim is to develop and disseminate family support research and training to inform more cohesive policies and practices related to family support. The FSRTC is housed at the Institute on Disability and Human Development at the University of Illinois at Chicago.

## Our Goals

1. Define the state of science in family support
2. Generate new knowledge in the critical policy areas of self-direction and managed care and in culturally competent peer-to-peer family interventions
3. Generate and implement a vision for policy and practice in family support through a national resource center

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## Introduction

Family members are a primary source of support for people with disabilities across the life course. Parents, siblings and grandparents provide care and support to children and youth with disabilities and many different family members provide a broad range of support to adults with disabilities. This includes individuals who are aging with disabilities and those who acquire disabilities in later life. Family support is an important area of research, policy and services and as a result, there was a federal call for the development of a national strategic research plan for family support. In response, the Family Support Research and Training Center (FSRTC) designed an iterative, participatory process to generate such a document. The Family Support Need to Know campaign was the first stage in this process. In partnership with Easterseals, the FSRTC set out to gather input about what family support topics need to be studied from a wide array of stakeholder groups.

In this report, we describe the findings of the Need to Know campaign and present the main topics and themes that emerged from our stakeholders. We will first present findings generated via IdeaScale, an online platform where stakeholders provided family support research topics, indicated agreement by voting topics up or down, and commented on topics to provide clarity or more information. We follow this by presenting the findings from stakeholder participation in the pen & paper version of the campaign. Finally, we summarize the findings and discuss next steps in developing the strategic research plan on family support.

## Methodology

Stakeholders for the Need to Know campaign included family members who provide support (also referred to as caregivers), people with disabilities or older adults who receive support from families, as well as service professionals, researchers and activists.

The research team worked closely with a large coalition of organizations across multiple disability categories (e.g., autism, Alzheimer's disease, intellectual disabilities, physical disabilities, psychiatric disabilities, etc.) to elicit participation that would reflect a wide variety of perspectives on and experiences with family support.

Furthermore, the project was designed to include three main modes of data collection; 1) participating in the IdeaScale online dialogue, 2) calling in to a toll free line to report an idea via telephone, and 3) responding via the pen/paper instrument. We developed these three modes in order to maximize participation of stakeholders across diverse ethnic, socioeconomic, geographic and relational groups. The research instrument (online, pen and paper) was translated into Spanish and bilingual staff answered the telephone line, allowing participants to provide their ideas in Spanish if desired across all three modes of data collection.

Stakeholders who were interested in participating were asked to respond to the following prompt:

***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 of healthcare/ social service providers know about family support***

Campaign participants responding through any of the three modes were also asked to provide demographic information including age, race/ ethnicity, and geographic region (rural, urban, or suburban). Similarly, respondents were asked to identify their connection to family support, selecting as many responses as appropriate. For example, the same participant could identify as both as a health care provider and as a family support provider (i.e., family caregiver).

Announcements and flyers were sent out to organizations on the FSRTC advisory committee who then shared it with their constituents and other groups. The announcements were shared by listserv, social media, newsletters, and other formats which explained the variety of modes that stakeholders could participate.

## IdeaScale

The University of Illinois at Chicago (UIC) Family Support Research and Training Center (FSRTC) spearheaded the Need to Know campaign in effort to gather input for the development of a national Family Support research strategy. UIC and Easterseals partnered to conduct a national online dialogue on caregiver support from March 9 to April 6, 2015 using a web-based platform called IdeaScale.

IdeaScale is an online platform that allows entities to collect ideas from various individual stakeholders. It takes surveying to the next level by encouraging participants' interaction with each other. It has been used by federal agencies and non-profit agencies to engage and survey stakeholders on specific topics or to receive feedback on a set of questions. IdeaScale requires participants to log on to the dialogue page in order to add any post. A dialogue allows the participants to post new ideas, vote for ideas they like or comment on existing responses. Therefore, a participant's post may spark an idea and lead to a new one.

IdeaScale has an analytics feature that is often combined with Google Analytics to collect participants' demographics and use of the dialogue website (e.g., site visits and click-through rates). It should be noted that in every dialogue, there are more registrants who do not participate than those who post ideas, votes or comments, and a higher number of dialogue viewers and visitors than individuals who take the step of registering for the dialogue. Each online dialogue attracts a different level of participation depending on the subject matter and draws from or is important to a broader or more targeted audience.

Core data for the Need to Know campaign included:

- Number of online dialogue participants
- Total ideas
- Total comments
- Total votes for ideas
- Geographic distribution of visitors in the U.S.

In addition to demographic data, UIC and Easterseals collected statistics for percent of participants who represent people with disabilities, older adults, caregiver/family member who provides support, health care professionals, home and community based (HCBS) providers, social service professionals, policy makers, and researchers.

The IdeaScale page for the Need to Know campaign included both English and Spanish (AF Diganos) dialogue pages. Given the limited participation in the Spanish dialogue, results of the IdeaScale in this report only address the English dialogue.

Participants accessed the IdeaScale through a web link and responded to the prompt by providing ideas and filling out the demographic information. They could also vote up or down other participant's topic ideas and could comment on them. Some participants provided unique topic ideas and others simply responded to others' topic ideas.

### Pen & Paper instrument

For the pen and paper instrument stakeholders completed the form manually, or emailed their response. The limited number of participants who reported research topics via telephone (in English or Spanish) had their ideas written onto a pen and paper instrument. These were later transcribed along with the rest of the pen and paper instrument responses and therefore, they are analyzed as part of this information.

The Need to Know campaign was originally designed for a duration of a one month. However, after the conclusion of that time, we determined that it was important to extend the pen and paper version for a longer period of time in order to reach more diverse stakeholders. Therefore, we extended the pen and paper version for three more months and conducted a more intentional outreach effort to Easterseals affiliates and other stakeholder organizations.
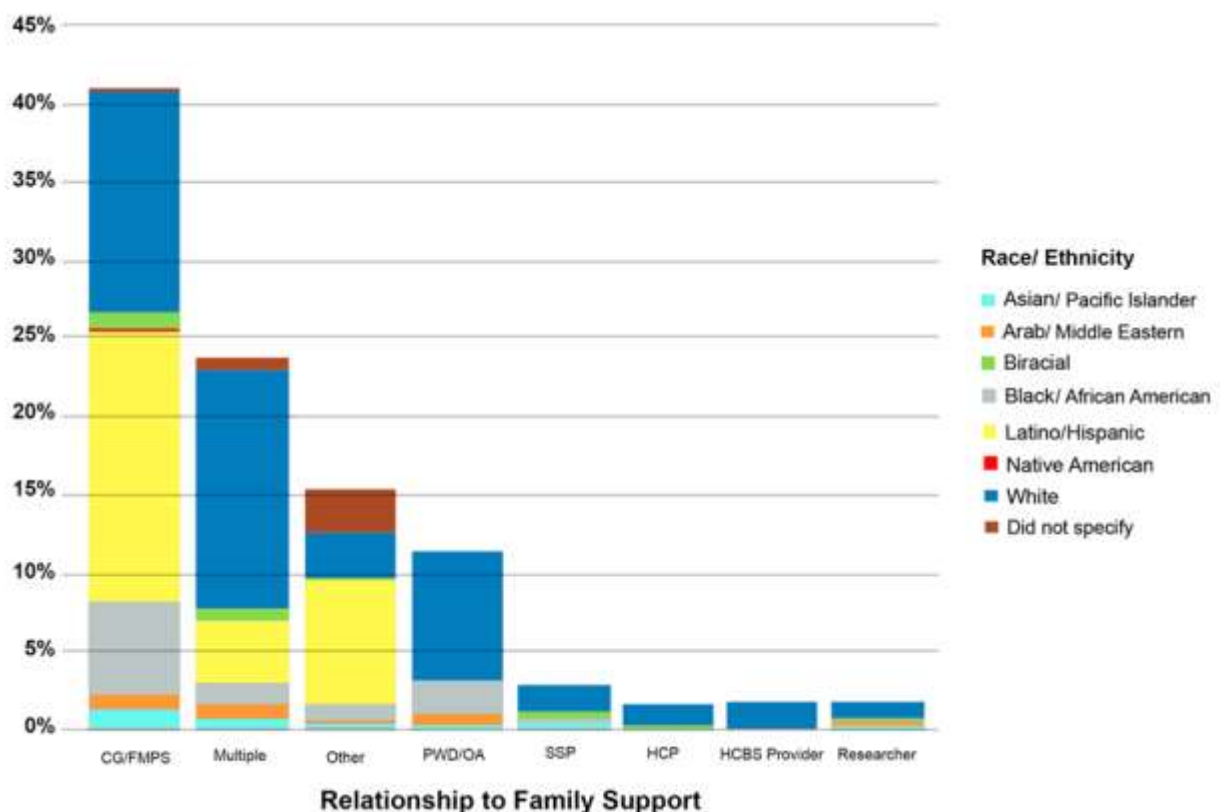
# Results

Overall, 500 stakeholders participated in the Need to Know campaign via the IdeaScale, the toll free number, and the pen and paper. As illustrated in Figure 1, the majority of participants who identified themselves as a caregiver or a family member who provides support (CG/FMPS) were diverse from racial and ethnic backgrounds with a large percentage identifying as Latino. However, those who identified as people with disabilities or older adult (PWD/OA) were mostly white. Generally, participants who checked other relationships identified themselves as advocates or future caregivers (e.g. grandparents or siblings). About 24% of participants checked multiple relationships. However, 85% of these participants identified as a CG/FMPS in addition to one or more relationship to family support. Approximately 9% of participants were researchers, HCBS providers, health care providers (HCP) and social service providers (SSP).

## Figure 1: Participants' Breakdown of Race/ Ethnicity Based on Relationship to Family Support

# IdeaScale

# Online Dialogue Results

# IdeaScale Online Dialogue Results

The online dialogue via IdeaScale attracted 151 registrants who provided a total of 42 ideas. These ideas received 39 comments and 356 votes

## Participation Characteristics

From a geographic perspective, participants represented 35 of the 50 states. Figure 2 illustrates the online dialogue participants' distribution across the states. Forty-three percent of the participants indicated that they live in suburban area, 36% lived in urban and 18% lived in rural areas. The reminder of the participants (3%) did not specify their location.

**Figure 2: Online Dialogue Participants by Location**

In terms of gender, 86% of the participants were female, 11% were male and 3% did not specify a gender. The majority of dialogue participants indicated that they have multiple relationships to family support (approximately 40%). However, in general most indicated being a caregiver, or a healthcare or support profession- al. Researchers and policymakers made up the second highest number of par- ticipants while 14% participants marked "Other".

Participants were also asked to provide their age ranges. As the following table indicates, the majority fell into the age ranges of 45-54 and 55-64.

**Table 1: *IdeaScale* participants' ages**

| Age Ranges | 151 Participants |
|---|---|
| 18-24 | 3 (2%) |
| 25-34 | 7 (5%) |
| 35-44 | 21 (14%) |
| 45-54 | 39 (26%) |
| 55-64 | 52 (34%) |
| 65 and above | 25 (16%) |
| Did not specify | 4 (3%) |

With regards to race and ethnicity, the majority (80%) of dialogue participants were White. The race/ ethnicity of the participants are distributed as follows:

**Table 2: *IdeaScale* participants' race/ ethnicity**

| Race/ Ethnicity | 151 Participants |
|---|---|
| Asian/Pacific Islander | 8 (5%) |
| Biracial | 4 (3%) |
| Black/ African American | 8 (5%) |
| Latino/Hispanic | 5 (3.5%) |
| White | 121 (80%) |
| Did not specify | 5 (3.5%) |

## Top Ten Ideas

IdeaScale participants posted 42 ideas in the IdeaScale dialogue. In response to the ideas, there were 39 comments and 356 votes for ideas. Participants were able to increase the rank of an idea by voting the idea up or decrease the rank by voting the idea down. A top idea is thus the one that has the highest score. The number of comments an idea receives are also an indication of interest in an idea. In the case of the Need to Know campaign, comments were posted for 14 ideas. The nature of comments ranged from opinions to examples of research and resources available related to the idea and are relevant to the dialogue. Therefore, some comments contained new or related ideas.

Below are the top ten ideas generated via the IdeaScale dialogue, presented in order of their final rank score (the number of up vote minus the number of down votes). Each idea is followed by a brief description and summary of respondent-provided comments. Table 3 illustrates the top ten ideas. We also display a column final rank score, and the order the idea was posted.

### Table 3: Top Ten Ideas

| Idea # | Topic | Rank score | Order posted |
|---|---|---|---|
| 1 | Cost Benefits of Family Caregiver Support Programs | 40 | 3 |
| 2 | Cost effectiveness of respite for family caregivers | 33 | 7 |
| 3 | Respite research | 25 | 8 |
| 4 | Provide tax credit for caregivers | 23 | 13 |
| 5 | Caregivers and the workplace | 18 | 11 |
| 6 | Database of Back-Up Caregivers | 15 | 6 |
| 7 | Concerns for people with disabilities who become parents | 14 | 2 |
| 8 | why caregivers have difficulty asking for help | 13 | 4 |
| 9 | Support for Siblings of People with Disabilities | 13 | 26 |
| 10 | Why don't more people take advantage of adult day programs? | 12 | 10 |

**Idea #1: Cost Benefits of Family Caregiver Support Programs**
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 overall health and well-being of people with disabilities.

Related comments:
Comments from participants emphasized the importance of providing family support services that help keep people with disabilities at home. They indicated that support at home is physically and emotionally rewarding for all family members and is cost effective. Participants extended the posted idea by pointing that research should focus on the economic impact of family support across life span.

**Idea #2: Cost-Effectiveness of Respite for Family Caregivers**
Research is needed to demonstrate how respite for family caregivers may be cost-effective in terms of preventing institutionalization of the care recipient, enabling caregivers to maintain their own good health.

**Idea 3#: Respite Research**
Research is needed on the role that respite plays as part of a comprehensive approach to family support as well as which components of respite are most important (location/setting, dose, quality and activities for care recipient).

Related comments:
Participants discussed the need to do more research on respite given the high demand for this form of support. Furthermore, they indicated that research should look at the impact of respite on caregivers and people with disabilities in relation to institutionalization that occur due to caregiver's burnout rather than due to a deterioration in the person with disabilities health condition.

**Idea #4: Provide Tax Credits for Caregivers**
Offering tax credits to caregivers can compensate them while saving taxpayers money. Family caregivers save taxpayers money because they offset government funded residential care, yet they are not compensated for their work.

**Idea #5: Caregiving and the Workplace**
Caregiving results in a cost to business of $33.6 billion per year due to absenteeism, supervisory time, unpaid leave, and reduced hours.

**Idea #6: Database of Back-Up Caregivers**
There is a need for a current and regular updated national database of skilled personal care workers who have received some training and are willing and able to help relieve the daily grind of caregiving at a reasonable cost.

Related Comments:
Participants indicated that a database of skilled personal care workers should be part of Centers of Independent Livings (CILs). They further suggested that there should be a database for respite workers that provides workers training, preferences, working hours and readiness to travel.

**Idea #7: Concerns for People with Disabilities who become Parents**
There is a need to know how many people with different types of disabilities are attempting to raise children, how many of them are involved with child welfare systems, and what kinds of supports are available to them.

Related Comments:
This idea received the most comments. Participants indicated that providing services for people with disabilities who are trying to raise children would reduce the need for child protective services and prevent the trauma of families who are being separated. Furthermore, research should investigate the overall burden that is related to having a child with disability, while illustrating the involvement of family member in the care process. Other comments discussed issues of providing services based on needs. Participants indicated that services should be tailored toward specific groups or disability to fill in any gaps across disabilities and ensure the rights of parents with disabilities as stated in the National Council on Disability 2012 report, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities*. Furthermore, future research should consider the collaboration between professionals and parents with disabilities, involve professionals and organizations that work with different disabilities and focus on identifying the numbers of existing parents with disabilities.

**Idea #8: Why do Caregivers have Difficulty Asking for Help?**
There are many resources available to caregivers but caregivers have challenges in reaching out and asking for help. How do we make it okay to ask for help?

Related Comments:
Participants agreed on the importance of this idea and indicated that research should discuss why caregivers might postpone asking for help. Further research should investigate if the magnitude of the problem or the requirement influences when help is sought. Research also should investigate if this issue is related to a lack of resources and the availability of user friendly search engines that help in identifying the types of support available for caregivers.

**Idea #9: Support for Siblings of People with Disabilities**
More research is needed to examine the role that siblings play in the support and caregiving of their brothers and sisters with disabilities across the life course.

**Idea #10: Why don't More People take Advantage of Adult Day Programs?**
Many adult day programs are reasonably priced but struggle with minimum attendance. How do they attract more participants?

Related Comments:
Participants indicated that there is a need to have a one place (e.g. website) that provides resources for families in addition to a rating system that enable families to rate adult day programs. They further emphasized that the affordability and cost of adult day programs should be evaluated as well as investigating the need for national policies regarding paid adult day programs.

## Identified Themes

We organized the listed topics from the online dialogue according to themes that can be formulated into research topics. These include:

### Costs of caregiving

Participants identified the costs associated with family provision of care, services and supports as an important topic for future research. From their perspective, the cost of caregiving could yield positive and negative outcomes. On the one hand, caregiving positively reduces out-of-home placement and the use of emergency rooms and hospitals. It also leads to a reduction in maltreatment and improves the overall health of people with disabilities. On the other hand, caregiving cost businesses due to absenteeism, supervisory time, unpaid leaves and reduced working hours. Therefore, future research should analyze the costs and benefits of caregiving and measure caregiving impact on multiple levels including the family member providing assistance, the family unit, the business sector, the government and society as a whole.

### Financial access/affordability

Financial affordability of support and personal assistance programs was discussed in terms of the cost for accessing these services. This included the current cost for accessing the services, class status and accessibility to services according to caregivers' wage, accessing affordable insurance coverage and locating free or low cost services. Moreover, participants indicated that research should investigate providing tax credit for the caregiver and accessing small grants such as those that are offered by faith organizations.

### Services for people with disabilities

Participants provided ideas and comments that discussed topics related to services for people with disabilities. The most prominent topic was related to services for parents with a disability. Participants discussed that future research should address training, education and child welfare issues when it comes to parents with disabilities as well as identifying the prevalence of parenting among people with disabilities. Furthermore, participants indicated that services for people with disabilities should be tailored according to the needs and wishes of the individual. Research should investigate whether or not decisions by people with disabilities regarding the provision of care services are acknowledged. They should be able to decide on who they want to take care of them, and any arrangement that they should need.

## Services for the family

Participants highlighted issues related to services for the family from three different perspectives; availability, accessibility, and inclusivity. Participants indicated that the availability of support services should be examined beyond the person with disability since they impact the entire family especially for those that deal with injury prevention programs, transportation, home modification, services for siblings, and health literacy. Therefore, research should explore the availability and the impact of services by considering the entire family as the consumer.

Moreover, participants indicated that there is a need to examine the issue of accessing support services. For instance, they discussed that services and resources are often difficult to locate, and that there are numerous barriers that hinder accessing to existing services. They further suggested that having updated searchable data bases could help in locating services.

Finally, participants discussed exploring the inclusivity of family support services. They talked about expanding the definition of family to include non-biological support dyads and address sexual orientation as well as gender identity in order to understand the needs of all caregivers including LGBT people.

## Cultural and social issues

Participants raised issues related to cultural and social attitudes and beliefs. They highlighted that the family's decision to provide support for people with disabilities is highly related to their cultural perspectives. Some families may be reluctant to ask for support from the government or agencies, while other families may not be able to afford needed services. Therefore, research should investigate how culture and contextual factors might impact accessing needed services or providing services when and if needed. Moreover, future research should investigate how families construct their expectations about people with disabilities, as in whether these expectations are impacted by peers, media, the internet, and their culture. Participants also highlighted the need to investigate issues that could foster or hinder caregiver's willingness to ask for help.

Employment
Participants raised the issue of caregiver employment and discussed the need for research to address this topic. They illustrated the need to understand the adjustments that caregivers make in their workplace due to the demands of caregiving. Moreover, research need to examine what assistance employers might be able to provide to caregivers. Therefore, future research should investigate employer best practices that are related to resources that help employees manage both their jobs and caregiving; and should investigate the impact of caregiving on caregivers' employment.

Care related services
An important topic highlighted by participants was a need to establish research that addresses issues related to direct care workers and adult day service programs. In terms of the former topic, participants indicated that there is a need to identify respite workers, caregivers, or other direct care workers who provide long term or intermittent support. Some participants stressed on the importance of providing rating systems in order to review the competence of the worker sought. Moreover, research should investigate outcomes related to providing such services.

Similarly, participants indicated that research should concentrate on access to adult day service programs as well as identifying a system that is available for family members in order to rate the quality of the program or services provided.

Service assessment and evaluation process
Participants highlighted the need to create evaluation systems in order to test the efficiency of services provided. This topic was mainly addressed in relation to existing Early Intervention (EI) services. Participants indicated that there is a need for research to examine EI interventions in each state with respect to evaluating the effectiveness and the accountability of a system-wide care coordination. Research should also investigate the process of transitioning the child with a disability out of EI and the use of lay language to enhance the caregiver participation in the process.

**Pen & Paper**

**Topics and Results**

# Pen & paper Topics and Results

There were 345 people who submitted the pen and paper version of the Need to Know Survey, including the four respondents whose information was taken via phone. Overall, they provided 199 distinct ideas.

**Participation Characteristics**

As noted previously, the majority of IdeaScale respondents were White. By contrast, the pen & paper version generated a notably more diverse set of stakeholders and importantly, those who provided ideas. As indicated in the following table, 33% of participants were White, while 67% were from other racial and ethnic groups. Of these, 41% were Latino, 13% were African American, 4.3% were Arab American, and 2.5% were Asian American. These demographics indicate that while we did better to increase overall diversity using the pen and paper version, we did not reach Asian Americans or Native Americans to the extent that we would have like to.

**Table 4: Pen & Paper participants' race/ ethnicity**

| Race/ Ethnicity | 345 participants |
|---|---|
| Asian/ Pacific Islander | 9 (2.5%) |
| Arab/Middle Eastern | 15 (4.3%) |
| Biracial | 10 (3%) |
| Black/ African American | 47 (13%) |
| Latino/Hispanic | 142 (41%) |
| Native American | 1 (0.02%) |
| White | 114 (33%) |
| Did not specify | 11 (3%) |

In terms of gender, most of the participants were females (77%), while 19% were males. One participant identified themselves as transgender and about 4% did not specify a gender. The majority of the participants lived in urban and suburban settings and only 5% indicated that they lived in a rural area. In terms of relationship to family support, approximately 25% of the participants indicated being a person with disability, 47% a caregiver or a family member who provides support and 23% checked multiple relationships. Participants also indicated their age, and according to the following table, pen and paper participants were somewhat younger than participants from the IdeaScale.

Ages ranged primarily between 35-44 and 45-54.

**Table 5: Pen & Paper participants' ages**

| Age Ranges | 345 participants |
|---|---|
| Under 18 | 7 (2%) |
| 18-24 | 11 (3.5%) |
| 25-34 | 49 (14%) |
| 35-44 | 75 (21%) |
| 45-54 | 77 (22%) |
| 55-64 | 57 (16%) |
| 65 and above | 58 (17%) |
| Did not specify | 15 (4.5%) |

## Identified Themes

The pen and paper version did not include voting and ranking of ideas, there-fore, we report the results according to themes and display two quotes to exemplify each theme in the tradition of qualitative analysis. While there is some overlap in topics between participants who entered their ideas through the IdeaScale, and those who used the pen and paper, in this section, we intention-ally report on the themes and topic areas that are somewhat unique to the pen & paper version. These themes include:

**A. Support needed by caregiver**
    1. Navigation
    2. Emotional support
    3. Training support
    4. Future Planning
**B. Services for people with disabilities**
    1. Employment
    2.Transition
    3. Rural versus urban
    4. Housing
    5. Miscellaneous
**C. Cultural Competency**
    1. Language
    2. Spirituality

## A. Support needed by the caregiver

Stakeholder responses on the support needed by caregivers fell into four categories; navigation of the services system, emotional support, training support, and future planning. Most of these were related to finding resources or creating services that support caregivers, or provide support to people with disabilities. Under the category navigation of the services system, stakeholders identified many barriers and offered alternatives that could increase access. Some barriers mentioned were lack of awareness of available services and supports, difficulty of navigation because the information is not easy to find, and the tendency of the system to be bureaucratic and thus impede access to services. Some suggestions offered were making available case managers who could help caregivers navigate the service systems, streamlining information to increase ease of access and taking into account the severity of disability or specific needs.

Stakeholders also expressed the need to research emotional support such as counseling, isolation felt by caregivers and making support groups available during hours more convenient for caregivers. Stakeholders also discussed support in terms of training. They mentioned the need for workshops on accessing services, advocacy and future planning. How can caregivers themselves provide guidance to other caregivers? Lastly, stakeholders suggested research on future planning. They expressed fear and uncertainty about their children's future related to care and community integration after the death of the caregiver. They also identified need for assistance for future planning related to medical, fiscal and legal issues and availability of state resources to support future planning.

## 1. Navigation

Participants identified navigation of support services for family members as a topic to which researchers needed to pay greater attention. Specifically, they described the challenges of working in the multiple, distinct systems that that people with disabilities and their caregivers face. Family members expressed frustration of their own experiences and that of the people who received direct care. Participants connected the navigational challenges they experience with the issue of access and suggested greater infrastructure (i.e., searchable databases, websites with information) and interpersonal supports for family caregivers. Future research should assess existing practices and identify promising programs to help users and family members navigate systems.

Additionally, research can document the experiences of people with disabilities and their families in navigating services and provide comparative analyses of these experiences across economic and cultural groups.

Example quotes that illustrate the issue of navigation:

- Data base of available program rated and broken down by severity of disability. Not every individual fits every program and often time finding the right fit is hit, miss and time consuming. An understandable handbook explaining waiver and finding things (plain every day language). (Person with disability)
- Family is not well informed of services available. They find out from friends & word of mouth. Also, too much use of initials and abbreviations. (Caregiver)

## 2. Emotional Support

Participants indicated that research is needed to explore the availability and the efficiency of services that are tailored toward providing emotional support. These services were identified as providing group and one-to-one counseling that would help the family member who provides support to cope with the caregiving demands. Furthermore, suggestions were made about the hours in which support groups are offered.

Example quotes that illustrate the issue of emotional support:
- One area of support I find families need is how to navigate the grieving process. Some families are aware of where they are emotionally regarding their loved one and some do not seem to be aware at all, or are very good at hiding it. (HCBS Provider)
- Physical & emotional aspects. 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. (Caregiver)

## 3. Training family caregivers

Participants explained that family members needed more informational support in their role as assistance providers. They suggested formal training or information should be available to family members providing assistance to help them access accurate information and be more successful in their efforts as family caregivers. Suggested areas for trainings included information on: community living services; advocacy; disease management and communication.

Future research should document existing family caregiver training programs, identify promising practices, and explore how access to these programs influence caregiver and care user outcomes.

Example quotes that illustrate the issue of training family caregivers:

- Dementia is a growing concern for families of color, particularly African Americans' awareness and knowledge about dementia of various forms. This topic is important because families lack knowledge of the disease and when they have knowledge about the disease they may not use it. (Researcher)
- How to help my child learn social skills. "Behavioral modification" -Services provided by the state to help individual with disabilities like social security. -Vocational training for children with disabilities (Caregiver)

## 4. Future planning

Family caregivers expressed a number of emotions related to the future, especially parents who were thinking of their children's future after their own deaths. These emotions included fear, uncertainty, and frustration. In addition to discussing their emotions, family caregivers identified a number of areas in which assistance was needed when engaging in future planning. These included finances, housing, medical, legal, and preservation of their child's current level of independence and/or community integration. One fear expressed by parent caregivers was that after their deaths, the strides toward community integration that their adult child would be retrenched. Parents feared that in their absence, their adult children would lack strong advocates to help them maintain and/or expand their access to a variety of integrated services including housing, employment and social activities. Given the desire for greater access to information and services related to future planning, future research projects could assess state support of future planning, model curricula, and the types of support that family members need to sustain (not just initiate) future planning processes.

Example quotes that illustrate the issue of 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. (Caregiver)
- 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 (Caregiver)

## B. Services for people with disabilities

Many of the participants who suggested topics related to services for people with disabilities were themselves people with disabilities. This theme fell into four topic areas: employment, housing, life course transitions and rural versus urban experiences. Some suggestions did not fit neatly into any of these categories, so they will be referred to as miscellaneous services. Participants posited research questions on how caregivers balance employment and caregiving responsibilities, the positive or negative impacts employers have on caregiving, the relationship between labor force participation of people with disabilities and that of other family members, the impact of closing sheltered workshops on the employment of people with disabilities and their families. Housing as a research topic was related to access to affordable and safe housing and home modifications. Research on life course transitions services was expressed in terms of sexual maturity of children with disabilities and transition to employment, social programs or college post high school. Some participants proposed research questions on the availability and expansion of services such as housing and transportation and transition services in rural and resource poor areas compared to urban areas. Finally, miscellaneous services topics included the availability of recreation for children with developmental disabilities, transportation and the need for low cost continuing education for people with disabilities.

## 1. Employment

Participants identified employment of people with disabilities as an important area of family support research. Issues related to employment should be investigated as they impact both the individual with disability and the family. For example, participants indicated that exploring existing jobs and accessibility for these opportunities is crucial for people with disabilities and caregivers. Furthermore, they indicated that jobs training services that are tailored toward the needs of people with disabilities is an area that should be investigated in research. Lastly, participants illustrated the need to explore the impact of employment status of the person with disability (e.g. currently employed, changed the job, not employed…etc.) on the family as whole especially the financial impact on the caregiver.

Example quotes that illustrate the issue of employment:

- Where sheltered workshops have been closed, what has happened to those clients? What percentage have actually found jobs and more important how many hours per week are they working? (Caregiver)
- I think exploring for jobs would help me get one. I think when I find a job that I enjoy I will be good at it because I really do good at things I enjoy and have experience in. (Person with Disability)

## 2. Housing

Participants mentioned housing as an important issue both in terms of affordable, accessible housing stock and programs to support home modifications for low-income individuals. Additionally, as stated earlier, housing was a particular concern for parents and other aging caregivers who were planning for the lives of their children after their deaths. Potential research topics in this area include: reviews of the policies/program offered by each state to assist people with disabilities and families to find accessible/affordable housing

Example quotes that illustrate the issue of Housing:

- Public housing unwilling to modify property for the needs of persons with disabilities, moving persons with disabilities into low income housing units in high crime areas. (caregiver)
- Affordable housing in a safe environment

## 3. Life course transitions

Participants described the specific challenges of life course transitions for the family caregiving dynamic. These transitions were varied and included: 1) the period leading to sexual maturity for people with disabilities living at home with parents; and 2) transition services out of school to employment, social programs, or college. There are opportunities for family support research in each of these transitional moments, addressing the unique types of support that families need in these times of change. More information is needed on what programs currently exist to help families with transition and how these transition relate to caregiving outcomes.

Example quotes that illustrate the issue of life course transition:

- As a new generation of individuals with autism comes of age, I would like to see research regarding mentoring programs for teens and young adults with ASD. How can we promote mentoring programs within the autism community? How can we work to establish positive role models for youngsters with ASD? What kind of training and support is needed to make these programs effective? (Caregiver)
- Transition services "after school" what's then? What are the services provided for children after school? In case they cannot work? (Caregiver)

## 4. Rural versus urban experiences

Participants described their experiences in less populous areas that had fewer financial, support service and informational resources for older adults and people with disabilities and the family members who provided assistance for them. This difference was particularly challenging in the areas of the direct care workforce, financial access/affordability, housing, and transportation. Future research opportunities would explore the innovative strategies that families employ to get support in these resource-limited areas. Additionally, needs assessments/capacity evaluations that focus specifically on rural and resource poor areas have the potential to direct family members and users to existing resources and to identify priorities for expanding services to facilitate greater access.

Example quotes that illustrate the issue of rural versus urban experiences:

- Limited resources in rural areas (Caregiver)
- Families who live in small areas where there are no providers and no adequate staff. (Caregiver)

## 5. Miscellaneous

Participants indicated that there is a need for research that discusses issues related to services for people with disabilities. Transportation was the highlight of these services as participants raised concerns about the availability and the quality of transportation.

Furthermore, participants indicated that there is a need to have accessible public spaces as well as age appropriate activities for people with disabilities. Future research would explore consumer satisfaction in terms of available transportation services and need assessments to further explore the gaps in available services for people with disabilities.

Example quotes that illustrate the topics that were highlighted in this topic:

- We need more recreation areas that are more accessible (Person with Disability)
- Transportation in my opinion all special need people should have this. In today's world I don't think it is safe for our people to ride public buses. It might be hard to find transportation to and from work (Caregiver)
- Our son needs continuing education, but not with other individuals with disabilities. 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? (Caregiver)
- Most activities, aside from Special Olympics, are geared for the 18 and sometimes 21 and younger group. There are few activities for the developmentally disabled, who are older. If there are activities for older adults, they are all grouped together (22-90 years). The interests and abilities of young adults are significantly different than that of the geriatric population (Healthcare professional)
- Transportation to and from day care facilities; how to make this a pleasant experience for the patients rather than being traumatic - when using insurance-provided services, offered by HMOs (Caregiver)

## C. Cultural competence

The cultural competence topics suggested by participants related to language and spirituality. Caregivers emphasized the lack of services and educational resources in their language and that are tailored to their culture as a barrier to access. Spirituality was identified as a research topic in terms of the experience of caregivers and finding direct care workers who are familiar with spiritual practices.

### 1. Language

Linguistic appropriateness and cultural sensitivity were both identified as specific barriers to access to information, resources, and services for family caregivers. From a research perspective, formal needs assessments would provide an opportunity to capture the degree to which providers demonstrate cultural competence in the provision of support for family caregivers and how this influences access and utilization of existing services. Additionally, there is a need for research on both the diffusion of existing family support caregiver programs across multiple cultural communities and an exploration of the program and community outcomes for those interventions that embrace cultural competence as a core value.  Lastly, research is needed to both explore the specifics of certain cultural groups (e.g., Arab Americans,) and to draw comparisons across groups (i.e., Arab Americans compared to Latino/as).

Example quotes that illustrate the issue of language:

- Providing more educational information in the form of sessions, workshops . . . etc. in Arabic language. Many Arabic families who live here in Chicago cannot communicate effectively in English and many of these families really need more information and empowerment to understand and manage any disability they may have. As many workshops and health education sessions are either in English or Spanish, it will be really good if there are Arabic versions (Researcher)
- I wish there were more services in Spanish for topics such as how to advocate in our schools for our children. To have more services more for our children recreation and socialization. More support for Hispanic fathers. (Caregiver)

## 2. Spirituality

Participants identified spirituality as both an important aspect of the family caregiving experience and as an area that warrants greater research attention. Spirituality seemed most salient for participants of color (Latino/a, Chinese American, Black/African American, Arab/Arab American) who described the role of personal faith and communities of faith in their experience of caregiving. Spirituality was also identified as part of cultural competence, specifically in terms of finding direct care workers who were familiar with spiritual practices and could support the user and their family in respecting these as part of daily practice. Opportunities for future research include: in-depth analyses of family caregiving in communities of faith, comparative studies of family caregiving across communities of faith, and assessments of spirituality and religious practice in relation to caregiving outcomes.

Example quotes that illustrate the issue of spirituality:

- I think spiritual support is the most important aspect and also the most left out. There are so many times where prayer is the only thing that has helped my son and my family cope and has given us answers and directions (Caregiver)
- Spiritual aspect. People have fear of the unknown and they don't want to talk to family about it. But they will talk to a stranger (Person with Disability)
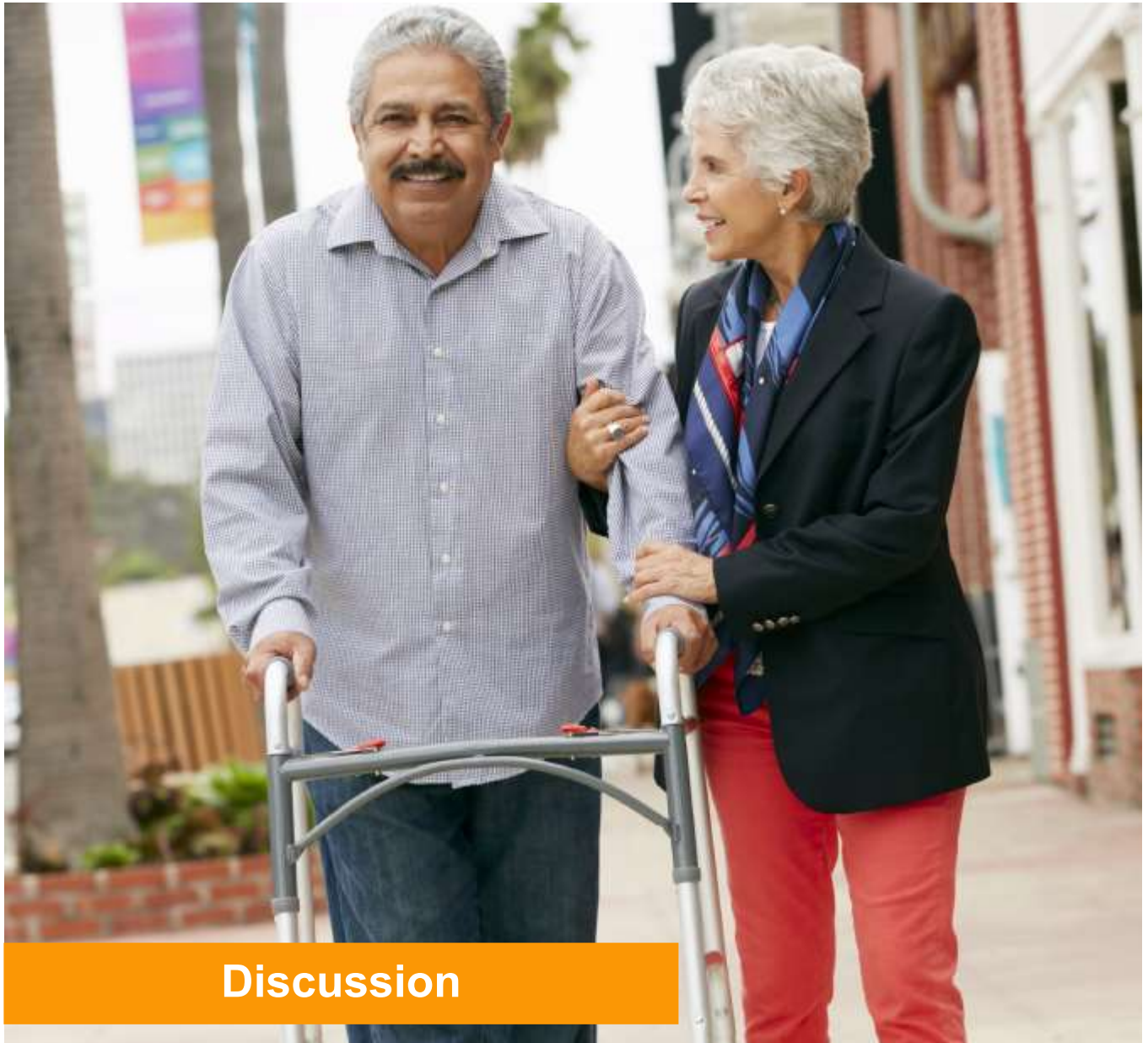
**Discussion**

**Developing the Strategic Research Plan**

# Discussion

FSRTC in collaboration with Easterseals conducted an iterative and participatory process to generate research topics that will contribute to a national agenda for family support research. The aim of this section is to highlight the main topics that were generated by stakeholders who responded to the Need to Know Campaign through the IdeaScale and the pen and paper methods.

Family support related topics were generated through the integration of several methods in order to reach out to diverse stakeholders and address the needs of different caregivers and family members across the life span. Overall, stakeholders who responded to the campaign were mostly caregivers and professionals. The IdeaScale approach attracted a limited set of stakeholders who tended to be more professionals and were most often White and middle class. However, stakeholders who participated through the pen and paper method were more diverse and included Latino, Asian/Pacific Islander, African American/Black, and Arab/Middle Eastern, and consisted of caregivers and people with disabilities. Through the process of the Need to Know campaign, we learned how important it was to use multiple methods in order to reach diverse groups.

We identified overarching themes that are similar across both the IdeaScale and Pen and Paper methods and topics are unique to the specific method. In the following, we will discuss the nature of the topics that are unique to each method as well as the ones that are cross-cutting across both methods.

Some topics that were unique to IdeaScale were program related such as discussion of self-determination of parents with disabilities, the need to investigate factors that influence families asking for help, and developing assessment and evaluation systems for EI services. Other unique topics included the need to establish a wider definition of families to include LGBT individuals, and the need to understand the impact of caregiving on their employment. Some topics were more policy oriented such as the importance of research that examines the cost-benefit analysis of caregiving support program, and the overall cost of caregiving to society.

Topics that were unique through the pen and paper method included person with disability focus topics such as identifying employment opportunities and job training programs for people with disabilities, exploring life course transitions, transportation, accessible public spaces and recreational facilities, and affordable and accessible housing.

The pen and paper version also highlighted topics related to caregivers that were unique such as the need to identify services that provide emotional support and future planning, which include planning for services, supports, and advocacy when the caregiver is no longer available to provide the support needed for the person with disabilities. Lastly, cultural and social issues that were raised by the stakeholders through the pen and paper mothed discuss the issue of cultural competency and providing services that are culturally and linguistically appropriate and that take into account spirituality.

In addition to the topics that were unique to each method, we identified cross cutting topics that are reported in both the IdeaScale and the pen and paper methods. These topics include financial affordability of services, providing tax credit for the caregiver and paying family members, disparities between high income caregivers and low income caregivers, training services for caregivers of color (i.e. Latino, African American), and the financial impact of caregiving on the family.

Accessibility to services is a major concern for stakeholders across both methods. Stakeholders indicate that access to support for family members is a topic that researchers need to focus on. Research should explore both facilitators (i.e. what increases access) and barriers (i.e. what stands in the way of access). For example, navigation systems, such as accessible websites, could be developed to increase access to services. Furthermore, access should be addressed in terms of cost and affordability of services, financial status of the family seeking the services, and whether the service is accessible for families residing in rural areas.

Finally, stakeholders illustrated the need for research that focus on services for the family including caregivers' health and health literacy, sibling needs and support services, grandparents support, and providing, or exploring existing, training opportunities that focus on educating families about behavioral modification techniques, and explaining the disability to other people.

## Next steps in developing the strategic research plan on family support

The Need to Know Campaign was a first step in developing a strategic plan for family support research. Our next steps include the following phases: 1) generating research topics through literature reviews, 2) merging and consolidating topics generated by the Need to Know Campaign and the literature reviews, 3) prioritizing research topics via a stakeholder survey, and 4) assembling a family support research meeting to develop research questions and methods for the topics.

### 1. Generating research topics through literature review

The FSRTC research team conducted four systematic reviews that covered family support across the following life course stages: 1) early childhood/ childhood, 2) youth and adolescence, 3) adulthood, and 4) old age. The outcome included publishing four papers in the Journal of Family Social Work. These articles are published online and will be published in a special issue called, Family Support of People with Disabilities across the Life Course.  Below is a link to the abstracts.

http://fsrtc.ahslabs.uic.edu/2016/09/20/fsrtc-journal-of-family-social-work/

### 2. Merging and consolidating topics

After generating topics, the research team summarized the topics that were generated through the Need to Know Campaign and the systematic literature reviews to identify gaps in research and areas that need to be covered, included, or expanded in future research. The team thus far have identified 40 research topics in which there need for more research.

### 3 . Prioritizing research topics via stakeholder survey

FSRTC will plan and conduct a stakeholder survey that aims at prioritizing generated topics. The survey will be conducted online through an accessible software and will be sent to the FSRTC Advisory Committee, and family support researchers that have been identified by the team. Results of this survey will be available through a report that will describe the process and the ranking of all research topics and questions.

## 4. Assembling a family support research meeting

This meeting will be held in Washington DC and will consist of approximately 20 family support researchers and organizational stakeholders who represent knowledge in family support across different phases of the life course. These participants will be considered the work group for this project. The aim of this meeting will be to develop research questions for the finalized list of topics. Participants will also discuss potential research strategies and methods that could be used to address the research questions and how these will be incorporated in a final strategic plan for research. Results from this meeting will be used to create the Strategic Plan for Family Support Research which will be written by FSRTC staff and shared with the work group for feedback.

A report on a national campaign to involve family Support stakeholders in developing a research agenda