Research on Family Caregiving Support in the United States: A Strategic Plan

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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. FSRTC staff 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 and funded by the United States Department of Health and Human Services, Administration for Community Living (ACL), National Institute on Disability, Independent Living & Rehabilitation Research (NIDILRR).

**FSRTC 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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Executive Summary

Research on Family Caregiving Support in the United States: A Strategic Research Plan is the product of an iterative, multi-layered process involving multiple stakeholders including family caregivers, persons with disabilities, health and social welfare professionals, policymakers, and researchers. Divided into four parts, this document outlines the next steps in researching family support by reviewing the current state of the field and identifying future directions.

The first section, exploration and discovery in family caregiving experiences, addresses eight areas for further study, outlining the need for research on caregiver experiences: in communities of color, of persons with disabilities, of different family members, across multiple social contexts, across multiple disability types, with health care access and systems navigation, with positive caregiving outcomes, and with economic and employment outcomes. Focusing on these areas will attend to underserved and previously under-researched populations (racial, ethnic, and cultural minorities; lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ) caregivers), include the voice of persons with disabilities in the family support literature, and situate family caregiving within larger familial, cultural, and socioeconomic contexts.

With a focus on family support interventions, the second section identifies three steps to enhancing research by: piloting, testing, and scaling up interventions; promoting promising practices; and building the evidence base. Developing research in these areas will facilitate the development of new interventions, assessment of existing interventions and possible expansion to new populations, and a more equitable distribution of family caregiver support across race, class, geography, and cultural or linguistic community membership.

Recognizing that the lives of persons with disabilities, caregivers, and families are influenced by family support policy, programs, and services, the third section suggests seven areas in need of greater research attention: consumer direction in home and community-based services, disability employment policies, Family Medical Leave Act, National Family Caregiver Support Program, No Wrong Door, the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiver Act, and respite. Across these diverse policy arenas, research needs to evaluate systems of information and referral, assess how these policies constrain and facilitate opportunities for persons with disabilities and their families, and examine the short-term and long-term impacts of these policies on family caregiver’s social, emotional, and financial wellbeing.

To generate new knowledge and expand the current understanding of family support, the final section highlights four research methods in family support to diversify the current approaches to studying family support: cost-benefit analysis and cost-effectiveness analysis research, longitudinal studies, qualitative inquiry, and secondary analysis of national data. Future research projects will benefit from engaging one or more of these research methods to find new questions to ask and new ways to answer these inquiries about family support and its impact on individuals, families, communities, and society at large.

Across this document, we recognize that there is overlap across these four areas with research in one section relating to and/or emerging from research in another (Figure 1). For example, knowledge generated through research in exploration and discovery in family caregiving...
experiences influences the development of family support interventions and family support policy, programs, and services. Additionally, research in family support interventions and family support policy, programs, and services helps to identify new areas that require attention in exploration and discovery in family caregiver experiences. Similarly, research on family support interventions influences and is influenced by research on family support policy, programs, and services. Each of these areas is shaped by the research methods in family support employed to collect and analyze information in response to research questions.

Figure 1. Relationships Between Family Support Research Areas

As a roadmap for future research on family support in the US, this document outlines opportunities for progress in each of four areas (exploration and discovery in family caregiving experiences; family support interventions; family support policy, programs, and services; and research methods in family support). Research on Family Caregiving Support in the United States: A Strategic Research Plan encourages funders and researchers to move forward in family support research by addressing topics and populations previously neglected, focusing on interventions and programs/policy, and supporting the use of novel methods.
Overview

Need and Purpose

Family members, including parents, spouses/partners, siblings, and others, are a primary source of assistance for persons with disabilities across the life course. They provide important support to their family members with disabilities, while receiving little or no services to facilitate their own effort, even as they provide considerable savings to the local, state and federal government. Persons with disabilities, too, support family members creating an important system of interdependence. Family support is an important area for research, policy, and services.

Research can help inform stakeholders about the state of family support, the challenges family members face, and the types of services needed to support their efforts. There is a broad range of research that has been conducted on family support and caregiver issues related to specific disability populations. However, it is important to synthesize this research and identify the gaps to determine next steps in research on family support. Consequently, the FSRTC conducted an iterative process to generate this document, a national strategic plan for family support research.

Development of Strategic Plan

This document was developed through an iterative, multi-layered process that solicited and engaged stakeholder input throughout. The resulting strategic plan weaves together suggested and prioritized research topics with the state of the literature and perspectives from family caregiving policy and research experts. To connect the perspectives of family caregivers, persons with disabilities, health and social welfare professionals, policymakers, and researchers, FSRTC staff completed five activities between 2014 and 2018: 1) the Family Support - Need to Know (FS-Need to Know) campaign; 2) literature reviews on family caregiver support research across the life course; 3) expert panel survey; 4) expert panel meeting; and 5) State of the Science in Family Support Research conference.

Activity 1: FS - Need to Know Campaign

FSRTC staff designed and implemented a campaign to generate important research topics identified by stakeholders, including family members who provide support (caregivers), service professionals, researchers, activists, and persons with disabilities. The research team worked closely with organizations across multiple disability categories (e.g., autism, Alzheimer’s disease, intellectual disabilities, psychiatric disabilities, etc.) to promote participation that would reflect a wide variety of perspectives (Appendix A). Stakeholders could offer suggested research topics and feedback through three modes of data collection: 1) participating in an online dialogue platform called, IdeaScale (n=151), 2) responding to a pen and paper version of the questions (n=354), and 3) calling in to a toll-free line to report a research topic (n=4). Each mode used the same prompt (Appendix B). FSRTC staff also collected demographic information about those who responded.

Overall, 500 stakeholders participated in the FS-Need to Know campaign. More than 40% of participants were caregivers or family members who provided support. About 11% were persons with disabilities, and about 9% were health care and social service providers, or researchers. These categories were not mutually exclusive. At least 24% listed themselves in multiple roles, usually
family members who were also providers or researchers. Both caregiver and persons with disabilities groups were racially and ethnically diverse. A majority were Latino, with White being the next most frequent category, followed by Black/African American, Asian American and Arab/Middle Eastern Americans. FSRTC staff found that the mode of data collection mattered with respect to diversity. For example, 80% of the online platform respondents were White, while only 33% of the pen and paper versions were White.

The IdeaScale online platform ranked ideas according to the number of “up” votes minus the number of “down” votes. Participants commented on topics to explain their choices. FSRTC staff compiled the top 10 ideas (out of 42) based on over 300 votes provided by participants (Appendix C). For the pen and paper and phone modes of data collection, FSRTC staff analyzed the responses by identifying themes. There was some overlap on topic areas between the online platform and pen and paper modes. However, three main categories (support needed by caregivers, cultural competency, and services for persons with disabilities) and relevant subthemes were unique to the pen and paper mode (Appendix D).

**Activity 2: Literature Reviews on Family Support**
FSRTC staff asked family support researchers to conduct four literature reviews to document the work that had already been done and to identify gaps in the literature. Reviews addressed family caregiving across the life course with a focus on families providing care for children and adolescents, and family caregiving in adulthood and later in life. The literature on children and adolescents tended to be mostly on children with autism and/or intellectual and developmental disabilities (IDD). The adulthood literature review focused on family caregivers of persons with serious mental illness, traumatic brain injury, and IDD. The review on caregiving of persons who were older adults focused on dementia-related disabilities, disabling chronic conditions and IDD. The literature reviews were published online in summer 2016 as a special issue at the *Journal of Family Social Work (JFSW)* entitled, Family Support of Persons with Disabilities Across the Life Course (Appendix E).

Each literature review described the existing research by addressing: 1) the types of support family members provide; 2) the impact on family members who provide support; 3) programs and resources available to family members who provide support; and 4) the impact of family support on society. Additionally, the reviews outlined 5) the gaps in existing research. Appendix F presents a summary of the caregiving research gaps that cut across life course stages.

**Activity 3: Expert Panel Survey**
FSRTC staff merged findings from the FS-Need to Know Campaign with the gaps identified in the literature reviews to generate a list of research topics. Our expert panel (Appendix G) then assisted in the process of prioritizing the topics through a Qualtrics survey.

**Activity 4: Expert Panel Meeting**
On December 7, 2016, FSRTC staff convened the expert panel to review and discuss the research topic list generated by our staff based on the survey results (Appendix H). The expert panel provided informal validation that topics were appropriate, relevant, and needed further research. Additionally, they discussed how these topic areas might be explored in future research projects and helped to think how the list connected to NIDILRR’s research development framework.
Activity 5: State of the Science in Family Support Research

On June 11 and 12, 2018, the FSRTC convened a State of the Science conference on Family Support Research in Washington, DC. Prior to this conference, a draft of the strategic plan was circulated to the attendees (Appendix I) with questions to consider about the appropriateness of the document as a “roadmap for the future of family support research”. On the second day of the State of the Science conference, there was a two-part discussion about the content of the strategic plan addressing both the topics identified for further study and the breadth of methods needed to adequately address these. Feedback from the State of the Science conference was used to further refine and finalize the list of topics included in this document (see Figure 2).

Structure of the Strategic Plan

Research on Family Caregiving Support in the United States: A Strategic Plan is organized in four sections reflecting a combination of NIDILRR’s four-part stages of research framework and the ecosocial model: 1) exploration and discovery; 2) services and interventions; 3) social policy and programs; and 4) research methods and approaches. We modified the NIDILRR stages of research framework for family support to reflect how research methods influence the relationships between discovery; piloting testing and scaling up interventions; and policy, programs, and services implementation and evaluation (Figure 1). The first section, exploration and discovery in family caregiving experiences, highlights how we need to know more about the different experiences of individuals and their families, and recognizes that previous research has not adequately acknowledged or measured certain groups of caregivers or caregiving outcomes. Next, the focus on family support interventions combines a focus on developing new family caregiver interventions with expanding existing ones to new communities and evaluating the effectiveness of interventions for multiple types of caregivers. Family support policy, programs, and services are the larger context surrounding family caregiving linking policy decisions at the state and federal level to opportunities and constraints on the lives of caregivers and their families. In the final section, research methods in family support, avenues for generating new information about critical areas of family support research are discussed, both what new data is needed and how to use existing data in new ways. All four sections address the need for more research about family caregiving in different moments of the life course (e.g., caring for a child with disabilities vs. caring for a spouse with dementia) and how family caregivers change and grow over time as they and their family members age. For each of the areas described in the plan, suggestions for future research are outlined highlighting how researchers could build on existing studies as a foundation for the questions that next need greater attention, exploration, and examination.

How to use this document

Please feel free to use the table of contents and/or the section header pages to guide your journey through this document. Research on Family Caregiving Support in the United States: A Strategic Plan is meant to advance knowledge about family caregiving in the United States by guiding future research inquiries and endeavors. FSRTC staff hope that you will find ways that the topics identified throughout this document inspire new questions in your existing research agenda, offer opportunities for new collaboration, and foster new connections between research on individuals and families, communities, and social policy in the arena of family support. Below are the final research topics that derived from our process.
Figure 2. Family Support Topics for Strategic Research Plan

**Exploration & Discovery**
- Family caregivers in communities of color
- Persons with disabilities
- Range of family caregiver types/contexts
- Range of disability/impairment contexts
- Healthcare access and systems navigation
- Positive caregiving outcomes
- Family caregiver economic/employment experiences

**Services & Interventions**
- Barriers to access and service utilization
- Impact of attitudes, structure, and system complexity
- Supports for the whole family
- Best practices
- Development and adaptation of services and interventions for families of color

**Policy**
- Consumer-directed home and community-based services
- Disability employment policies
- Family Medical Leave Act
- National Family Caregiver Support Program
- No Wrong Door policies
- Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiver Act
- Respite services

**Research Methods**
- Cost benefit analyses/social benefit of family caregiving
- Longitudinal studies
- Qualitative research
- Secondary analysis of national data
I. Exploration and Discovery in Family Caregiving Experiences

Family support research is needed to explore and discover experiences and outcomes that are not adequately measured in current research. By describing family caregiver experiences (including those reported by persons with disabilities), exploration and discovery will generate research to address unmet needs and advance family support research.

An overarching priority for exploration and discovery is to design studies that adequately include caregivers across racial and ethnic populations by oversampling underrepresented groups, examining outcomes and factors within underrepresented groups, and comparing outcomes and factors across groups. Within this priority, we identified eight relevant areas for future research to explore and discover family caregiving experiences:

01 In Communities of Color
02 Of Persons with Disabilities
03 Of Multiple Family Members
04 Across Multiple Social Contexts
05 Across Multiple Disability Types
06 With Access and Systems Navigation
07 With Positive Caregiving Outcomes
08 With Employment and Financial Security
Family Caregiving Experiences in Communities of Color

White caregivers represent the largest number (26.5 million, or nearly 61%) of those providing care for persons aged 18 and over in the United States. However, among White individuals, the percentage of caregivers as a share of total population (16%) is smaller than that of Latinos/Hispanics, African Americans, and Asian Americans (21.0%, 20.3%, and 19.7%, respectively). At 7.6 million, Latinos/Hispanics account for the second largest group of caregivers in the United States.³

Despite the large numbers of people of color who are engaged in caregiving, research about the family support needs, experiences, and services available for them across the life course is sporadic and at times inconsistent. Family caregiver research has focused primarily on White family caregivers or offer White family caregivers as the appropriate comparison group for all other family caregiver groups. For example, in the literature review exploring family support for caregivers of adolescents, people of color accounted for 20% or more of the sample in only 8 of 32 studies reviewed that reported information on the race/ethnicity of participants.⁴ Similarly, people of color accounted for a majority of participants in about one-quarter of the studies included in the literature review on family caregivers of children with disabilities.⁶⁻⁵ And in the literature review covering family caregiving in late life, most studies included at least two racial categories. However, Asian Americans, Arab Americans, and Native Americans were under-represented.⁶

Future Research

A major research priority that permeated through all stages of our process was to conduct studies of caregivers across racial and ethnic populations. Future research should build on existing studies using varied methodologies (e.g., longitudinal, quantitative, qualitative, mixed-methods) to:

- Oversample underrepresented racial and ethnic groups, immigrants and refugees.⁷⁻¹¹
- Compare family caregiver experiences across race/ethnicity and culture.¹⁻²
- Examine within group factors among specific racial and ethnic groups.³⁻¹²
- Examine cultural issues such as cultural values, and practices including religion and spirituality that should be considered in services and intervention development.
Family Caregiving Experiences of Persons with Disabilities

Of the 43.5 million United States adults who provided care to someone 18 years or older, 85% were caring for one or more family members. Family caregiving involves a relationship between persons with disabilities who receive or use care services and the family member who is providing them. However, the bulk of family caregiving research has focused only on the family member providing the care – in terms of the quality of their experience and the bio/psycho/social and economic outcomes that arise from caregiving.

Limited research has attempted to include the perspective of those receiving/using services and supports provided by family members alongside family caregiver perspectives. For example, in the area of family caregiving for adolescents, only two studies examined how the adolescents with disabilities experienced their parents as caregivers and one looked concurrently at adolescent and parental experiences of transition planning. Similarly, only a small number of studies on family caregiving in late life incorporate the perspective of the older adult, for those with mental illness or dementia.

Future Research

An important priority for family support research is to include the persons with disabilities as part of the family. These studies should build on existing research with questions and outcomes related to the family member with disabilities in addition to caregiver outcomes. For example:

- Questions of autonomy, consumer- or self-direction, and independent or supported decision-making within the family-caregiving dynamic.
- Self-reported and objective measures of the physical, mental/emotional, and social outcomes for persons with disabilities who are cared for by family members.
- Educational, volunteer, employment, and civic and social engagement outcomes of persons with disabilities cared for by family members.
- Experiences of adults with disabilities, particularly co-residing adult children, as engaged in a mutual caregiving relationship with their aging parents.
- Experiences of LGBTQ adults with disabilities as they negotiate power dynamics in parental and sibling relationships and navigate intimacy in partnered/spousal relationships.
Family Caregiving Experiences of Multiple Family Members

Excluding those caring for children under the age of 18, more than half of family caregivers in the United States were caring for a parent or parent-in-law or grandparent or grandparent-in-law. At 14%, spousal caregivers accounted for the next most frequent form of family caregiving followed by the nearly 6% of caregivers providing services and supports to siblings and siblings-in-law, and 5% caring for adult children. Research on family caregivers has concentrated on certain familial roles for particular life course stages. In early childhood and adolescence, the focus has been on parents rather than other family caregivers, and more often on mothers than fathers. Depending on the impairment type, family caregiving research in adulthood has focused on parents, adult children, and spouses, often devoting too little attention to the role of siblings, particularly around moments of transition, or to experiences of compound caregiving, as lifelong caregivers take on additional caregiving roles with aging parents. Research on spousal caregiving in adulthood and late life has neglected the experiences of those who are unmarried but living together (i.e., cohabiting) and lesbian or gay adults who were either or both unable to marry or unable to identify themselves in datasets. Research that addresses adult children caring for parents overwhelmingly focuses on caregivers over age 50, overlooking the experiences of younger caregivers with parents with functional support needs.

Future Research

An important research priority is to broaden the research populations beyond maternal caregivers and spouses. While these encompass the majority of caregivers, new research is needed to better understand:

- Grandparent caregivers, particularly in communities of color, helping single or married parents raise children with autism or mental illness.
- Aunt, uncle, cousins, and other extended family member caregivers, particularly in communities of color.
- Younger adult children who are caring for family members. Current research on adult children caregivers is almost exclusively focused on caregivers age 50 and older, neglecting adult children caring for parents prior to mid-life.
- Sibling caregivers across the life course, exploring how these roles change and develop over time and in relation to other forms of caregiving.
- Men who provide caregiving to family members as brothers, spouses, husbands/partners, uncles, and grandparents.
Family Caregiving Experiences Across Multiple Social Contexts

Family caregiving is experienced differently across social contexts. There are unique needs for research on LGBTQ family caregivers, caregiving in rural settings, and compound caregivers.

Lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities. LGBTQ people account for 9% of US caregivers. Compared to their heterosexual peers, LGBTQ caregivers were more likely to report financial strain, emotional distress, and poor health. LGBTQ people report high rates of providing informal caregiving for both friends and family, identifying mutual benefits for caregiver and persons with disabilities, and experiencing increased stress and depression when caregiver access to social support is limited. However, LGBTQ older adults were less likely than their heterosexual peers to have access to a caregiver, despite higher disability rates among lesbian, gay, and bisexual older adults. Interpersonal and institutional experiences of homophobia and transphobia affect the experiences of both LGBTQ people with disabilities and caregivers. Additionally, changing policy contexts (e.g., Supreme court decisions legalizing gay marriage) and increasing rates of LGBTQ parents, demonstrate a need for new research on the current strategies and needed supports of LGBTQ caregivers across the life course.

Rural locations. Just over one-quarter of caregivers in the US live in a rural setting, with higher rates for whites, Blacks, and Latinos than Asian Americans. Services and resources are often limited in rural areas, making issues of access and systems navigation more challenging.

Compound caregiving situations. Additional caregiving relationships and responsibilities may emerge over time as a caregiver’s other family members develop disabilities. For example, a mother providing support for her high school age child with intellectual and developmental disabilities may also begin caring for her mother-in-law after a fall. Described as compound caregivers, these individuals continue to support one individual as they take on new caregiving for other family members.

Future Research

Within certain social contexts, family caregivers are more likely to be underserved and more research is needed to understand their experiences and how best to address their unmet needs for support. More information is needed about:

- LGBTQ young and middle-aged adults engaged in family caregiving for “chosen” and/or biological families;
- LGBTQ people with disabilities as they navigate systems with assistance from “chosen” families;
- LGBTQ people with disabilities and family caregivers’ experiences of homophobia and other cultural barriers to accessing caregiving supports and services;
- Rural caregivers’ strategies to find support despite limited resources and their needs for services.
- Compound caregivers’ health and non-health outcomes related to new caregiving responsibilities, with a focus on temporary and longer-term compound caregiving;
- Compound caregivers’ access to services and supports as the family dynamic/need for caregiving changes in response to a family member’s new disability status.
Family Caregiving Experiences Across Multiple Disability Types

In the United States, nearly six in ten caregivers of adults (age 18+) were providing services and supports for persons who had long-term physical conditions, while more than one-quarter had memory issues, and another 21% had emotional/mental health problems. Caregiving for adults with behavioral issues (7%) and intellectual and developmental disabilities were less common (4%). At each life course stage, there are clusters of research: autism and intellectual disabilities in early childhood; serious mental illness in adulthood; and dementia in old age. However, there is a need to broaden the focus to account for a wide array of impairment/disability types across the life course with diverse family members providing care. For example, research on parent caregivers is focused heavily on young persons with autism including adolescents but is less likely to focus on adults with autism. There is limited research on older adults with autism or schizophrenia and even less research on family caregivers of older adults within these disability populations.

Future Research

An important research priority is to examine experiences of family members caring for persons with types of disabilities that previously received little attention in the literature, including:

- Caregivers of adults and older adults with autism; young adults and adolescents with mental illness; and children and young adults who use personal care assistance to maintain their independence.
- Service and support needs of family caregivers when a family member’s impairments or functional needs are acquired later in life, including recovering from falls, stroke, or cardiac events, or living with degenerative disorders like multiple sclerosis.
- Experiences of family members caring for persons with disabilities explored in the literature in new points along the life course.
- Same-age caregiver experiences compared across disabilities (e.g., midlife or older adult caregivers caring for family members with developmental, physical, and mental disabilities.)
Family Caregiving Experiences with Access and Systems Navigation

Family caregiving may take on many forms, including providing informational and administrative support as persons with disabilities navigate complex and varied educational, health, and social service systems and act as advocates to help to ensure they gain and maintain access to services for which they qualify on the basis of their impairment/disability (and possibly, economic status). For children and adolescents with disabilities, this advocacy includes participating in the individualized education program (IEP) process. For adults and older adults with disabilities, this form of caregiving may involve transportation to, presence at, and various levels of assistance with paperwork for health, social service, social welfare, and employment services.

Service systems in the United States are very decentralized, siloed, and complex. Persons with disabilities and family caregivers from culturally and linguistically diverse backgrounds often report significant difficulties in accessing information, services, and supports that are relevant to their culture and in their native language.

Many of these issues of access and systems navigation are even more complex in rural areas where services and resources are limited, and even more challenging to access for low-income and immigrant populations. For persons with disabilities who have complex health care needs, the greater time, distance, and resources required to travel to a provider can pose a significant barrier to access to services. Currently, Medicaid recipients often report a limited number of Medicaid providers and a lack of coverage for needed services, further challenging the access and utilization of services for persons with disabilities and their family caregivers. Additionally, families living in lower socioeconomic households face additional barriers in accessing specialist care services, having consistent primary care provider, and are less likely to receive preventative care services for persons with disabilities.

Future Research

An important research priority is to understand the experiences of family caregivers with respect to how they access and navigate different service systems (i.e., educational, housing, health, social services, employment services) and long-term effects of systems navigation. Some important areas for further investigation include:

- Experiences of family caregiving responsibilities as they shift at moments of transition (e.g., persons with disabilities aging from childhood to adolescence, young adulthood to middle adulthood, into and through old age, and when needs/desires for coresidence or living outside of the home change).
- Family caregivers as perceived and understood by educational, social service, and health systems and how these systems provide outreach or support.
- Experiences of rural caregivers in terms of access and utilization across systems, as well as disparities in physical and mental health outcomes.
- Experiences of low income and immigrant caregivers in navigating complex systems in the context of language barriers and limited flexible resources.
Family Caregiving Experiences with Positive Caregiving Outcomes

Caring for a family member is a challenging and demanding task. Research has demonstrated potential negative consequences such as high level of subjective and objective burden for caregivers\textsuperscript{74–77} while less frequently studying potential positive outcomes. For example, caregivers of older adults reported satisfaction and rewards while providing care.\textsuperscript{78} Similarly, caregivers of children and adolescents indicated high levels of quality of life and feeling closer to their child.\textsuperscript{79,80} In addition, caregiving provides financial opportunities for family members including paid work and training in a field that might lead to future employment.\textsuperscript{19} Caregiving also increases levels of intimacy and support across family members.\textsuperscript{81}

In general, research that examines positive caregiving is scarce across the life course, especially longitudinal studies that examine the changes and dynamics in caregiving role. In addition, studies pertaining to families of color are inconsistent in relation to the impact of caregiving. For example, when comparing Latinos with White caregivers, some research illustrates a negative impact of caregiving and a high level of burden\textsuperscript{82} while other studies indicate a high level of positive impact and satisfaction across Latino caregivers.\textsuperscript{83} Overall, reasons for positive outcomes of caregiving include filial piety,\textsuperscript{84} familism,\textsuperscript{85} and access to family-centered care and consumer directed services.\textsuperscript{20}

Future Research

A research priority is to examine positive outcomes and contributing factors. More research is needed on:

- Different worldviews on family support\textsuperscript{86,87} and comparison of reasons for increased satisfaction across caregivers of color.\textsuperscript{88}
- Longitudinal research on how structural, social, and economic factors may foster positive outcomes for the caregivers.\textsuperscript{89}
- Positive caregiver outcomes in relation to outcomes for persons with disabilities,\textsuperscript{90} including interdependence.\textsuperscript{91}
- Disability type and symptoms (functional status) in relation to positive outcomes of caregiving across the life course.\textsuperscript{16,92}
- Positive caregiving experiences of siblings, including influence on school performance, family cohesion, emotional strength, and plans for the future.\textsuperscript{93,94}
Family Caregiving Experiences with Employment and Financial Security

Households engaged in family caregiving incur unique expenses in comparison to non-caregiving households. For parents caring for children with disabilities, there are increased costs associated with medical care, some of which are only partially covered or not covered by insurance. Sibling caregivers of adults with intellectual and developmental disabilities (I/DD) were more likely to be poor (have incomes below 300% of the federal poverty guideline), receive government assistance (Supplemental Nutrition Assistance Program and Supplemental Security Income), and to experience food insecurity than the general working age adult population. Economic deprivation is more likely among the youngest (under age 45) and oldest (age 65 and older) family caregivers of adults with I/DD, measured in terms of asset poverty (where debts are greater than assets) and income poverty (using the European Union’s measure of 60% of median income).

Middle-aged and older caregivers reported lower job satisfaction than their non-caregiving counterparts. Caregivers may be less likely to be employed or consider leaving work to focus on caregiving. For family members caring for children, particularly mothers, these effects can be cumulative – with temporary work reductions or leaves leading to missed opportunities for advancement in position and pay or permanent labor force exits. These decisions, may in turn, impact the cumulative earnings and retirement eligibility for caregivers, especially women caregivers.

Future Research

A research priority is to examine the impact of caregiving on employment and economic outcomes. New research should examine:

- Gaps in employment wages, advancement, and individual and familial wealth when comparing caregiving and non-caregiving households.
- Family caregivers of color, examining issues of immigration status, parental nation of origin, limited English proficiency, intergenerational households, in relation to job characteristics (duration, location from home, autonomy and flexibility, part-time v. full-time status, opportunities for advancement).
- Unmet service needs for persons with disabilities in middle- and low-income family caregiving households.
- Food insecurity and family level of economic deprivation/need among low-income family caregiving households.
- Impact of cross-state differences in Medicaid on financial impact for family caregiving households.
II. Family Support Interventions

Interventions help family caregivers by offering social and emotional support across caregivers, informational and navigation support as caregivers learn new skills or manage systems, and/or instrumental support in the form of goods (e.g., equipment) or services (e.g., transportation, respite). More research is needed to develop, implement, evaluate, and expand interventions to respond to the needs of family caregivers across populations, social and economic context, family member type, and life course stage. Existing interventions need to be expanded to new populations and evaluated to strengthen the evidence of their effectiveness. New interventions need to be developed and piloted to respond to unmet needs, as well as to facilitate culture change among health and service professionals. Interventions can be informed by identified promising practices, offering the opportunity to incorporate these into research studies and develop the evidence base for these practices.

The overarching priority is to design studies that increase efforts to develop, adapt, and tailor family support interventions for culturally diverse persons with disabilities and their family caregivers. We outlined three ways that family support intervention research should proceed:

01 Piloting, Testing, and Scaling Up Interventions

02 Promoting Elements of Promising Practices

03 Building the Evidence Base
Piloting, Testing, and Scaling Up Interventions

To improve outcomes for family caregivers and persons with disabilities across the life course, a variety of interventions have been designed and evaluated. For families of children with disabilities, parent training programs, some of which include feedback on videotaped parent-child interactions, have shown promise for improving parental confidence and problem-solving, as well as decreasing children’s challenging behaviors.\textsuperscript{113–116} Interventions that addressed parents alongside their adolescent children with mental illness, demonstrated both positive adolescent mental health outcomes and parental attitude and behavior change, including responding to challenging behaviors and seeking services.\textsuperscript{117–120} Culturally appropriate interventions have been associated with positive outcomes for both the person with a disability and the family caregiver, for Latino families that include a person with schizophrenia and for Latina mothers of children with disabilities, including autism.\textsuperscript{121–125} Family caregivers of older adults with dementia had improved outcomes after participating in interventions.\textsuperscript{59,126,127} Technological interventions, including telephone-coordinated services, also helped family caregivers of older adults.\textsuperscript{58,128–130}

Future Research

New interventions need to be developed and piloted, including those:

- To train providers and change attitudes and practices toward persons with disabilities and family caregivers in communities of color;\textsuperscript{65,67,131,132}
- To appropriately meet the needs of underserved populations, including family caregivers in communities of color, recent immigrants to the US, and those with limited English proficiency;
- To address the needs of sibling caregivers, independently, and as unique part of the family in family-centered support models; and
- To assist family caregivers in rural settings.

Interventions that have been piloted need to be tested in new populations and settings, by:

- Culturally and linguistically tailoring interventions for the needs of family caregivers in communities of color; and
- Incorporating technology into interventions.

Interventions that have a strong evidence-base need to be scaled up (expanded) by:

- Adapting interventions developed in one setting (e.g., the Veterans Affairs) or with one disability type (e.g., dementia) for a more general population; and
- Distributing interventions developed in one community or state to a national scale.
Promoting Promising Practices

Promising practices can be mapped and explored via a three-part framework developed by FSRTC staff: 1) connection and partnership, 2) discovery and navigation, 3) goods and services.\(^{133}\)

Interventions that demonstrate promising practices in **connection and partnership** include one or more of the following elements: peer-led interventions, support groups, and advocacy skills. Peer-led interventions on future planning, methods to implement child related treatment programs, and reducing caregiver’s emotional stress have demonstrated positive outcomes across various family members (mothers, fathers, siblings) and disability types across the life course.\(^{121,122,134–136}\) In adult and late life, caregiver interventions focused on developing and enhancing caregiver constructive problem-solving have shown demonstrated benefits for caregivers and persons with disabilities.\(^{137–139}\)

Interventions focused on **discovery and navigation** assist family caregivers by building skills and increasing efficacy in systems navigation. Examples include, problem solving skills interventions and personalized systems navigation tools.\(^{134,140}\)

Interventions that provide **goods and services** facilitate access to respite, transportation, and connect family caregivers with adaptive equipment or assistive technology.\(^{141}\)

Future Research

Future research should be informed by promising practices using the framework above to design, implement, and test interventions to:

- Expand and replicate programs to new populations, disability types and life course stages by:
  - Promoting person-centeredness/self-direction,\(^{142,143}\)
  - Enhancing peer-led interventions across the life course with a focus on future planning,\(^{144}\)
  - Exploring the effectiveness of technology in family support interventions especially in relation to accessing information,\(^{58,128,145,146}\)
  - Developing, adapting, and tailoring services and interventions for culturally diverse persons with disabilities and their family caregivers.\(^{121}\)

- Address the complex needs of caregivers by attending to all three domains (i.e. connection and partnership, discovery and navigation, and goods and services).

- Continue to identify promising practices in family support.

- Develop the evidence base for promising practices in family support.
Building the Evidence Base

Interventions that are piloted and tested are published in the scientific literature (i.e., peer-reviewed journals) or in governmental reports. To build the evidence base on interventions, there needs to be more concerted and coordinated communication among family caregiver researchers across disability type, life course stage, and health or social service system. Additionally, there needs to be an increasing level of methodological sophistication that strengthens the evidence for pilot and tested interventions, so they can be diffused and used broadly.

Also, existing federal standards for evidence aid in examining research related to family support. In addition to NIDILRR’s stages of research framework, two national models provide guidelines for evaluating the evidence of family support interventions:

1. The NIH stage model consists of six stages: basic science (Stage 0), intervention generation, refinement, modification, and adaptation and pilot testing (Stage I); traditional efficacy testing (Stage II); efficacy testing with real-world providers (Stage III); effectiveness research (Stage IV) and; dissemination and implementation research (Stage V).\(^{147,148}\)

2. The CDC’s evidence based decision-making model includes two forms of evidence beyond the best available research evidence, a) experiential evidence, which focuses on documented evidence based on previous experiences or research, and b) contextual evidence, which focuses on soliciting insights from experienced stakeholders.\(^{149}\)

Future Research

Building the evidence base for family support interventions includes:

- Increasing the frequency of using randomized clinical trials (RCTs) to demonstrate the effectiveness of interventions;
- Reviewing the literature on the state of the science in family caregiving interventions for people of color;
- Generating meta-analyses that examine the differences in family caregiver outcomes across a variety of measures for caregivers and persons with disabilities, disability types, family member roles, and life course stages;
- Encouraging follow-up studies that increase the longitudinal component for evaluating the long-term effects of interventions and following families before, during, and after times of transition;
- Employing criteria\(^{148,149}\) to chart and evaluate the evidence-base for interventions; and
- Gathering, maintaining, and disseminating a database of evidence-based interventions by disability type, family member role, and life course stage.
III. Family Support Policy, Programs, and Services

Social policies, programs, and services are the large context that surrounds family caregiving. Research related to social policy links decisions at the state and federal level to opportunities and constraints in the lives of caregivers and their families. Future research will evaluate changes to current policies, programs, or services and those newly developed and introduced, seeking to improve family support experiences and outcomes.

The overarching priority for family support policy, programs, and services is to design studies to determine utility, effectiveness, and cost-benefit of the policies that affect family support of persons with disabilities. We identified seven family support policies that should be considered in future research:

01 Consumer Direction in Home and Community-Based Services
02 Disability Employment Policies
03 Family Medical Leave Act
04 National Family Caregiver Support Program
05 No Wrong Door
06 Recognize, Assist, Include, Support, and Engage Family Caregiver Act
07 Respite
**Consumer Direction in Home and Community-Based Services (HCBS)**

Consumer direction, also known as self-direction, is a philosophy that puts persons with disabilities who are getting help to be in control of who provides the help (including family members) and how the help is provided (through training and management of caregivers). That is, the person with a disability can hire, train, manage, and fire their caregiver. Two programs allow for persons with disabilities who need assistance with certain daily tasks to hire and pay family members to be their personal care attendants: Medicaid and the Veteran-Directed Care Program (VDC).

Medicaid home and community-based services (HCBS) are services and supports used by persons with disabilities who have need assistance with activities of daily living and express a preference for community living. All states and territories with Medicaid programs are required to offer home health. However, most HCBS are provided through one of two optional mechanisms – as a personal care services amendment to the state’s Medicaid plan or as an HCBS waiver (i.e., waiving an eligibility requirement). Nearly 3 million individuals access these services through Medicaid, which is the largest payer for services in the United States.

Despite research that demonstrates positive outcomes for persons with disabilities, family members, and paraprofessional/direct care workers, consumer direction is not evenly available across or within states. As of 2016, all states have at least one option that allows consumers to self-direct their personal care assistance. However, access is unevenly distributed across Medicaid programs with 43 states offering at least one self-directed HCBS waiver, while 24 states provided access to self-direction through the state plan and only seven through home health services.

Modeled after the Cash and Counseling demonstration, the VDC program offers Veterans at risk of nursing home admission the opportunity to have control over a monthly budget that they can use to hire family, friends and neighbors to provide services that help the Veteran continue to live at home in the community. The VDC program enables Veterans to design their care to fit their life rather than requiring them to change their life to fit the care delivery system.

**Future Research**

Developing family support research on consumer direction in HCBS is a priority. Future policy and program evaluation should examine:

- Impacts of consumer direction for both adults with disabilities and family caregivers with a focus on positive impacts, including family harmony, mental health, satisfaction, and economic stability.
- Impacts of state policies restricting legally responsible individuals from being paid caregivers on family caregiver stress, well-being and family relationships.
- Efficacy of paying family caregivers on participant-family caregiver dyadic health.
- Training and support needs of consultants (support brokers) in self-directed programs and their impact on participant and family caregiver outcomes.
- Caregiver needs and service utilization in consumer-directed programs.
- Cross-state comparisons in the relationship between access to consumer-directed services for adults with disabilities and family caregiving service utilization and caregiving outcomes.
Disability Employment Policies

Research on disability, employment, and caregiving has primarily focused on the impact of a family member with a disability on the employment of the caregiver. Limited research has addressed the impact of employment of persons with disabilities on family caregiver outcomes. Future research needs to consider how the employment of persons with disabilities impacts family caregivers, especially in light of two sets of state and federal policy efforts aimed at increasing the rates of persons with disabilities employed in meaningful, compensated work: Employment First (EF) and state and federal efforts to phase out segregated work settings (i.e., sheltered workshops).

Employment First (EF) is a federally-promoted framework for statewide systems change to increase the opportunities for competitive, integrated employment for persons with disabilities.155 EF aims for states to rebalance their educational, vocational rehabilitation, and employment systems so that, for persons with disabilities, integrated employment is “the priority option”.156 Currently, forty-six states have moved forward with some form of EF initiative, the majority through legislation and/or executive order.157

National and state efforts have been advanced to increase competitive, integrated employment by closing sheltered workshops.158-162 In part, this is a response to the new Medicaid home and community-based services rule that requires all services be provided in an integrated (as opposed to segregated) setting in order to qualify for federal reimbursement.163

Future Research

An overarching priority in this area is to understand family caregiver outcomes (economic and mental, physical, and social health) in relation to local state and federal disability employment policies and programs. For example:

- Longitudinal studies of labor force participation for family caregivers in relation to state disability policies (Medicaid coverage of supported employment; Employment First; sheltered workshops).
- Impact of transitions of persons with disabilities out of segregated employment to integrated employment on persons with disabilities and family caregivers.
- Impact of transitions of persons with disabilities from school or unemployment to employment on persons with disabilities and family caregivers.
Family Medical Leave Act

The Family Medical Leave Act (FMLA) was originally passed in 1993 as the first federal policy designed to assist employers and employees with absences associated with medical and family care. The FMLA as it currently stands provides up to 12 weeks of unpaid leave for employees during a 12-month period of time to care for dependents, spouses, and parents. However, FMLA only applies to employers who have over 50 employees employed for at least 20 weeks in a year or are state or federal government employers, including schools. In July 2015, the language was updated to also cover employees who were acting “in loco parentis [in the place of a parent],” which represents siblings, grandparents, and other family members who care for persons with disabilities.

Despite the significant assistance that protected leave can have on family caregivers in supporting family members with disabilities, little is known whether this policy is effective and successful in supporting family caregivers and persons with disabilities. Results from the 2012 United States Department of Labor (DOL) Family and Medical Leave (FMLA) Employee Survey finds that employees who were younger, had lower incomes, or who were racial minorities were less likely to be aware of FMLA benefits. Additionally, only 56.6% of employees who were aware FMLA were informed by their employer or human resource office. These results suggest that greater work is needed to inform eligible employees of FMLA benefits, particularly among typically underserved groups (e.g., racial minorities, low-income families).

Among family caregivers of persons with disabilities, FMLA can provide critical support. However, data suggests that many family caregivers are not aware of the policy or know how to access the benefits. When family caregivers attempt to access FMLA, they face a tedious process with inconsistent or inaccurate information. Additionally, family caregivers who provide care to multiple persons with disabilities (e.g., parent, spouse, child, grandchild), may quickly use up the 12 weeks of protected leave, leaving few options for these families.

Future Research

Future policy research on family support needs to prioritize how family caregivers access FMLA and the benefits of this policy for individuals, families, and society at large. Specifically, we need to better understand and evaluate:

- Federal, state, and business outreach strategies to inform employees of their rights to access FMLA as family caregivers, assessing specific strategies to increase knowledge among workers who are younger, low-income, and/or people of color.
- Labor force trajectories and household economics of family caregivers who access FMLA through prospective, longitudinal studies.
- Experiences of family caregivers who are acting “in loco parentis”.
- Experiences of compound caregivers (i.e., individuals engaged in multiple caregiving relationships simultaneously) with FMLA.
National Family Caregiver Support Program

The National Family Caregiver Support Program (NFCSP) was established in 2000 as part of the reauthorization of the Older Americans Act, adding an additional section (Part E, Section 371) to Title III, Grants for State and Community Programs on Aging (P.L. 106-501). In 2016, the program was reauthorized, along with the rest of the Older Americans Act (OAA), through fiscal year 2019, when the OAA is scheduled for its next routine reauthorization (P.L. 114-144). Since 2013, the NFCSP has operated on federal appropriations of $146 million each year.168

The NFCSP provides grants to states and territories to distribute funds through the Aging Network (the area agencies on aging, or AAAs) to grantees to provide five services:

1. Information about caregiving services;
2. Help to caregivers so they can access services;
3. Caregiver support in the form of counseling, support groups, and training;
4. Respite services; and
5. Supplemental services (including home modifications and assistive technology)

These services are available to both adult (aged 18 and over) family members and informal caregivers who are caring for either someone who is over the age of 60 or someone living with Alzheimer’s or dementia, regardless of age. Additionally, these services are available to any non-parent family member aged 55 and older who is caring for a child with disabilities, as well as any family member (including parents) caring for an adult with disabilities, aged 18-59.169

The process evaluation of the NFCSP reported that caregivers of adults over age 60 and/or those with Alzheimer’s dementia are benefiting from NFCSP, finding the program helped them to be better caregivers and provide caregiving for longer than possible without these services.170 Outcomes evaluations are underway.

Future Research

A main research priority is to assess the utility of NFCSP to caregivers within and across states. Other research studies could examine:

- Tailoring of services (counseling, support groups, and caregiver training) as well as information about services to address the needs of family caregivers of color and of different levels of English proficiency, LGBTQ family caregivers, those in rural areas, and a broad array of family members engaged in caregiving;
- Integration of state Family Caregiver Support Programs and other home and community-based services programs (including No Wrong Door);
- Cost-benefit analyses of investments in family caregiving support and continued employment for caregivers, as well as positive outcomes (health, reduced hospitalization) for persons with disabilities;
- Challenges experienced by family caregivers and persons with disabilities who move across states due to interstate variation in caregiver support programs.
No Wrong Door

No Wrong Door (NWD) is a partnership between the Administration on Community Living (ACL), the Veterans Administration (VA), and the Centers for Medicare and Medicaid Services (CMS) to help individuals and families find information and gain access to appropriate long-term services and supports (LTSS). The goals of NWD are to reduce confusion, help individuals get accurate information, and to facilitate access to services for those who need it. NWD systems are expected to include four key elements:

1. Public outreach and coordination of key referral services;
2. Person-centered planning;
3. Streamlined eligibility for public programs (e.g., Medicaid); and
4. State governance and administration.¹⁷¹

The federal government encourages states to develop and maintain NWD systems with grants offered by ACL and by offering guidance for how to claim federal matching dollars (i.e., Federal Financial Participation or FFP) through Medicaid. As of 2018, two-thirds of states (n=33) have offered legislative or gubernatorial support for NWD.¹⁷² An extension of earlier efforts known as aging and disability resource centers (ADRCs), NWD was originally an initiative of the Administration on Aging (AoA) and CMS, and legislatively introduced as a part of the 2006 reauthorization of the Older Americans Act (OAA, P.L. 109-365). ADRCs migrated to the purview of ACL in 2010. Between 2003 and 2010, the federal government invested over $111 million to ADRCs through CMS’s Real Choice Systems Change grants and AoA funding.¹⁵²

Evaluations of improvements to state LTSS systems have found change to be slow. Researchers found no improvement for support of working caregivers or transportation policies in nearly 80% of states and no improvement on nurse delegation and scope of practice in about half of states.¹⁷³ However, they also found that more than 80% of states improved their person- and family-centered care, responding to spousal impoverishment requirements under the Affordable Care Act (in effect until 2019) and the passage of the Caregiver Advise, Record, and Enable (CARE) Act. These states are assessing family caregiver needs, notifying family caregivers before hospital discharge, and providing caregivers with education on how to perform medical tasks at home.

Future Research

It is critical that future family support research address system complexity and evaluate efforts to increase access to needed services. We need more information about and analysis of:

- Family caregivers trained in person-centered thinking, planning, and practices.
- Cost-benefit analyses of a statewide NWD system measured in terms of caregiver access to LTSS.
- Market penetration of state NWD access systems and impact of public outreach on client diversity (people of color, LGBTQ, caregivers other than parents and spouses).
- Coordination between NWD efforts and NFCSP.
- Cross-state differences in person-centered planning efforts and implications for persons with disabilities who cross states during periods of transition (e.g., parental retirement or death; relocating with sibling who is moving across states or to live closer to a sibling).
Recognize, Assist, Include, Support, and Engage Family Caregiver Act

Congress passed and in January 2018, the President signed into law the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiver Act. This law was a bi-partisan effort introduced in the United States Senate by Senators Susan Collins (R-ME) and Tammy Baldwin (D-WI) and by Representatives Gregg Harper (R-MS) and Kathy Castor (D-FL) in recognition of the tremendous work that caregivers do. This law requires that the Secretary of Health and Human Services (HHS) develop, maintain and update an integrated national strategy to recognize and support family caregivers. However, RAISE does not authorize additional funding to HHS. The law mandates the development of a strategy within 3 years through the creation of an advisory council that will report to the HHS secretary within a year of the law’s enactment. The strategy is to identify actions that Federal, State, and local governments, communities, service providers, and others are taking or should take to support family caregivers.

Future Research

While the advisory council has yet to be formed at the time of this writing, many of these topic areas are ones identified by the Strategic Research Plan. We recommend a state-by-state study of programs and policies that contribute to these actions, which could assist with the Advisory Council’s work. Furthermore, policy research on the implementation of the RAISE strategy once it is developed should address:

- Promoting greater adoption of person and family-centered care in all health and long-term care services and supports settings, with individuals receiving services and supports and family caregivers (as appropriate) at the center of care teams.
- Assessment and service planning (including care transitions and coordination) involving family caregivers and care recipients.
- Information, education and training supports, referral, and care coordination, including with respect to hospice care, palliative care, and advance planning services.
- Respite options.
- Financial security and workplace issues.
- Delivering services based on the performance, mission and purpose of a program while eliminating redundancies.
Respite

Respite includes planned or emergency services that caregivers receive resulting in measurable improvements that impact the caregiver, care recipient, and/or family unit. Respite has a positive impact on caregivers and persons with disabilities. For example, respite is reported to enhance marital quality and reduce stress levels across parents of children with autism. In a national sample of caregivers of children with disabilities, respite was associated with reduced family stress and financial worry and increasing the child academic achievements. Respite is also considered a vital service for caregivers who co-reside with an older adult allowing them to remain employed and get emotional breaks from caregiving.

The majority of respite services are provided on the state level and funded in partnerships with private organizations, even when funded in part or full through federal dollars with programs like Medicaid, the National Family Caregiver Support Program (NFSCP), or respite resources for veterans and military families programs. On average, agencies or individuals spend $1,423 yearly to provide 12 hours/month of respite services.

In 2006, Congress authorized the Lifespan Respite Care Program under Title XXIX of the public Health Service Act (42 U.S.C 201). The Lifespan Respite Care Programs work to improve the delivery and quality of existing services through:

1. Expanding and enhancing respite services in the states;
2. Improve coordination and dissemination of respite services;
3. Streamline access to programs;
4. Fill gaps in services where necessary; and
5. Improve the overall quality of the respite services currently available.

Respite services are limited and impacted by state legislation and federal budget cuts. Current research illustrates that respite services are sporadic, limited, and inconsistent across states. For example, in Illinois one in five caregivers (age 55+) of adults with IDD reported unmet needs including respite. Respite was also highlighted as one of the most needed services by caregivers of older adults in Washington state.

Future Research

Respite remains a priority for family support policy research. In addition to existing evidence of the benefits of respite for family caregivers, we need to address:

- Respite access and utilization among caregivers of color and LGBTQ caregivers.
- Cost-benefit analyses of respite services especially its impact on reduction of hospitalization, nursing home utilization, and foster or other out of home placements.
- Collaborative decision-making between caregivers and persons with disabilities in planning for and managing respite services.
- Evaluation of cross-state differences in respite access and workforce in relation to caregiver outcomes.
IV. Research Methods in Family Support

Family support research needs expanded methods to adequately and appropriately describe the family caregivers’ experiences and outcomes. Enhancing current research methods will support new forms of analysis and deeper understanding of the influence and the impact of caregiving, interventions, and the policies, programs, and services aimed at supporting families.

For research methods in family support, the overarching priority is to design studies that address the changing experiences of disability, family, and family caregiving over time. Research needs to connect caregiving to a variety of health, financial, and family functioning outcomes, and document the unique needs and experiences of underserved communities. We suggest future research consider employing one or more of the following four methodological approaches:

01 Cost-Benefit Analysis and Cost-Effectiveness Research
02 Longitudinal Studies
03 Qualitative Research
04 Secondary Analysis of National Data
Cost-Benefit Analysis and Cost-Effectiveness Analysis

Interventions and supports for family caregivers can yield significant positive effects for persons with disabilities and their families that translate into cost savings for society. Methodologically, cost-benefit or cost-effectiveness analysis examine the economic cost of programs and interventions in relation to the educational, health, and functional outcomes of persons with disabilities, family caregivers, and more broadly, society.

Cost-Benefit Analysis (CBA)
CBA examine programs in terms of the monetary savings and include health and non-health outcomes. For example, one study found that Texas could save an average of $208,500 in special education costs per child for 18 years of education (4 to 22 years) by providing early intensive behavioral intervention to children with ASD. Families of toddlers who received the Early Start Denver Model (ESDM) for two years experienced lower annual-health related costs by an average of $19,000 in the child’s sixth year than families of toddlers with ASD who received existing community supports. These studies make an economic case for investing in behavioral interventions for young children with ASD, serving as a model for other programs, interventions, and services that cater to family caregivers of persons with disabilities.

Cost-Effectiveness Analysis (CEA)
CEA evaluate the impact of programs, interventions, and services in terms of the cost needed to obtain a defined unit of change in health, such as quality-adjusted life-year (QALY) or the disability-adjusted life-year (DALY). Guidelines for CEA of services and programs recommend that high quality studies should include randomized comparison groups and should specify the costs associated with the intervention/program and its implementation. However, CEA have limitations in that the costs included in the analyses often exclude indirect costs such as unpaid caregiving time and costs. Failure to include these costs can affect the validity of CEA as many programs, interventions, and services for persons with disabilities and their family caregivers depend on caregivers’ time and effort. Furthermore, with CEA, program, intervention, and service outcomes may often not be readily observable or measurable. When outcomes are not evident for an extended period of time, the organization may not be prepared to track persons with disabilities or family caregivers, thus calculating CEA may become cumbersome.

Future Research

Future family support research based on this method could generate new information about:

- Impacts of family caregiving on family finances, especially for families from communities of color and low socioeconomic backgrounds.
- Perspectives of persons with disabilities on the value of caregiving.
- Non-health related outcomes for family caregivers, including financial security, continued employment, lower levels of stress, increase in quality of life, and contributions to the community (e.g., volunteering).
- Long-term impacts of policies with direct (e.g., financial) and indirect (health and function) outcomes for persons with disabilities and family caregivers.
- New tools to assess the benefits and effectiveness of programs.
Longitudinal Studies

Longitudinal studies consist of applying continuous or repeated measures to monitor individuals over extended periods of time. Longitudinal studies are observational in nature, often expand over years or decades, however experimental methods can also be employed to explore certain outcomes. In family support, longitudinal studies can be utilized to explore outcomes for caregivers and persons with disabilities across the life course. They are specifically imperative in comparative analysis within and across cohorts to examine mortality rates, disability onset and course, and caregiving change over time.

Existing longitudinal studies in family support help in understanding the relationships between the impact of caregiving on families (positive/negative) and the nature of disability. Well-designed longitudinal studies can help determine the direction of effects, while cross-sectional research can only report on correlations. Most of existing research illustrates that during childhood and adolescence caregivers’ burden (e.g. stress, anxiety, etc.) increases over time with the increase of disability severity. In addition, research illustrates a bidirectional correlation between parental stress and disability severity that may lead to increasing the child challenging behaviors. Longitudinal studies that compare outcomes across cohorts illustrate that caring for adolescents with disabilities may reduce family conflict in comparison to caregivers of adolescents without disabilities. In general, longitudinal studies demonstrate that caregiving outcomes are contingent on disability onset, the degree of established social roles, race and culture, and family life.

In addition, longitudinal research illustrates a correlation between support provided to the family and caregivers and health, social, and financial outcomes for persons with disabilities. Studies illustrate that providing support to family caregivers reduces burden, increases services satisfaction, and reduces the prevalence of unmet needs over time. For example, providing respite services to parents of children with disabilities reduced stress and increased children’s academic achievement.

Future Research

Producing family support research that employs longitudinal methods is a priority. New knowledge from these studies would allow us to analyze:

- Changes in the well-being across the lifespan of families of persons with disabilities.
- Immediate and long-term outcomes of support services, including positive outcomes, on both persons with disabilities and their family members.
- Impacts of disabilities of sudden onset such as mental illness, TBI, and stroke.
- Change in family relationships, dynamics, and social roles especially the social positions that establish compound caregivers.
- Changes in outcomes for caregivers and persons with disabilities related to health policies.
- How race, economic status and family dynamics are experienced across families of color and LGBTQ families.
- Impacts of caring for persons with disabilities across family members (i.e. comparing outcomes for mothers, father, siblings, friends, etc.).
Qualitative Inquiry

Qualitative inquiry is a way to investigate human experience and to explore how individuals understand and assign meaning to what they do and what happens to them. By gathering information through ethnography, observation, interviews, and focus groups, qualitative researchers collect the words and stories of others for analysis through coding; memoing; content, thematic, and concept identification; and theory building. Data for qualitative research may be gathered in-person, via the phone or mediated technology like internet chat, or online or paper surveys. Qualitative research can be an independent method or used in conjunction with quantitative data, a practice called mixed methods.

Qualitative inquiry has generated new knowledge through exploration and discovery, as well as by assessing and evaluating services, intervention, and the impact of policy on the lives of caregivers, persons with disabilities, and their families. Across the life course and across caregiver type, qualitative methods have produced new ways to understand parent caregivers of children and adolescents with disabilities, sibling caregivers in mid-life, and spousal caregivers in old age. Additionally, qualitative research has enhanced the understanding of the cultural specificity of support needs and utilization for family caregivers of color across the life course, with a particular focus on Latino family caregivers. Analyzing qualitative data has helped to documenting unmet need for family support services across the life course and across various types of disabilities. Furthermore, qualitative inquiry has contributed to the assessment and evaluation of programs, services, and policies for family caregivers and persons with disabilities, including peer-to-peer interventions and consumer-directed home and community based services.

Future Research

Qualitative research is essential to address experiences of family caregivers and persons with disabilities in family, community, and policy contexts. These methods will generate rich information for exploration and discovery, as well as when assessing interventions, or designing or evaluating programs. For example, researchers could design studies that include:

- Interviews and focus groups with persons with disabilities as knowledge producers.
- Bicultural, bilingual interviewers.
- Interviews and focus groups with family caregivers from communities of color, especially African American, Asian American, and Native American communities.
- Interviews and focus groups with LGBTQ caregivers and persons with disabilities navigating family caregiving.
- Caregiver experiences of fathers, husbands, grandparents, siblings, and “chosen family”.
- Longitudinal qualitative studies with multiple interviews or focus groups with the same participants over time along a caregiving trajectory.
- Vignettes to illustrate impacts of policy on caregivers and persons with disabilities.
- Professional perspectives and experiences working with family caregivers and providing support to the family as a unit.
- Service system cultures for providing services to families across the life course and across disability type.
Secondary Analysis of National Data

Current caregiver-specific datasets provide a partial understanding of family caregivers (e.g., prevalence, demographics), but integrating caregiver questions into national data collection efforts on health will help generate new information on caregiving contexts and outcomes, the impact of caregiving on families, and access and utilization of family support services. One of the challenges researchers face in this approach is that national datasets often do not include adequate caregiver and family support questions and variables. In March of 2016, the FSRTC developed a report and recommendations to improve existing data sets to monitor and evaluate family support. Part of this report included an environmental scan that found seven national datasets that provide representative data and include some disability and caregiving related questions.

Future Research

Generating better, more consistent data for analysis is key to future family caregiving research. For example:

- **Development/Agreement on a core set of family caregiver questions that could be added to national surveys.** The core set could include demographic caregiver questions to identify basic information such as caregiver status, characteristics of care recipient, level and duration of caregiving, and types of caregiving tasks performed. NIDILRR and other funders could invest in the development and testing of these core questions and help to promote their use within existing datasets.

- **Add demographic caregiver question(s) to the core Behavioral Risk Factor Surveillance System (BRFSS) survey.** BRFSS, conducted by the CDC is the nation's premier system of health-related telephone surveys that collect state data about United States residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services. In 2009, the BRFSS included a question to identify caregiver status in the core BRFSS which is completed by every state, however, it is no longer included. The report recommended that CDC add this question back to the core survey and consider additional questions to provide context of the caregiving situation, such as amount of caregiving.

- **Incentivize states to complete BRFSS voluntary caregiving module at least every five years.** A voluntary BRFSS Caregiving module has been available to states to use. However, historically very few states have included it. Due to advocacy and financial assistance from the Alzheimer’s Association, approximately half of states completed this module in the past year. The federal government should consider providing incentives to states to conduct this module at a minimum of every five years.

- **Add caregiver questions to National Health Interview Survey.** The National Health Interview Survey (NHIS) currently does not include specific caregiving-related questions. The NHIS is a nationally representative survey providing data on the health of the civilian, non-institutionalized population of the United States.

- **Add caregiving supplement to American Community Survey (ACS).** The American Community Survey currently does not include caregiving-related questions. The ACS is a continuous data collection effort by the United States Census Bureau that is used to produce annual estimates at the national, state, and local level on the characteristics of the United States population.
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References


Appendices
Appendix A: FSRTC Partner Organizations

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 and Resource Center
- AUCD’s Family Support Special Interest Group
- Easterseals
- National Alliance for Caregiving (NAC)
- National Alliance on Mental Illness (NAMI)
- National Adult Day Services Association (NADSA)
- National Association of Councils on Developmental Disabilities (NACDD)
- 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)
- RTTC 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
- The Arc
- Through the Looking Glass
- Wisconsin Family Assistance Center for Education, Training & Support (WI FACETS)
Appendix B: FS-Need to Know 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 for national and local decision makers of health care/social service providers to know about family support.
### Appendix C: Top Ten Ranked Ideas from the IdeaScale

<table>
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<tr>
<th>Idea Ranking (out of 10)</th>
<th>Topic</th>
<th>Rank Score (out of possible 42)</th>
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<tbody>
<tr>
<td>1</td>
<td>Cost benefits of family caregivers support</td>
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<tr>
<td>2</td>
<td>Cost effectiveness of respite for family caregivers</td>
<td>33</td>
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<tr>
<td>3</td>
<td>Respite research</td>
<td>25</td>
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<td>4</td>
<td>Policy to provide tax credit for caregivers</td>
<td>23</td>
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<td>5</td>
<td>Caregivers and the workplace</td>
<td>18</td>
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<td>6</td>
<td>Database of back-up caregivers</td>
<td>15</td>
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<tr>
<td>7</td>
<td>Concerns for persons with disabilities who become parents</td>
<td>14</td>
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<td>8</td>
<td>Why caregivers have difficulty asking for help</td>
<td>13</td>
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<tr>
<td>9</td>
<td>Support for siblings of persons with disabilities</td>
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<tr>
<td>10</td>
<td>Why don’t more individuals take advantage of adult day programs?</td>
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Appendix D: Topics Themes from Pen and Paper Mode

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<tr>
<th>Support Needed by Caregivers</th>
<th>Cultural Competency</th>
<th>Services for Persons with disabilities</th>
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<tr>
<td>Navigation</td>
<td>Language</td>
<td>Employment</td>
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<td>Emotional support</td>
<td>Spirituality</td>
<td>Transition</td>
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<td>Training support</td>
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<td>Rural versus urban</td>
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<td>Future planning</td>
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<td>Housing</td>
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</table>
Appendix E: Family Support of Persons with Disabilities Across the Life Course

A special issue of the Journal of Family Social Work (JFSW)

The editor of the Journal of Family Social Work (JFSW) was excited to allow us to produce a special issue entitled, Family Support of Persons with disabilities Across the Life Course. Undergoing the journal’s peer-review process, we published the following articles in JFSW:


Appendix F: Summary of Gaps in Family Caregiving Research

The following are the caregiving research gaps that cut across life course stages identified by authors of the literature reviews, some of which were common across the different papers. These gaps helped to shape the priorities outlined in the strategic research plan.

### Non-traditional family caregivers
- Most research is on maternal or female family caregivers as they provide the majority of caregiver support. We need more research on fathers, grandparents and siblings, aunts and uncles, spouses.

### Understanding barriers to access and utilization of services
- There are disparities in who accesses and receives important family support and disability related services. Underserved populations tend to be across racial and ethnic lines, geography and socioeconomic status. Need to improve our understanding of barriers and facilitators to support services.

### Family support in diverse communities
- Need more research to understand sociocultural context of children and adults with disabilities and their families across communities of color and LGBTQ families.

### The impact of caregiving on employment of caregivers
- This includes investigating supports and policies that support working caregivers.

### The effectiveness of family support intervention across disabilities and life course
- Interventions and promising practices at the individual, family, and community levels need to be further developed and tested. Research on policies and systems of care is needed that includes the entire family rather than compartmentalize their needs into different systems.

### Positive impacts of caregiving
- Most caregiving research focuses on negative effects of providing care on the caregiver; need to look at how caregiving affects the family in positive ways and the strengths and resiliency families have.

### Need to diversify research methodologies
- Need longitudinal, qualitative, comparative, and policy related studies.
**Appendix G: Expert Panel on Family Support**

<table>
<thead>
<tr>
<th>Name, Position and Affiliation</th>
<th>Area of Expertise</th>
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</thead>
<tbody>
<tr>
<td>Randa Abdelrahim, MSc</td>
<td>Culturally diverse families of members with disabilities</td>
</tr>
<tr>
<td>Research Assistant, FSRTC</td>
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<tr>
<td>University of Illinois at Chicago</td>
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<tr>
<td>Katie Arnold, MS</td>
<td>Siblings of persons with developmental disabilities</td>
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<tr>
<td>Director, Technical Information and Dissemination, FSRTC</td>
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<tr>
<td>University of Illinois at Chicago</td>
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<tr>
<td>Concepción Barrio, PhD, LCSW</td>
<td>Research on diverse persons with serious mental illness and their families</td>
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<tr>
<td>Associate Professor, School of Social Work</td>
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<tr>
<td>University of Southern California</td>
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<tr>
<td>Hugh Berry, Ed.D.</td>
<td>Project Officer, research on persons with disabilities</td>
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<tr>
<td>Administration for Community Living (ACL)</td>
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<tr>
<td>National Institute on Disability, Independent Living and Rehabilitation Research (NIDDR)</td>
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<tr>
<td>Joe Caldwell, PhD.</td>
<td>Long-term Services and Supports Policy, family support evaluation research</td>
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<tr>
<td>Director, Long-term Services and Supports Policy, National Council on Aging</td>
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<tr>
<td>Letha Chadiha, PhD, Professor Emerita</td>
<td>Research on African American caregivers of older adults</td>
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<tr>
<td>School of Social Work</td>
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<tr>
<td>University of Michigan</td>
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<tr>
<td>Leann Smith Dewalt, PhD</td>
<td>Families of adolescents and adults with autism and developmental disabilities, intervention research.</td>
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<tr>
<td>Senior Scientist, Waisman Center</td>
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<tr>
<td>University of Wisconsin-Madison</td>
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<tr>
<td>Rick Greene, MSW</td>
<td>Caregiving research and policy</td>
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<tr>
<td>Executive Advisor</td>
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<td>National Alliance for Caregiving</td>
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<tr>
<td>Brian Grossman, MSPH, PhD</td>
<td>Research on cross state services and policies for persons with disabilities and families, aging research</td>
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<tr>
<td>Assistant Professor</td>
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<tr>
<td>University of Illinois at Chicago</td>
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<tr>
<td>Christine Grosso, MS</td>
<td>Disability policy analysis</td>
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<tr>
<td>Public Policy Analyst, Association of University Centers on Disabilities (AUCD)</td>
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<tr>
<td>Name</td>
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<tr>
<td>Tamar Heller, PhD</td>
<td>Head, Department of Disability and Human Development, Director of RRTC on DD and Health, University of Illinois at Chicago</td>
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<tr>
<td>Mercedes Hernandez, PhD, LCSW</td>
<td>Assistant Professor, School of Social Work University of Texas at Austin</td>
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<tr>
<td>Amy Hewitt, PhD</td>
<td>Senior Research Associate, Director, RRTC on Community Living University of Minnesota</td>
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<tr>
<td>Robert Hock, PhD, LMSW</td>
<td>Associate Professor, College of Social Work University of South Carolina</td>
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<tr>
<td>Jed Johnson, MSW, MBA</td>
<td>Vice President, Strategic Initiatives Easterseals</td>
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<tr>
<td>Sandy Magaña, PhD, MSW</td>
<td>Professor, Steve Hicks School of Social Work, University of Texas at Austin</td>
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<tr>
<td>Miguel Morales, MPH</td>
<td>Assistant Director of Research and Training, FSRTC, University of Illinois at Chicago</td>
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<tr>
<td>Susan Parish, MSW, PhD, Dean</td>
<td>Bouvé College of Health Sciences Northeastern University</td>
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<tr>
<td>Philip Rozario, PhD</td>
<td>Professor, College of Social Work Adelphi University</td>
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<tr>
<td>Sandra Vanegas, PhD</td>
<td>Assistant Professor, School of Social Work Texas State University</td>
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Appendix H: Family Support Research Topics List

The following are the topics that resulted from merging the FS-Need to Know Campaign with gaps defined in the literature reviews and the Qualtrics survey.

I. Individual/Family Caregiver Experiences
   1. Experiences of family caregivers from diverse ethnic backgrounds:
      a. cultural beliefs
      b. interactions with service providers and systems
      c. barriers to seeking help and obtaining information
   2. Family caregiver experiences of employment, work history, and career plan/trajectory
   3. Family caregiver experiences of family functioning and caregiving
      a. family dynamics
      b. marital quality
      c. sibling relationships (reciprocal influence)
   4. Family caregiver experiences in navigating service systems
   5. Financial impacts of family caregiving
   6. Experiences of rural caregivers
   7. Family caregiver knowledge and attitudes about future planning
   8. Experiences of sibling transition to, and acting as, primary caregivers
   9. The relationship between family caregiver satisfaction (and other outcomes) and levels of self-determination for persons with disabilities

II. Family Support Programs and Services
   1. Service providers and cultural competence, including: attitudes, barriers, and facilitators, health literacy
   2. Quality, cost, and availability of respite services
   3. Quality, cost, and availability of transition services
   4. Development of culturally appropriate services for families from previously underserved communities
   5. Development of family caregiver training programs inclusive of diverse communities:
      a. family-centered care
      b. supporting the self-determination of persons with disabilities
      c. future planning
      d. managing challenging behaviors or care needs
   6. Service and system development and/or evaluation
      a. managed care
      b. systems navigation supports

III. Policy Level
   1. Cost, benefit, and impact of family support programs:
      a. family support program type (financial compensation, tax incentives/credits)
      b. individual and societal outcomes (reduced institutional placement and hospitalization, improved health/wellbeing of persons with disabilities, improved health/wellbeing of caregivers)
## Appendix I: State of the Science in Family Support Research

<table>
<thead>
<tr>
<th>Name, Position and Affiliation</th>
<th>Name, Position and Affiliation</th>
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<tbody>
<tr>
<td>Hebatallah Naim Ali, MD, MS/HPM Research Assistant Lurie Institute for Disability Policy Brandeis University</td>
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<td>Concepción Barrio, PhD, LCSW Associate Professor, School of Social Work University of Southern California</td>
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<td>Mercedes Hernandez, PhD, LCSW Assistant Professor, School of Social Work University of Texas at Austin</td>
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<tr>
<td>David Horton, MSSW, LMFT-A Board Member Sibling Leadership Network</td>
<td>Marji Erickson Warfield, PhD Senior Scientist and Lecturer, The Heller School for Social Policy and Management, Brandeis University</td>
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<tr>
<td>Sandy Magaña, PhD, MSW Professor, Steve Hicks School of Social Work, University of Texas at Austin</td>
<td>Ellen Mahoney, PhD, RN, FGSA Department Chair, Associate Professor, Connell School of Nursing, Boston College</td>
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<tr>
<td>Kevin Mahoney, PhD Professor Emeritus, Director, National Resource Center for Participant-Directed Services School of Social Work, Boston College</td>
<td>Miguel Morales, MPH Assistant Director of Research and Training, FSRTC, University of Illinois at Chicago</td>
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<tr>
<td>Sumithra Murthy, MBBS, MPH Department of Disability and Human Development, University of Illinois at Chicago</td>
<td>Randall Owen, PhD Associate Director, Institute on Disability and Human Development, Clinical Assistant Professor, Department of Disability and Human Development, University of Illinois at Chicago</td>
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<tr>
<td>Nelsinia Ramos, B.A. Wisconsin Family Assistance Center for Education, Training &amp; Support (WI FACETS)</td>
<td>Jenny Sladen, MS Director, National Initiatives The Arc of United States</td>
</tr>
<tr>
<td>Sandra Vanegas, PhD Assistant Professor, School of Social Work Texas State University</td>
<td>Grace Whiting, J.D. President and Chief Executive Officer National Alliance for Caregiving</td>
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<td>Yue Xu, MSW Research Assistant, FSRTC Department of Disability and Human Development, University of Illinois at Chicago</td>
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