



What Family Caregivers Need: Findings from Listening Sessions

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Summary

This report¹ is one of two components of the RAISE Family Caregivers Act specifically designed to provide multiple forums for family caregivers to express their needs and challenges and to identify the specific services, supports or policy initiatives that can best address those needs. One mechanism for obtaining input was a Request for Information (RFI) published in the Federal Register (Vol. 84. No. 236) on December 9, 2019, asking family caregivers and the organizations that support them to share thoughts and concerns. More than 1,600 responses were received and analyzed. These findings have been published in a report released February 16, 2021. The listening sessions provided an opportunity to delve more deeply into issues raised in the Request for Information (RFI) analysis.

Overview

Using insights from the RFI analysis, the team developed a research strategy and corresponding discussion guides for the groups. Listening Sessions were conducted separately with:

- Parents caring for a child with a disability or special needs; and
- Caregiver in any other situation

The sessions were conducted on a virtual Zoom platform. Participants were recruited using a screening tool developed by the team. Recruitment and the technology platform for these sessions was conducted with the support of a qualitative research vendor, Focus Pointe Global (now Schlesinger Group).

The sessions were each 60-minutes and followed a prepared Discussion Guide, one specific to the parent caregiver group and another version for other types of caregivers. Additionally, groups were divided roughly evenly by topic. Half the groups focused on a discussion of services and supports; the other half focused on issues of workplace accommodations and financial well-being. The specific domains within each of these broad categories are shown in Figure 1 below.

Areas of Inquiry for Caregiver Solutions

Caregiver Services and Supports	Financial Well-Being
Respite Care	Workplace Positions
Adult Day Care	Tax Incentives
Information & Referral	Retirement Support
Caregiver Training/ Education	Direct Pay Support
Care Transitions	Technology

Additional focus groups with specific types of caregivers were facilitated in partnership with the following organizations and were conducted by the researchers using their own Zoom platform:

- **Latinx Caregivers.** BakerRipley, a nonprofit service provider that offers support services to older adults, recruited participants for a focus group of Latinx caregivers. The groups were conducted in Spanish and included caregivers that speak only Spanish and those that speak English and Spanish;
- **Teen Caregivers.** The American Association for Youth Caregiving (AAYC) recruited teen caregivers, ages 13 to 18, for a session specific to that unique caregiver segment; and
- **Grandparent/Kinship Caregivers.** Generations United (GU) convened participants for a listening session with grandparent and kinship caregivers to discuss the unique issues they encounter.

Participant Characteristics

A total of 80 individuals participated in the listening sessions. With the exception of the teen caregiver group, participants ranged in age from 28 to 77 years old. Each group was recruited to represent diversity in terms of demographics and their situations as caregivers. Each group had a mix of respondents in terms of marital status, gender, education and income, race/ethnicity, and other demographic characteristics. Also, participants represented a variety of caregiver situations. The groups included adults caring for a parent or grandparent, a spouse, a sibling or other individual. There were situations in which the caregiver and care recipient shared a household and in some cases where the caregiver was living separately or even more remotely.

The detailed session summaries offer additional information about the session participants.

Major Findings

Overall, caregivers' highest priority concerns included the following domains:

- Caregiving education and training
- Respite care; and
- A range of financial considerations including:
 - Having workplace flexibility
 - Direct pay for being a caregiver and
 - Changes in tax policy to benefit caregivers.

Other priority solutions had to do with improved access to information and referral services and getting help with care coordination and care transitions.

Diving deeper into each of these topics, caregivers expressed the need for training and education to support both the medical aspects of caregiving, and the behavioral challenges they encounter in providing everyday care and support, especially when caring for a loved one with Alzheimer's Disease and related dementias.



Caregiver Training

Other priority solutions had to do with improved access to information and referral services and getting help with care coordination and care transitions.

Diving deeper into each of these topics, caregivers expressed the need for training and education to support both the medical aspects of caregiving, and the behavioral challenges they encounter in providing everyday care and support, especially when caring for a loved one with Alzheimer's Disease and related dementias.

“Caregiver training is a service that’s needed that you don’t know that you need.”

“She had a serious infection. I had to be trained to deal with her PICC line. I got 15 minutes of training. That was really uncomfortable. It would have been nice to have more training before I did that.”

“When your mom starts balking at taking these different medications, how can you explain this to her?”



“It’s kind of like going to a battlefield in war. You learn as you go. There’s no training program.”

“He went from able-bodied to ‘can’t do anything.’ I didn’t know how to handle that. That was really hard. I definitely would have benefitted from a checklist of strategies.”

Respite Care

The dilemma regarding respite care was that, even though the need for it was very keenly felt by caregivers in all situations, participants worried both about finding qualified caregivers and being able to afford respite care. Across all groups, there was a general sense that “No one can do the caregiving job as well as I do it.”

“For me, it’s truly just the break from everything....resources that could come in to take some of the burden off.”



“I know it’s hard to find. It’s like interviewing a caregiver, but it’s harder because you can’t promise them regular hours, but you need someone who meshes with your child. It is so hard to get and so needed.”

“I definitely think it’s an important service...It doesn’t have to be a lot of time, just time to get a shower, to go do something that you wouldn’t normally be doing.”

“I love the concept of respite care but....I get afraid of the notion just because we don’t really know what’s happening when we’re not there.”

Information and Referral

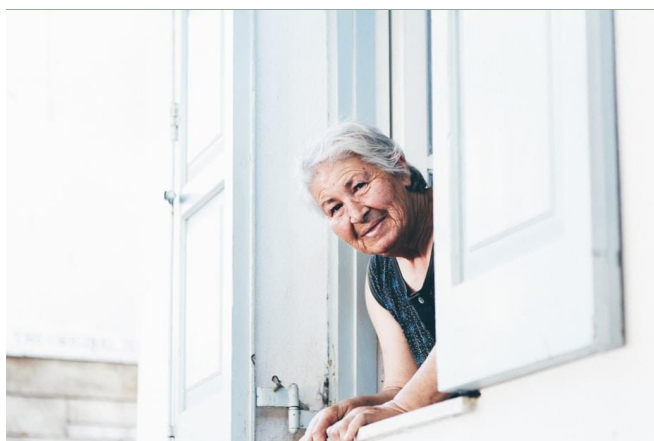
Caregivers want help understanding how to meet care needs as they change over time and as life circumstances change. Help with care transitions is especially acute for parent caregivers; while they feel well-supported within the school system, once their child transitions out, they feel at a loss.

While caregivers are eager to find resources that can offer referrals to services and providers to meet their needs, they worry about whether agencies are being totally transparent about those referrals. For example, they wondered whether agencies are making referrals based on their own self-interest or based just on what's convenient for them. They also worry about whether the referrals are truly person-centered.

“I don't really have full confidence with the resources that are offered -- there is not really much alternative to pick from.”

“I definitely think it's an important service...It doesn't have to be a lot of time, just time to get a shower, to go do something that you wouldn't normally be doing.”

“A lot of the referrals you get are to their own affiliated places. You really want someone who's unbiased caring about the person.”



Financial Impacts of Caregiving

Some of the most compelling conversations during the listening sessions focused on the financial impacts of caregiving. Participants talked about the struggles of managing with limited finances both because of the inability to continue working while caregiving and from the out of pocket costs not covered by insurance. One way or another – retirement accounts were also impacted. Some caregivers had to take early withdrawals on funds from their 401k in order to pay care-related expenses. Others acknowledged that being out of the workforce meant they would have earned more limited benefits for their own retirement.

“Financial is one of our... biggest issues with all of this.”

“I had not planned to use my 401(k) until I was 72....I had no one else that would care for [mom]. I had to tap into my 401(k)...That has been a critical impact financially.”

“I looked at my last 15 years of Social Security benefits....it’s sad because I got zero for several years. What am I going to do...when I’m 62?”



“If you have a lot of money, then you can afford the care. If you’re lower income, you get assistance. But everybody else somewhere in the middle – there seems to be quite a gap. It’s...sad to lose everything you own because the care is so expensive.”

“The financial responsibility that comes with having a child with needs for us has been very large.”

Several possible solutions were presented for discussion. Caregivers responded favorably to all of them. Many expressed the need for greater flexibility in the use of workplace leave and time off policies and having employers offer flexible work schedules or work from home options. (The “COVID-19 stay home” orders in place at the time of the focus groups helped those caregivers who did not normally have a work-from-home option.) For those employers who have FMLA, participants wanted to see an easier process for approval and an expansion of the qualifying categories. While participants were unsure how to structure tax incentives and whether there currently were tax advantages for caregivers, they thought this would be an idea worth pursuing. Some caregivers, especially those that had left the workforce because of caregiver responsibilities, liked the notion of building up credits toward Social Security for caregiving hours.

There was enthusiasm within each group for direct pay for caregiving work. Some of the caregivers were participating in their state Medicaid program that pays family caregivers. Others in the group were very interested and receptive to this idea. There were only a few participants who felt it would be inappropriate or uncomfortable for them to be paid for their role as a caregiver.

Group Differences. While there were many similarities across all the groups, some differences did emerge. Parent caregivers expressed a more pressing need for caregiver training that would address the broad spectrum of medical, behavioral and other needs their children face. The financial and workplace accommodations were also a higher priority for parent caregivers who are facing a life-long caregiving situation and thus a life-long financial challenge as well. The more complex care needs their children typically have also seem to make it harder for them to find respite care or extended family willing and able to help out. Because of these challenges, there was also greater interest in direct pay for caregiving among parent caregivers. And of course, help with planning for the future for their children is a worry that these parents have.

In contrast, those caregiving for other aging or disabled adults put higher priority on respite care, tax incentives and retirement security. Some of them (especially those caring for parents) felt an obligation to provide care and did not like the idea of being paid to be a caregiver.

Special Population Listening Sessions. The group with teen caregivers – ages 13 to 17 – was quite moving. While it was difficult to get them to open up at first, when they did, they talked both about the pride they take in protecting and supporting their loved one, along with the incredible stress and anxiety of being a teen caregiver. They identified the need for emotional support, peer group counseling, extra help and flexibility with school assignments, caregiver training and help learning how to manage their anger and stress.

Within the Latinx caregiver group, the most obvious difference cited was the need for language-specific and culturally appropriate programs and materials, especially when it comes to information, referral and caregiver training. The group also talked about the different cultural attitudes about “taking care of family.”

It is often taken as a given that their role will include being a caregiver when the need arises, although participants talked about emerging push back against this expectation. Another difference mentioned was the stigma around disease in the Latinx community. This can lead to isolation for the caregiver in some situations – e.g., caring for someone with Alzheimer’s Disease and related dementias.

The needs of grandparents and kinship caregivers were also quite unique. Their top priority was on legal and financial issues. Yet, they were reluctant to ask for help out of fear that their ability to care for the children might be called into question. Their needs focused on:

- Financial and legal assistance
- Information and education
- Peer support and opportunities to interact with others in the same situation
- Respite care
- And of course, future planning was seen as critical to the safety of the children for whom they are caring

Impact of COVID-19 Pandemic. While we conducted these sessions during “stay home orders” for the most part, we didn’t want COVID to “distort” the listening sessions. We wanted to know about caregivers’ priorities under “normal” circumstances. But we did also talk about the impact that the pandemic is having on their caregiver challenges. We asked them to identify whatever additional challenges or advantages they might be experiencing because of the many changes brought on by the pandemic.

On the positive side, the ability to work from home and to have more time with other family members was the primary advantage caregivers mentioned. The expanded availability of delivery services for food, meals, and other goods was another plus to caregivers that often find it challenging to find time to run even simple errands.

There were more challenges to face, however. Obviously, the financial impact of losing a job or being on furlough was at the top of the list. Also mentioned was the disruption of care relationships – day services being closed or in-home care workers no longer able to safely come into the home. The burden on caregivers of also having to take on the role of “teachers” to their children doing remote learning was also mentioned. And for children with special needs and disabilities, the additional screen time of trying to do either therapy or socialization virtually was often problematic.

Conclusion

In addition to this overview, we have prepared a summary of each listening session. Additional caregiver quotes and the unique themes that emerged during those sessions are provided within those summaries.

We are grateful to the family caregivers who gave so generously of their time and their stories to help illuminate for us the challenges they face. They thoughtfully engaged in these sessions to creatively identify priorities and solutions that would help address their needs.

About This Project

To better support family caregivers, Congress passed the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act in 2018, which established the Family Caregiving Advisory Council tasked with creating the country's first national Family Caregiver Strategy.

To support the council's work, NASHP has created the RAISE Act Family Caregiver Resource and Dissemination Center in collaboration with the U.S. Administration for Community Living with support from The John A. Hartford Foundation to:

- Develop family caregiving resources for state and federal policymakers and other stakeholders;
- Provide support to the council and its subcommittee member as they craft policy recommendations;
- Convene experts and thought leaders to provide perspectives and expertise to the council; and
- Support states as they develop policies to address family caregiver issues.

Acknowledgements

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Notes

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	Session Date	Group Type	Topic
Phase I	May 28	Parent caring for disabled/special needs child	LTSS & Financial, Workplace Issues
	June 1	Parent caring for disabled/special needs child	LTSS & Financial, Workplace Issues
	June 2	Other Caregiver Situations	LTSS & Financial, Workplace Issues
	June 3	Other Caregiver Situations	LTSS & Financial, Workplace Issues
Phase II	July 28	Caregiver for aging/disabled adult relative	Financial/Workplace Issues
	July 29	Caregiver for aging/disabled adult relative	LTSS Issues
	July 30*	Parent caring for disabled/special needs child	Financial/Workplace Issues
	Aug 4	Caregiver for aging/disabled adult relative	LTSS Issues
	Aug 5	Parent caring for disabled/special needs child	Financial/workplace Issues
	Aug 6	Parent caring for disabled/special needs child	LTSS Issues
Special Interest Groups	Aug 11	Spanish-only and Spanish/English Caregivers	LTSS & Financial, Workplace Issues as modified to be applicable to group
	Aug 24	Teen Caregivers	Specific issues tailored to the groups' needs
	Sept 24	Grandparent Caregivers	Specific issues tailored to the groups' needs

* Technical difficulties in capturing transcript

Parents caring for young or adult children with disabilities

Overview: Phase I focus groups covered both LTSS and finance and workplace issues and included family caregivers of adults with support needs.

Participant Profile: The group was balanced with respect to demographics and caregiver situation. This group was, by design, more oriented toward individuals with higher levels of education and/or income. There were four (4) females and two (2) males. The group was also diverse with regard to racial and ethnic identity. Only one participant was working full-time and all of them had other children under age 18 at home. Participant ages ranged from 35 to 54.

With respect to their situation as caregivers, participants reported the following:

- 6-year-old daughter with epilepsy, hydrocephalus, and other delays
- 15-year-old son with autism (one of triplets), also has 17-year-old
- Son with cystic fibrosis and three other children
- 8-year-old boy with cerebral palsy, hypotonia and right arm integration
- 4-year-old son with autism
- 2-year-old son with numerous developmental delays

Priority Concerns: Based on the closed-category question from the RFI, participants were asked to identify their most important concern from that list: (1) caregiver training; (2) care coordination; (3) day services and programs; (4) direct pay to caregivers; (5) information, education and referral; (6) respite care; (7) technology solutions; (8) tax incentives; and (9) workplace accommodations. Of these, the following emerged as most important:

TAX INCENTIVES AND DIRECT PAY FOR CAREGIVERS

“Something needs to happen to recognize that, as a full-time caregiver to my son, I am working . . . in fact . . . harder than I’ve ever worked in my life.”

“Financial is one of our biggest issues with all of this. The financial responsibility that comes with having a child with needs for us has been very large.”

CAREGIVER TRAINING

“My son is autistic . . . I didn’t even know what it meant when he was diagnosed . . . if someone could have explained to me how I would have been able to help him in the beginning.”

“Nobody ever taught me how to do the medical portion of taking care of my son . . . It can be scary. I wish someone like a nurse . . . could have spent more time teaching me how to use his medical equipment.”

RESPITE CARE CONCERNS

“We don’t have family here . . . I’m 99.9% of the time taking care of his needs . . . so it’s not really possible to ask for too much help. So, it’d be nice to have respite once in a while.”

Participants were asked to discuss the specific services, supports, financial and workplace considerations important to them. Some expressed worry about being inadequately trained for the medical aspects of caregiving (administering a PICC line, for example), providing everyday support, and managing agitation and anxiety. Care coordination concerns also emerged, especially when care needs change and when families relocate (for their jobs). Several expressed concern about the specific service referrals they are given by the hospital, aging services network, or other source. They whether the referrals to service providers were made out of convenience or self-interest, rather than due to a full consideration of a child's unique needs. Overall, parents want more transparency and confidence in the information and referral services they receive.

Financial Well-Being and Workplace Accommodations. While respondents expressed concerns with information, education and care coordination, financial considerations and workplace accommodations were cited as more pressing. Specifically, FMLA and one's ability to use PTO are not sufficient in their current forms. Without additional consideration for a child with a disability, the group felt it was unlikely that both parents would be able to work, further exacerbating a difficult financial situation. There were strong voices in support of direct pay to caregivers, tax incentives, additional financial support for home modification or medical expenses, medication, and the like. This group was less supportive of having caregiving hours count toward Social Security, a trend that emerged in subsequent groups with younger participants.

"Having sick [time] that counts for both self and family members . . ."

"Something needs to happen to recognize that, as a full-time caregiver to my son, I am working harder than I've ever worked in my life. What financial compensation can be matched to that?"

"Even something similar to what they just put out for COVID [would help]. Being in a job that doesn't count having a kid sick as PTO or sick leave; it has to be taken as vacation days."

"Tax incentives – you'd be able to see it every year vs. retirement something you can't see for another . . . many years."

COVID-19. The session closed with a discussion of how the COVID-19 pandemic is impacting the already fragile balance of caregiving. COVID-19 offered some opportunity for more family time than usual; siblings usually out at activities were able to spend time with the child with the disability and expanded work from home for a spouse meant both parents could help out. On the other hand, the change in routine and isolation from friends and regular caregivers brought additional challenges. Parents also felt that most of the therapy and educational work their children were receiving could not translate to a virtual platform, nor did the parents have the skillset needed to take the tasks on themselves. Tele-help options with teachers and therapists were sorely lacking.

Surprises. One unanticipated finding was the extent of agreement on interest in pay for direct care and other types of financial solutions. Also, there seemed to be little awareness or use of respite, along with some concern that no one else can be a good enough care substitute, despite the fact that caregiver burnout was definitely present. In fact, the focus group participation was seen as a great excuse to have an hour away from those responsibilities; and the group seemed to bond over their shared experiences and worries.

Parents caring for young or adult children with disabilities

Overview: Phase I focus groups covered both LTSS and finance and workplace issues and included family caregivers of adults with support needs.

Participant Profile: The group was balanced with respect to demographics and caregiver situation. This group was, by design, oriented toward individuals with lower levels of education and/or income. Four (4) females and two (2) males participated in the group, ranging in age from 28 to 71. The group was also diverse with regard to racial and ethnic identity. In contrast to the higher income group, four (4) participants in this group were working full-time.

With respect to their situation as caregivers, participants reported the following:

- 28-year-old caring for her 21-year-old sister with severe autism (no other family caregivers)
- Recent widow taking care of 40-year old non-verbal son with cerebral palsy, seizures and other disabilities
- Teenage son with bipolar schizophrenia
- 9-year-old son who is Type 1 diabetic (also caring for 88-year-old mom living in the household)
- Two nephews with severe autism; and another participant with a young son with cerebral palsy

Priority Concerns: Participants cited their top concern from the closed-category RFI list. Two participant cited Direct Pay to Caregivers. The top votes went to: Care Coordination; Day Services; Respite Care and Tax Incentives. While participants acknowledge the value of respite care, they also expressed concern about the quality of care provided in their absence.

RESPITE CARE CONCERNS

“I think it is important as caregivers to also try and get away from a little bit of the chaos. Being able to have a little bit of personal time to yourself.”

“You can’t relax if you don’t know that somebody isn’t being looked after properly. It’s not respite. It’s not time off.”

“I love the concept of respite care, but I think personally I do get afraid of the notion just because we don’t really know what’s happening when we’re not there.”



Participants discussed further the specific LTSS that are important to them. Some expressed concern that the amount caregivers are paid makes it harder to find quality caregivers for reliable and sustainable respite or for other supportive care for their loved one. As in the first group, they questioned the adequacy and transparency of service referrals. Care coordination and the challenge of “finding what’s out there” to meet care needs was also mentioned as a significant challenge. The participant with the 40-year old son raised the issue of “future planning” -- help in planning for the future, especially with ensuring that her son is safe and cared for when she is no longer around. Others acknowledged that concern but saw it as an overwhelming issue that they didn’t have the luxury to even consider as they deal with day-to-day challenges. Finally, respondents spoke about the “red tape” they confront as they go through the process of getting a diagnosis or doing paperwork to apply for programs and services in a network that seems disjointed and repetitive. They cited the frustration of “re-going through all these hoops” to get services.

“The higher the pay, the higher the quality, the more the respect.”

“Pay these people what they’re worth because they keep your individual with you. You don’t have to institutionalize them . . . if they are as good as the young lady who works for me.”

“The programs are out there, but you have to know how to get them.”

“I don’t really have that full confidence and with the resources that are offered there is not really much alternative to really pick from.”

Financial Well-Being and Workplace Considerations. There was a robust discussion of workplace accommodations and financial well-being. Four of the participants are juggling full-time work with their caregiving responsibilities. Respondents expressed interest in more flexibility at the workplace, such as the ability to earn time off specifically for family caregiving in addition to current provisions for earning leave, with a broader definition of the type of dependent that can qualify for family caregiver time off or FMLA. A few participants liked the idea of caregiver working hours counting toward Social Security.

“The last thing you want to be worrying about is money.”

“I’m not . . . making enough to sustain taking care of two people, especially . . . having to pay for outside help because I have to work so much to just to make as much money as I can to take care of both of us.”

“Just any amount, any additional amount going toward Social Security would be a great benefit . . . I’m not close to retiring, but I wouldn’t mind adding hours toward Social Security.”

“I don’t know if there is a way to create another program that is very paralleled to family medical leave, but it applies to these dependents that you have to care for.”

“I said tax incentives, whether it is direct payment upfront or through a tax incentive. Just the cost of medication is significant . . . insurance only covers a portion of it. “

Family Caregivers for Adult Loved Ones

Overview: Phase I focus groups covered both LTSS and finance and workplace issues and included family caregivers of adults with support needs.

Participant Profile: The group was balanced with respect to demographics and caregiver situation. This group was, by design, oriented toward individuals with higher levels of education and/or income, with three (3) females and three (3) males, ranging in age from 39 to 64.

Priority Concerns: Based on the closed-category question from the RFI, participants were to identify which was most important to them or which would have been most helpful to them as caregivers. Respite care received a lot of interest, along with some interest in financial incentives and workplace accommodations and day care. The need for financial support for the out-of-pocket expenses families are paying for medications, therapy, transportation, doctor visits and more also emerged.

“I don’t work. I pay for all my mother-in-law’s [care costs.]. She gets a very small Social Security check that won’t cover any of that. It would be nice if I could go ahead and tell the government that this isn’t enough for her.”

“Mine [priority] was respite care, it’s truly just the break from everything. I have other family members that don’t participate as much as I do. Resources that could come in to take some of the burden off . . . that was number one for me.”

“Someone to come in where the government would offset the cost of this person coming in and helping provide care. That would be a big plus.”

LTSS Concerns. Participants were asked to discuss the specific LTSS considerations important to them. Care coordination was the first topic to get the conversation started. Others talked about having help in the home so they could run errands for their loved one or having help with transportation to medical appointments. Specifically, finding transportation help specific to the special needs of someone who is frail or has mobility limitations was mentioned. Caregiver training also emerged as an important need, with an emphasis within this group on how to deal with emotional or behavioral issues. The concept of a caregiver assessment -- having a way of systematically determining where they as caregivers might need support -- was a novel concept, but well received. Regarding their own emotional needs, some participants talked about wanting help learning to meditate, learning how to avoid stress eating and other types of emotional or mental health support, so that they can become better caregivers.

Caregiver Training: “I need training on how to emotionally deal with my mom. “

Care Coordination: “. . . to be able to set up a schedule so that you’re really getting the most out of your day. Like things that should have been taken care of because it wasn’t organized. So, I would like to see something of that nature coming in to help organize the day.”

Transportation: “I would love some service . . . that has people that could handle her properly and get us to the doctor. I have a really tough time. This is just the biggest stress for me.”

“I started stress eating and . . . gaining a lot of weight. And I can’t leave the house to go out and exercise because she’s with us.”

Caregiver Needs Assessment: “A needs assessment would give me new information and resources. That would be great. I think that would be really helpful.”

Financial and Workplace Considerations. Some participants found they were unable to use FMLA at work because they were caring for a grandparent rather than a closer family member. Others found they needed to use vacation time or paid time off. Most group participants were working full-time and juggling work from home or taking whatever time off they could manage. One individual working for the State had good workplace protections and the ability to work from home. Participants liked the idea of tax incentives for being a caregiver, while those who had been out of work for some time liked the idea of having caregiving hours count toward Social Security. One person in the group was already being paid as a caregiver under California’s IHSS program; one or two others felt that direct pay for caregiving was a reasonable idea.

“They don’t give any FMLA for a grandmother. You won’t get any pay unless you have vacation time or PTO.”

“I said that would be a good idea to count the caregiving hours, because I’m out of work now 15 years. If those hours would’ve counted, I’d probably be fully vested.”

“I work for the state of California, so I have great benefits. And I’m an employment attorney. I work for the agency that enforces them.”

“I think if they would give a tax credit, that would probably be the best way to do it . . .”

What’s Most Important. In closing, participants were asked to identify the caregiver supports that are most important to them. Many participants cited caregiver training as a top interest. Others mentioned technology such as smartphones, sensors and easy to use remotes that could be helpful.

“If somebody could come to the house and could show us what we should be doing.”

“We should focus on the training, make it easier, even online training where we can watch videos just to help with the day to day activities. “

“Instead of trying to do this all by myself, there are probably awesome programs in California that I have no clue exist. If there was just an expert that I could talk to . . . I think that would be more helpful for me.”

“I would think education, if there was a one stop resource center that could cover of these bases.”

Family Caregivers for Adult Loved Ones

Overview: The Phase I focus groups covered both LTSS and finance and workplace issues. Participants cared for adults of various ages.

Participant Profile: The group was balanced with respect to demographics and caregiver situation. This group was, by design, oriented toward individuals with lower levels of education and/or income, with two (2) females and four (4) males ranging in age from 38 to 61.

Priority Concerns: Based on the closed-category question from the RFI, participants were to identify which was most important to them as caregivers. The challenge of juggling work and family caregiving and workplace accommodations were mentioned as highest priorities. Day services, caregiver training, care coordination, and help with care transitions were also cited as priorities.

“The biggest challenge for me is juggling work and taking care of my family members.”

“I think one of the biggest obstacles I had was probably the care coordination and the care transitions. You tend to be in a round robin situation where you’re calling someone and leaving a message.

Then they call you, you . . . miss their call, then you leave them a message, and then you don’t hear back from them . . .”

LTSS Concerns. Participants were asked to describe further the specific services, supports, financial and workplace considerations important to them. They mentioned a need for respite, but some commented that their care recipient was not always open to changes in where and how they would be receiving care, even on a temporary basis. Others expressed concern over being able to find a good source of respite. Participants also mentioned the challenges of finding information about services and supports, as well as the challenges of trying to coordinate and arrange for services. As in other groups, participants voiced concerns with the transparency of information and referral services – whether the information was appropriate and unbiased. Few families mentioned on-going support from a health care professional who helped them to “navigate” the system. Once the care recipient received a diagnosis, participants said they felt pretty much on their own. Others spoke about not feeling adequately trained to provide the medically – or behaviorally – related care and support that their loved one needed. Those that were aware of day services programs felt that, as care needs advanced, the programs were not equipped to deal with those needs.

Information and Referral: “Education on what’s out there, what works for some people, what doesn’t work for others.”

“A lot of referrals you get are to their own affiliated places that they try to point you to . . . You really want to have someone who’s unbiased.”

Day Services: “The toughest thing about the day service is . . . they’re not one on one. As he progressed, he needed one-on-one care.... Some places, sometimes they just don’t accept advanced cases.”

Respite Care: “Respite care would be really helpful. Coming home and then having to take care of family – it’s draining.”

Caregiver Training: “She had a very serious infection. I had to be trained how to deal with her PICC line . . . I got about 15 minutes of training and that was really uncomfortable. It would have been nice to have a little more training before I did that.”

Financial and Workplace Considerations. Each participant had a different workplace situation, each with its pros and cons. Those fortunate enough to have a flexible employer were able to adjust their work schedule to part-time or to a position with little or no work travel. Some were able to work from home. But many of these changes involved loss of income. Those sharing the caregiving burden with other family members were better able to balance work and caregiving than those without family members who would or could pitch in.

“If you have a lot of money, then you can afford the care. If you’re lower income, you get assistance. But everybody else somewhere in the middle, there seems to be quite a gap. It’s kind of sad to lose everything you own because the care is so expensive.”

“Even though you’re taking care of somebody, you still need to be able to support yourself. There are laws in place, like FMLA, but it only goes so far, and you still need health insurance for yourself and still some kind of income coming in.”

“It does take a financial toll . . . Even though I was making some money, I was still losing three days’ a week, basically. It does build up.”

Participants expressed interest in tax incentives and credits toward Social Security, in order to help with the financial impact of caregiving, including both direct costs and income lost due to workplace accommodations. There were mixed views on being paid directly to provide care for their loved one, with only one or two participants expressing interest in that. Finally, there was also interest in financial support to help with out of pocket expenditures for certain types of home modifications and technologies that could be helpful for caregiving.

“I think direct pay support probably would be most helpful for me.”

“I’ve never really thought of the whole idea . . . to be paid to take care of my parents. I think honestly that’s just something that it’s my responsibility. They took care of me; I’m going to take care of them. What would be nice is maybe some tax incentives or caregiving hours for Social Security.”

“You’re not going to buy something for your parent to make things better for them and expect them to pay for it. Over time, it really does add up. One of the biggest expenses was having their bathroom converted so he could have a walk-in shower.”

“If you’re looking for some sort of financial incentive, for me, I support getting the credit hours toward Social Security.”

“If your family member has a diagnosis and you’re taking care of them, definitely, I think it would be great to have tax incentives.”

End of life and hospice care issues emerged in this group. For participants who had experienced the loss of a loved one, the experience of hospice was very positive, but much too limited -- mostly because they lacked the information they needed to put hospice care in place at an early stage. Many of them just didn’t know about it or exhibited a poor understanding of it.

“We keep getting warned that if you call hospice too soon, they only give you the three months and then you’re cut off . . . and it’s hard to get them back out. “

“By the time I got her on hospice, she was on it half a day. I just wished it would have been known about a long time before that . . .”

Family Caregivers for Adult Loved Ones – Financial/Workplace Considerations

Overview: In the Phase II listening sessions, we divided sessions into those focused on either financial/workplace concerns or LTSS concerns, allowing for deeper discussions of each of these topics.

Participant Profile: The group was balanced with respect to demographics, including four (4) females and two (2) males, ages 41 through 70. The racial and ethnic identities of participants were diverse. Two (2) participants live in the same household as the individual for whom they are caregiving, while others are within an hour’s drive.

Opening Comments: The session started by asking participants to describe (without prompts) how caregiving has affected their sense of financial security, including what they saw as the biggest financial impact. The bottom line for all was concerns about a less certain financial future for themselves and their families as two participants said they needed to tap into their 401(k) early, which proved a financial hardship. Others talked about financial losses from cutting back at work to provide care, both directly as a result of lost wages and indirectly through lost years of contributing to social security.

“I had not planned to use my 401(k) until I was 72 . . . I had no one else that would care for [mom] – just me. I had to tap into my 401(k) for survival reasons. That has been a critical impact, financially.”

“We have a small family. I had to go part-time to help out. It takes a lot of a toll. It’s financial . . . You love your loved ones and you want to take care of them...but it takes a lot.”

“The last seven years were the ones that were the most difficult. I could keep a part time job before that, but now I have blank [referring to loss of contribution to Social Security earnings].”

Participants were asked to elaborate on each of the financial and workplace issues identified in the RFI analysis.

- **Workplace Accommodations.** Some participants felt that the caregiving and career was an “either/or” situation because it was very difficult to do both. They noted that FMLA doesn’t go far enough because it is time-limited and does not provide paid leave, making it unaffordable for many. While work at home provides great flexibility, it comes at the cost of a 24-hour workday, combining career and caregiving. One participant suggested employers provide adult day care at work. Another mentioned that some types of jobs (e.g., restaurant manager) don’t lend themselves to any type of “work from home” or other flexible arrangements.
- **Tax Incentives.** Overall, the idea of tax deductions or credits was well received. Some felt it was appropriate both because of the monetary value attached to the hours spent in caregiving and the additional expenses incurred as a result.

“Some kind of tax incentives would be better than nothing at all, especially since we are adjusting our incomes by caregiving.”

“Every day personal needs and things . . . should be able to be deducted . . . Those things are very expensive. Depends are very expensive!”

- **Direct pay support.** A few participants had this option available in their state but opted out of it because they did not want to deplete the finances/pension of their loved one in order to qualify. Another objection to direct pay was from a participant who preferred using her income from work to finance paid care, since this arrangement provided her with some time off (respite) from the constant demands of unpaid family caregiving. Others saw interest in the concept.
- **Technology.** Participants also liked the notion of receiving support from various technologies that could help their loved ones. Items mentioned included LifeAlert devices, in-home cameras and monitors, and devices to detect and prevent wandering.

“I could have gotten paid for taking care of him. However, he would have given up more than I would have gained.”

“I think direct pay support is more valuable than a tax incentive because to take advantage of a tax incentive, you have to have income; some people don't have enough to take tax write-offs. Direct pay support would be more valuable to all of us.”

Social Security Retirement Credits. This concept met with interest-- not surprising given that group participants had tapped into their 401(k) and lost years of work (and contributions to Social Security), due to time out of the workplace providing care. One participant mentioned allowing tax-free (penalty free) withdrawals from the 401(k) when the money is used to support caregiving.

“I looked at my last 15 years of social security benefits. And it's sad because I got zero for several years. Not going to benefit me when I'm 62. What am I going to do?”

“One other idea . . . For those who have to take money out of their 401(k), sometimes that creates a taxable event; they could prevent taxes on withdrawals if they're used for caregiving.”

Most Important. In closing, participants were asked for their priorities among these options. Direct pay for caregivers received two votes, caregiving hours counting toward social security received three votes, and workplace protections received one.

Family Caregivers for Adult Loved Ones – LTSS Concerns

Overview: Phase II listening sessions were divided into those focused on either financial/workplace concerns or on LTSS concerns, giving more depth of discussion to each of the topics explored in phase I.

Participant Profile: The group was balanced with respect to demographics, including three (3) females and three (3) males, aged 26 through 62. The group was also racially and ethnically diverse. Four (4) participants lived in the same household as the person for whom they are caregiving, while the others are within an hour’s drive.

Opening Comments: The session started by asking participants how caregiving has affected them overall, and to identify what types of services and supports, if any, they found most helpful. In response, some mentioned getting in-home care to manage the more medical aspects of caregiving or to train them in how to handle those tasks. Another mentioned having a specialized transportation service to take her mom to appointments so that she didn’t have to take the entire day off work for an hour-long doctor appointment.

Participants were asked to respond to each of the LTSS considerations identified in the RFI analysis.

Respite Care. Many participants in this group shared caregiving responsibilities with other family members and therefore did not feel the need for respite care. Some were not entirely familiar with the resource; one only heard about it when their loved one was in hospice. Others found it helpful or felt it would have been if they had known about it.

“Just having someone there when someone gets to that place where they can’t be left alone.... I would definitely think that would be a benefit to anyone.”

“They offered to have someone here at night so I could sleep. Oh my God, I needed that.”

Adult Day Services. Some participants knew of the service and used it pre-COVID, but most did not feel it fit their needs, either because they had other family to help or because they were available to provide care at home. Some caregivers seemed reluctant to give themselves the time off that daycare would provide unless they had a compelling reason (e.g., full-time work). Taking care of oneself or using it as “respite” was not seen as a priority.

Information and Referral. Caregivers dealing with more medical care needs felt confident in the information they were able to receive from their loved one’s medical provider, for the most part. Some did express frustration with lack of coordination when multiple caregivers were involved.

“You just feel like you’re getting pushed from one place to another . . . in the circle of the health care system.”

“[Her doctor] was very on top of the situation and that made an already stressful . . . experience better on all of us.”

“. . . it was stage two dementia . . . she was even forgetting how to talk, so it was pretty important that the doctor went over all the information.”

Caregiver Training. Participants had diverse experiences with caregiver training. Some mentioned video-taping the in-home nurse as she demonstrated medical tasks, so that they could refer back to it. Others were satisfied with the information they received from the disease-specific support organization. One California-based respondent, who received compensation as an IHSS caregiver, felt that the IHSS program gave him the information and education he needed. But several others felt they were not prepared for the behavioral and other caregiving tasks before them and didn't know where to go for support or guidance.

"He developed ALS. He went from able-bodied to 'can't do anything.' I didn't know how to handle that. That was really hard. I definitely would have benefitted from a checklist of strategies."

"When your mom starts balking at taking these different medications, how can you explain this to her?"

Care Transitions. For this group, with more medically oriented caregiving needs, the discussion of care transitions focused on palliative or hospice care. Recommendations and support typically came from the care recipients' physicians – although information was sometimes provided too late or not at all. One respondent made a compelling case for advance planning as a routine part of various routine tasks in adulthood: for example, in getting a driver's license we decide about organ donation – why not specify end of life preferences at those times also.

"That would have been something that I think my father would have chosen. I don't think he understood that ALS was terminal."

"I think we always knew that was out there [hospice]. Nobody really . . . it was up to us to ask for it."

Caregiver Needs Assessment. Response was favorable to the idea of helping caregivers identify what their needs are so they could be directed to supports for those needs. In particular, participants expressed interest in support groups -- both to share information and to provide socialization and mental health benefits.

"When you're starting the journey, you don't have enough knowledge to know what you need."

"I think it would be very helpful if they had a list of things that were common needs."

"It would have been immensely helpful to just hear other people and know that I'm not alone in this."

Most Important. In closing, participants were asked for their priorities among these options. Direct pay for caregivers received two votes, caregiving hours counting toward Social Security received three votes, and workplace protections received one.

Family Caregivers for Adult Loved Ones – LTSS Concerns

Overview: Phase II listening sessions were divided into those focused on either financial/workplace concerns or LTSS concerns, giving more depth of discussion to each of the topics explored in Phase I.

Participant Profile: The group was balanced with respect to demographics, including three (3) females and two (2) males, ages 53 through 71, with one 21-year old. The racial and ethnic identities of participants were diverse. Three (3) of the five participants live in the same household as the person for whom they are caregiving.

Opening Comments: The session started by asking participants to identify what types of services and supports they found most helpful in their role as caregivers. The group had some new ideas to offer, along with others we heard before, namely taking advantage of services that deliver a wide variety of goods and services to the home. Caregivers appreciated the convenience of this increasingly available option (due in part to COVID). In addition, having respite care from family you can trust is helpful, and having companion care to take a loved one outside of the home so the caregiver can have “me time” at home was cited as an unmet need by one caregiver.

Next, participants responded to each of the LTSS considerations identified in the RFI analysis.

Respite Care. Some relied on other family to provide respite care and others used paid care or supplemented family respite with paid care. One participant from Wisconsin said she received grant-funded respite care to pay family members for her father’s overnight care.

“I definitely think it’s an important service . . . It doesn’t have to be a lot of time . . . just time to get a shower, to go do something different that you wouldn’t normally be doing.”

“My husband . . . needs some male-bonding, so to have a volunteer that could take him to breakfast for a couple of hours and to spend some time with him, I think that would be great. It would be more me-time.”

“My mom and I . . . would take turns most of the time . . . We would hire respite care, but it was usually only a couple of hours at a time at the most.”

Adult Day Services. Three families spoke about using Adult Day Services (ADS) but having a poor experience, either due to resistance from their loved ones or feeling bad about leaving their loved one there. The most common complaint from the person needing care was that they didn’t feel they needed to be there. In this group, no one reported a successful experience with the service, although they all acknowledged they felt the programs they attempted seemed like good ones.

“My dad is a retired New York cop, Irish . . . he’s stubborn . . . He hated it the entire time he was there and didn’t want to go back again.”

“My husband would say, ‘I’m not like those other people. I don’t belong here.’”

“I tried, and it was like . . . I felt so sorry, like if I was leaving, leaving her . . . How can I leave her there?”

Information and Referral. This group was aware of and used their ADRCs for information and referral services, particularly participants from FL and WI. Caregivers dealing with a specific disease (e.g., ALS) said it was easy to get information and support from local or national groups for that condition. People especially mentioned the value of the support groups to which they were referred. Others, left to do the research on their own, felt that they didn't get complete information from the sources they had, and, as a result, felt less satisfied with their experience.

"[I'd want] . . . a better understanding of the information that we needed to perform our services."

"I had just gone to my local ADRC office . . . We have 13 support groups in the area . . . You name it, they've got a support group for it."

"A lot of it we had to kind of source ourselves . . . I would think they would have everything, but they didn't. Sometimes the piece was just missing."

Caregiver Training. Most participants saw great value in caregiver training. Some had experience with it (e.g., Alzheimer's Savvy Caregiver Training Program), and said it was invaluable. Others felt the best way to learn caregiver tips was from support groups where they could learn from other families. And then many learned the hard way – through their own everyday experience but would have preferred to have had more preparation and support.

"Having more information . . . on caring for someone with Lou Gehrig's disease would have been helpful . . . We really had to learn as we go."

"I would look it up myself and just like learn, yes, just learn by myself I guess."

"The best came from the support groups, from other family caregivers that were sharing."

Care Transitions. Most participants were not at the point of thinking about care transitions and not aware of how they could get support for that. One person mentioned needing to rely on his prior experience (as a caregiver for his grandmother with dementia) now that he is taking care of his sister. Having a sense of what to expect, he feels better able to anticipate future needs.

Caregiver Needs Assessment. As in other groups, response was favorable to the idea of helping caregivers identify what their needs are in order to direct them to ways of getting those needs supported. The Wisconsin participant mentioned the non-profit Family Caregivers Rock, which was described as a kind of "Make a Wish" for family caregivers.

"I absolutely think that if you address some of your needs, it makes you a better caregiver."

"We need to have some kind of help mentally, physically, to help us get through what we're doing."

"We've got jobs, and kids, and bills, and . . . caregiving."

Most Important: Most respondents felt that respite care, caregiver needs assessment and information and referral were the most important LTSS for them. There was also support for caregiver training.

Parents caring for young or adult children with disabilities – Financial Concerns

Overview: In the Phase II listening sessions, we divided sessions into those focused specifically on either financial/workplace concerns or LTSS concerns, respectively.

Participant Profile: This group had more females (5) than males (1) but was diverse in all other regards. Participants ranged from age 35 to 59 and cared for children with a variety of conditions including epilepsy, scoliosis, autistic spectrum disorder, Tourette’s, ADHD, severe anxiety and depression, and others. One grandmother caring for her grandson with autism participated.

Opening Comments: The session began asking participants how caregiving has affected their sense of financial security. This group of parent caregivers talked about the loss of income from the time taken off of work (or leaving work to be a full-time caregiver), and the out-of-pocket costs for medications, therapies and transportation.

“If it’s four or eight hours a day, that’s the amount of pay you’re going to lose because you have to work around your loved one getting to their appointment, and you’re doing what you need to do for them.”

“Financially, yes, it’s definitely taking a toll . . . every month – it seems like they are . . . prescriptions come quicker.”

“The cost of medications I have to pay . . .”
“It has affected me . . . as far as transportation because I don’t drive.”

Participants discussed each of the financial and workplace considerations identified in the RFI analysis.

Tax Incentives. As in other groups, the idea of tax deductions or credits was well received. Some with older children were surprised to learn that the earned income tax credit ended when their child turned 16, even though significant costs and dependencies continue. Some felt that the tax advantage should extend to any disabled family member – not just a special needs child – for whom you might be a caregiver.

Workplace Accommodations. Participants expressed a great deal of stress over the lack of flexibility at the workplace to accommodate caregiver needs. In one case, the paperwork requirements to obtain FMLA were too onerous to be completed in the time needed. Another participant was grateful for the FMLA from her job, not realizing until the focus group that it was not universally available to all working caregivers.

“I had to resign from my job.”

“A lot of jobs have warnings and attendance issues. They don’t understand about if you have to stay home and take care of your loved one.”

“I just wish . . . they would have a little bit of leeway to assist the people that take care of [family.]”

“FMLA protects my job, and . . . if I didn’t have that, I don’t know what I would do. I thought it was part of the labor laws . . . I guess some companies just don’t choose to elect it. I’m not sure.”

Direct pay support. One participant in the group was familiar with California’s IHHS program and greatly appreciated the direct pay support she was receiving from the program. She was not aware that it was not available in all other states. Others in the group chimed in with, “how do we get that?”

“I like it (IHHS) because I don’t have to go out to work. I can stay home and do the job all day long, and I get paid.”

“Yes, it is a very good program.”

Technology. Participants expressed a need for improved Wi-Fi access and lower Wi-Fi costs, as these have become so critical in supporting care (especially during the pandemic). They mentioned relying on it for telehealth, therapies, and for communication more generally. Therapy devices and home modification for accessibility and safety were also mentioned as needs – particularly, knowing where to go to find help with these things.

Social Security Retirement Credits. As with the other parent groups, some were too young to have given this much thought. But the older participants were interested in the concept of having caregiver hours count toward Social Security retirement credits; they understood that their retirement earnings were disadvantaged as a result of years of caregiving and were keen for a way to address this.

“Retirement is one of the last things that’s on my mind right now. Retirement is a long way to go for me, so there’s a lot of other things to take care of and think about . . . at this point in my life.”

“I haven’t given it much thought . . . My son is still young and I’m still young myself.”

“It would be nice to have hours count toward my social security.”

“If you don’t work enough hours, you don’t get a chance to pay into the retirement.”

“How do you plan for retirement when you’re taking care of your family members?”

Most Important. In closing, participants were asked for their priorities among these options. Workplace protections and direct pay for caregivers received the most votes. There was also interest among the older participants in having caregiving hours counting toward social security. Tax incentives and technology received some support but less so than the other items.

Parents caring for young or adult children with disabilities – LTSS Concerns

Overview: In the Phase II listening sessions, we divided sessions into those focused specifically on either financial/workplace concerns and LTSS concerns, respectively.

Participant Profile: Participants in this group ranged from ages 49 to 65. Two grandparent caregivers participated, one of whom cared both for a grandchild with autism as well as a daughter with schizophrenia. Other disabilities represented include neurological problems, Rhetts Syndrome, Cerebral Palsy, and Kleine-Levin Syndrome.

Opening Comments: This group was keen to identify what would have been most helpful to them in their role as caregivers. They mentioned respite care, peer support groups, future care planning, and information and referral. There was a shared sense of frustration at having to find one’s own way at nearly every stage, especially once the child is no longer in the school system.

“I didn’t have a break of any kind.”

“Just a resource to know what you don’t know, what you should be doing, what you need to prepare for . . .”

“. . . when your child is in school, you get connected with other parents; there is nothing to connect you with the community [after that]. You feel like you’re so isolated.”

“I would offer peer support groups. I’m creating it. If it was already in existence it would be one less hassle.”

Participants had the following comments about each LTSS considerations identified in the RFI analysis.

Respite Care. Participants spoke about challenges in accessing respite care. Some didn’t know it existed or only accessed it when they came across it in a referral during a time of crisis. Two others (one in Nevada and one in Virginia) had been on waiting lists, faced “mountains of paperwork”, and had yet to qualify.

“I know they are hard to find. It’s like interviewing a caregiver, but it’s harder because you can’t promise them regular hours, but you need someone who meshes with your child. It is so hard to get, and so needed.”

“The waitlist for it is a long time. They don’t have any more resources. I still have to recertify every six months.”

Day Services. Parents expressed some disappointment with their experience with day services due to the lack of need-based or consumer-directed programming. Another felt it was not compatible with work: the hours were limited (e.g., 10 am to 3 pm) and, due to lack of transportation, the respondent could not utilize the service (as a working single parent). A parent in New Jersey spoke highly of the self-directed services program there, where the budget she receives allows her to create a “meaningful day” for her daughter – which she feels is easier now that the day services program is closed during COVID, due to her lack of confidence in the program’s ability to serve her daughter well.

“I went around to every day program in the area. Not a single one could tell me what my daughter might be doing in this program other than sitting there staring at the wall or TV. Now, she’s out and about in the community every single day. She has activities . . . she has friends. But it’s a “do-it-yourself” program for sure.”

Information and Referral. Caregivers cited a mismatch between the information they were given and what they felt they needed. While they often received information about the care recipient’s diagnosis, what they really wanted was information that was actionable and local – identifying where to go for what types of services and what to expect next. Another parent spoke about the diversity of her information needs – they were medical, educational, and psycho-social. The fact that I&R is siloed among different information sources (e.g., school, doctors, etc.) emerged as a common theme for these parents, who face a lifetime of cross-cutting needs. In closing, parents expressed more confidence in the information they would get from peers – other parents who had shared experience – than from professionals.

“My granddaughter was diagnosed . . . with autism. They gave me a 5-inch binder full of information. It had no local information. It didn’t tell you how to access [services.] . . . It didn’t have a roadmap of community organizations to reach out to . . . What’s the next step and who’s there to help me?”

Caregiver Training. Participants did not feel adequately supported by the training provided by professionals, in part because they felt professionals were likely to misread situations or provide generic advice not tailored to individual needs. As with information and referral, many in this group preferred to rely on support from other parents who have encountered similar situations. No one could identify a resource specifically for training and support for parent caregivers.

“It’s kind of like going to a battlefield in war. You learn as you go. There’s no training program.”

“. . . these professionals have limited time . . . you have a child with behavioral issues. The professionals who are overwhelmed will sometimes erroneously put the blame of your child’s behavior on the family when that has nothing to do with it.”

“I’d like to see more parent advisory councils.”

Care Transitions. The most challenging part of care transitions mentioned in this group was leaving the educational system and finding support for your child’s disability (and peer support for yourself) once they age out of the school system.

Caregiver Needs Assessment. Participants expressed interest in having an objective third-party assess caregiver needs, particularly ways that caregivers could get help and support, especially around mental and emotional help.

Most Important: The greatest enthusiasm was for caregiver needs assessment, and information and referral.

Spanish – Spanish/English Speaking Caregivers

Overview: This piece summarizes a community-based listening session in the Houston, Texas area focused on the experiences of Latinx caregivers. Participants were recruited through their relationship with BakerRipley, a nonprofit service provider that offers support services to older adults. The session was conducted in Spanish.

Participant Profile: The group was comprised of family caregivers ages 58 to 77 who identify as Latinx. The group was diverse in terms of region of origin, including those who identify as Puerto Rican, South American, and Mexican. All were caring for older adults with physical and cognitive challenges, most typically, Alzheimer’s. One participant spoke only Spanish, while the others were bilingual.

Opening Comments: The participants are all faced with the challenge of being the primary caregiver for an older adult with very limited assistance from other family members, health systems, or government programming. They expressed a strong desire for respite care and other supports in the home, such as a care coordinator to help them understand behavioral challenges that come with dementia and other cognitive disorders. For all of these caregiver supports, cost was a significant barrier.

The focus group discussed how the nuance of Latino/a culture influences their experiences as family caregivers. They agreed that cultural attitudes toward communal support for family members is different in the United States, and that they were put into the difficult position of being the sole caregiver for their family member with very limited outside supports. The group also discussed cultural stigmas around disease in the Latinx community, and how a dementia or Alzheimer’s diagnosis can be an isolating experience.

Next, participants responded to each of the LTSS considerations identified in the RFI analysis.

Information, education and referral: There was a clear need for more bilingual programming and information. Multiple participants expressed a need for a comprehensive online resource web page.

“What I’ve found very important that we’re lacking and is missing from the list, is a website where we could find all the information we need, for self-training, for the caregiver to learn how to look after themselves, all the resources available from the government . . . sort of a clearing house, where we can find everything.”

“I’ve learned about these topics because my mother was ill for eight years and I had to read and research and enquire, but it’s tough. There should be a coordinated place online, facilitated by the federal government, where we’re able to learn everything we need.”

“[Area agencies on aging] provide relatives with information and they contact you to know about your necessities and assess you to know what you’re eligible for. Many people with whom I’ve shared this information have received visits in their houses and they’d look after their relatives up to 4 hours per day . .

Adult Day Services: While the participants have found day services, they often have difficulties navigating resources and connecting with trusted providers. Cost was also a barrier to service use.

“if it weren’t for BakerRipley, I don’t think my mom would’ve lived as long, because she’s already 93 and her mind is still going . . . but in my opinion, BakerRipley has been fantastic.”

“I don’t know what services they offer here in Houston, for example, if there are any low cost or free services or if everything needs to be paid through a medical insurance.”

Respite care: Respite care was an immediate concern for many. Cost again was cited as a significant barrier to using respite care.

“... if you happen to need to take that person somewhere and take a weekend off... the places are there, but they’re pretty expensive. That would be a pretty big help for the family on that regard.”

“... if you need to take the patient or the person, you’re caring for somewhere, you need to pay for that, because I don’t think this is a free service anywhere.”

“Sometimes you think no one will look after your relative the way you do it, but as you start getting tired, you need to realize the fact that you need to let others support you.”

Caregiver Training. Participants were eager to learn more about how to better support their loved ones and develop self-care strategies. They welcome educational opportunities, including trainings and seminars, and have learned a great deal from the educational events they have had access to.

“If we don’t understand them and put ourselves in the [their]... shoes, we won’t know how to help them .”

Care coordination: Many expressed concerns about the lack of care coordination. Caregivers felt overwhelmed and unsupported by care providers in understanding the care needs of their loved one.

“There is no communication between [providers], so, sometimes they’d give them medications which harmed him because those would raise their sugar levels. Thankfully I was on top of everything and keeping track of each and every single medicine, as well as talking to each one of the doctors, it was crazy.”

Financial and Workplace Accommodations. Some participants faced workplace pressures due to a lack of care support. One participant had to stop working due to their caregiving demands.

“I had to stop working, I wasn’t able to continue due to all of my responsibilities, and sometimes my mom would be in intensive care and I’d have to leave home, leave everything for a month and then come back, and so on.”

The concept of direct pay for caregivers was well received. One participant thought it was not available in Texas, while another thought it was something they could be eligible for. Some participants were open to the idea of tax credits. Some wished the tax deduction process was clearer but others were receiving tax benefits for caring for their loved ones.

“I think it should be a little clearer because the way it’s shown to you at the moment of doing your taxes, it’s not clear for you to see that you’re able to claim deductions from expenses as an independent.”

“We need to get some sort of financial relief, to look after our parents or partners and all.”

Most Important. The following emerged as most important to the participants: Respite care; day services and programs; and information, education and referral, with an emphasis on bilingual resources.

Teens caring for adults with serious illnesses or chronic conditions

Overview: Teen caregivers (ages 13-18) were recruited for this listening session, aided by the American Association of Youth Caregiving (AAYC). Males and females of different racial and ethnic backgrounds participated, but all were from Florida and lived with the care recipient. Most cared for a parent or a grandparent and lacked help with caregiving, although some had occasional support from a younger sibling or a relative living outside the home (e.g., an aunt).

Care Provided: The teens reported that they supported adults with a range of care needs and conditions (e.g., cancer, arthritis, diabetes and mobility problems), and performed many tasks, including transferring, help with mobility, personal care needs, medication management, and help with instrumental activities of daily living (laundry, housekeeping, meal preparation, and more).

Opening Up: The teens in this group were reluctant to talk freely about caregiving. They showed “acceptance” – that this is simply what they do and not something to be pitied or admired. At the same time, they see their caregiving as private, or something that is not to be shared with school authorities or other teens – they do not want to be seen as “different.” They are also fiercely protective of the person they care for (and take pride in the care they offer) and were reluctant to talk about the challenges they face lest it be viewed as “complaining” or being disloyal to their family.

“It hasn’t really had an impact on me.”

“It’s nothing to me. It helps her out, there’s nothing negative for me. It’s positive to her.”

Major Impact of Being a Caregiver: Some of the responses included feeling stressed, having to make sacrifices, feeling easily irritated and isolated, and having difficulty controlling anger or impatience.

“I would cry about it . . . because I don’t see any other kids doing this . . . Then my mom would start crying because she feels bad, she doesn’t want me to do this.”

“It seems as though we’re trying to behave like an adult to support the person we’re taking care of but like we’re still children.”

Impact on Schoolwork. Some teens talked about how added stress affects their ability to focus and perform at school. While there was some interest in extra support at school (e.g., flexibility to turn assignments in late, tutoring programs, on-site support programs), some feared stigma (from teachers or other teens) if they asked for help. Others said that resources were only available for students who were having trouble – not to those who wanted to avoid problems. Some wanted safe spaces to relax and unwind at school since school is one of the only times/places they have that isn’t caregiving.

“It’s kind of hard for me to focus due to everything.”

“. . . like maybe you could hand in something a little later...”

“they were offering tutors, but . . . they can like only give it to you if you’re either a C or D in the class already.”

Where does support come from: There are few support systems in place for these teens. They value the support they do get from AAYC and Caregiver Youth Programs at their schools. A few mentioned being able to talk to other family members who might also be teen caregivers. Some liked the idea of a summer camp “get away” experience or on-line support group similar to the focus group in which they were participating. Some felt they could benefit from learning relaxation, meditation and other self-calming techniques. After one teen talked about the benefit she derived from an affordable weekly therapy session, others saw value in that as well. The notion of “taking a break” or having a caregiver come to the home so they could have time off was well received. The teens talked about needing help handling certain situations especially around providing medication, helping with mobility, and doing care transfers.

“My cousins like they actually go through the same thing . . . we kind of talk to each other. They give me advice.”

“The Caregiving Youth Project at school; those are the only kids and adults that know . . . I don’t like to tell other kids because I don’t want them to pity me or . . . change how they act around me.”

“The Caregiving Youth Group . . . at school. It taught me a lot . . . taught me how to control my anger better.”

“I want to learn how to like, if she’s sitting on a chair . . . like I want to know how to properly lift her up without causing any pain to her.”

“I think it might be helpful because the doctors can give you more information on how to do your job even better.”

Worry about finances: While most of the teens are not responsible for finances, they do worry about it. One teen had a part-time job to cover her own expenses; she felt the stress of juggling school, work and caregiving. Others expressed guilt over not contributing to household finances.

“I’m worried about that. What if something happened? What if we’re not able to financially keep ourselves stable?”

“I sometimes do worry . . . When [my dad] is late on a bill I kind of feel bad, like, ‘Oh, should I get a job to help out stuff like that.’”

“It makes me like . . . wonder what I am here for if I like . . . if I can’t help.”

Pride in what they do: For all the stress and anxiety, the love these teens expressed for their roles as caregivers and for the family they care for was very moving. They have ambitions for their future; one young teen wants to be a physician, motivated in part by her caregiver experience.

“It makes me feel good that I know that I make them feel good.”

“The more you pour into others, the more you have to pour into yourself. Being a caregiver can be very nice and rewarding because you know you’re doing something for someone that you care about.”

Grandparent and Kinship Caregivers

Overview: Eight (8) grandparents and kinship caregivers were recruited for this session, aided by Generations United (GU). There was diversity in terms of age, geography, race, and caregiving arrangement. Some participants are caring for one or more of their grandchildren and some are caring for a sibling’s child or children.

Priority Concerns: Participants expressed their reluctance to ask for help for fear that doing so might leave authorities questioning their capability and possibly result in removal of the children from their care. Another concern was the less favorable treatment/support provided to grandparent/kinship caregivers vs. foster caregivers, despite the fact that both do the same work and face the same challenges.

“And CPS is always lurking kind of in the background. If you ask for additional assistance or need something . . . you have to be aware of what you’re saying or what you’re asking for.”

“I should be able to say what’s really going on without fear that they’re going to say, ‘Oh, you’ve got too much on your plate. We’re going to have to take the children.’”

“If I mentioned any kind of stress . . . or difficulties, they would say, ‘Well, we could just put them with a trained foster parent and we’ll just take them away.’ So, it made me feel as if I could not . . . explain any of my stress . . . or ask for help.”

“I have never been able to understand why foster parents’ benefits are so much more than kinship benefits, or grandparents in my case.”

Most Important Needs. Participants cited needs for financial and legal assistance, information and education. Some found “parenting classes” helpful; even though they already were parents, for some that was a generation ago, much has changed, and many are caring for children experiencing very difficult circumstances. Grandparent caregivers expressed struggling with isolation from peers – as they suddenly find themselves caring for young children they are isolated from their existing social network. Some spoke of a need for emotional and mental health support as they cope with this challenging role.

Financial considerations. “Money, money, money . . . that’s our biggest need.”

“I think there is a stigma around if family asks for financial help to raise children; that we’re just doing it for the money.”

Legal assistance. “I have worked in the child welfare system for over 15 years. I thought I was very prepared . . . But I had a hard time navigating the system.”

“The biggest thing for me is how do you ask for what you don’t know you need. Every day is bringing on new issues.”

“There is no guidance . . . no direction . . . no information . . . no resources.”

“So, information and referral are the key because with information you can make cogent decisions and then decide what you’re going to do, how are you going to move forward. But without that, you’re sort of caught in fear and shame.”

Mental health for the caregiver. I agree . . . mental health . . . there were times that I was just like really stressed out.”

Other LTSS Priorities. As with other caregivers, participants expressed a need and interest in respite care, but felt that they could not afford it or that resources were less available to grandparents than to foster parents. Caregiver training and education were also seen as very important. As mentioned above, participants that found their way to “parenting classes” were very glad that they had done so.

Respite Care. “There was no one to offer it to use, so it was always good from the foster care parents, they get that respite care. But as grandparents you’re basically on your own. So, it was just one of those things you just made do because you didn’t have it and you couldn’t afford to pay it.”

“I’ve heard from kinship caregivers who would like to have respite. They haven’t had it because – various reasons. One is the amount of money that it would cost.”

Caregiver Training. “Caregiver training and education is a service that’s needed that you don’t know that you need.”

“When they brought my granddaughter to me, she was medically fragile . . . They dropped her off at my house. So that was a big learning curve for me because I had to jump in and find the resources and things to help with her.”

“I remember when my granddaughter was much younger, I would have liked to have had respite care.”

Financial and Workplace Accommodations. In addition to the financial burdens previously mentioned, caregivers spoke about the following: the financial strain from having to quit work due to the additional demands of caregiving; the fact that FMLA does not apply to kinship caregivers; the loss of contribution to their Social Security from being out of the workforce earlier than anticipated; and the need to make early withdrawals from a 401(k) to make ends meet.

“What happens when . . . that single caregiver . . . had to leave their job due to the medical or behavioral issue with the children . . . and now they are stuck because they can’t even get Social Security?”

“I was forced to . . . take from my 401(k) because we were so financially stressed out . . . I don’t receive any kind of financial support for my niece.”

“I had to quit work so then it became a financial issue.”

Future Planning. These caregivers were especially concerned with transition plans and having legal rights and control over who has guardianship of the children in their care should something happen to them; without a termination of parental rights (TPR), they worry that the children will be returned to an unsafe situation instead of another relative they specifically designate as a guardian in their will.

Most Important Priority. In closing, participants were asked to select their “top three” from the list of priorities from the RFI. The most popular were direct pay for caregivers, education, information and referral and tax incentives. Respite care and caregiver training were also mentioned.