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Identifying key components of a web-based long term care planning intervention for family caregivers of individuals with intellectual/developmental disabilities

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Abstract

Background: Few family caregivers of individuals with intellectual or developmental disabilities develop long-term care (LTC) plans for their relative. Web-based interventions promoting LTC planning have potential for widespread adoption into clinical practice.

Methods: We conducted focus groups with 49 primary caregivers of individuals with intellectual or developmental disabilities in NY, PA, OH, DE, and TX to identify barriers and facilitators of LTC planning, review existing tools, and identify critical features for web-based LTC planning interventions. Participants also answered questions on demographic characteristics and functional status.

Results: NVivo qualitative analysis software was used to analyse focus groups using a grounded theory approach. Caregivers identified web tool accessibility and topics such as finances, housing, and government benefits as critical. Caregivers also described desired features for a LTC planning tool.

Conclusions: This study identified desired characteristics of web-based LTC planning tools and ways in which existing web-based interventions might be adapted or enhanced.

KEYWORDS
caregiver, intellectual or developmental disabilities, long-term care planning, planning tool

1 | INTRODUCTION

The COVID-19 pandemic highlighted the vulnerability of family caregivers and people with intellectual and developmental disabilities around long-term care (LTC). As schools and adult day programs closed and stay at home orders were enforced due to the pandemic, family caregivers increasingly shouldered the full brunt of teaching, therapies, and caregiving (Navas et al., 2021; Wright et al., 2020). As these caregiving pressures persisted or as family caregivers became ill secondary to COVID, an increasing number of families requested emergency placement of their dependent with intellectual or developmental disabilities in a nursing home facility (Wright et al., 2020). Crises similar to what was observed with COVID-19 also occur when persons with intellectual or developmental disabilities and parental caregivers age and become increasingly susceptible to age-related health and functional decline, and parents become less able to cope with the demands of caregiving (Innes et al., 2012). Insufficient backup caregivers, compounded by insufficient knowledge of social services and legal supports, frequently lead to disabled individuals losing needed supports, being placed in restrictive environments, or potentially being stripped of their legal rights altogether (Innes et al., 2012). Consequently, creation of LTC plans is critical to mitigate these risks.

Lack of LTC plans may lead to crises and emotional trauma for all concerned, unexpected dilemmas for siblings or extended families, and at its worst, inappropriate or unwanted placement in nursing home settings, unsafe living conditions, or harm to individuals with intellectual or developmental disabilities (Chang & Schneider, 2010; Ducharme et al., 2012; Heller & Caldwell, 2005). Long term care planning can ensure appropriate provisions are put in place for caregivers, individuals with intellectual or developmental disabilities, and other family members. Despite this, most discussions around LTC planning are vague and lack specificity and concrete planning (Lee et al., 2019). Additionally, families may feel uncomfortable discussing future planning due to the emotional weight associated with it (Lee et al., 2019). LTC plans for these individuals are created fewer than half of the time (Burke et al., 2018). Furthermore, few evidence-based interventions exist to support LTC planning specifically for people with intellectual or developmental disabilities and/or their caregivers: a 2020 systematic review found only four high-quality studies assessing approaches to future care planning for adults with intellectual or developmental disabilities and their family caregivers (Brennan et al., 2020). For most families, usual care consists of families navigating disability social services websites independently (Caton et al., 2019; Hostetter & Klein, 2018; McLean et al., 2021), being introduced to LTC services as part of transition planning of a graduating student's individualised education plan (Grigal et al., 2011; Powers et al., 2005; Shogren & Plotner, 2012), or being referred to case management services through a health system or agency. Although case management programs may lead to enhanced planning for the future and increased access to services (Bigby et al., 2002), these approaches are limited by accessibility. That is, only 55% of family caregivers of people with intellectual disability nationally report being able to contact his or her case manager when they need or want to (NASDDDS & HSRI, 2021a, 2021b).

A systematic review of web-based tools for caregivers of individuals with chronic illnesses illustrated that web-based interventions for this population can have positive effects on self-efficacy, self-esteem, and caregiver strain (Ploeg et al., 2018). Current web-based approaches to future planning for individuals with intellectual disabilities include efforts by the Plan Institute in Canada (Plan Institute, n.d.), the Australia Department of Social Services (Department of Social Services, Australian Government, 2021), and the Arc Center for Future Planning (The Arc's Center for Future Planning, n.d.). The Future Planning Tool developed by the Plan Institute for Canadian residents first screens users to identify their needs and displays material to fit those needs. Each topic page suggested gives a summary of relevant information and steps to follow in order apply for programs or plan for that specific area. Planning for the Future: People with Disability booklet was co-created by people with disabilities. Intended for Australian residents, it has accessible templates with questions that identify the needs of the individual. Both the Future Planning Tool and Planning for the Future: People with Disability booklet are comprehensive; however, they cater to individuals outside of the United States. The Arc Center for Future planning is intended for United States residents and helps families build future plans.

Web-based approaches to LTC planning have the potential for wide adoption into clinical practice both for the scalability of web-based interventions and for widespread accessibility to caregivers and individuals with intellectual disabilities. In this study, we identify desired characteristics of web-based long-term planning tools among family caregivers of adults with intellectual or developmental disabilities, and identify ways in which existing web-based interventions might be adapted or enhanced.

2 | METHODS

2.1 | Participant recruitment

Eligible participants were adult family caregivers of individuals with intellectual or developmental disabilities. We recruited participants from health systems, community-based organisations, and conferences and community events serving people with intellectual disabilities in New York, Pennsylvania, Ohio, Delaware, and Texas. Community-based organisations were asked to send recruitment information to potentially eligible participants through email or mail. Health system clinical programs that serve individuals with intellectual or developmental disabilities were asked to send recruitment information to potentially eligible families through patient portal, email, mail, or posted flyers. Participants could also refer eligible friends or family members. Recruitment flyers were also available at conferences and community events. Participants received a $25 gift card for participating. Because of limited bilingual staff, individuals without English proficiency were excluded. Forty-nine caregivers agreed to participate. Of the 49 caregivers, 12 lived in Delaware, 10 lived in New York, 18 lived in Ohio, 7 lived in Pennsylvania, and 2 lived in Texas.

2.2 | Data collection

Between April 2018 and October 2019, 49 family caregivers of individuals with intellectual or developmental disabilities participated in eight focus groups across five states. At the beginning of the focus groups, the participants completed a survey that asked the caregivers questions about their relative with intellectual or developmental disabilities, including demographic characteristics of both the participant and care recipient with intellectual or developmental disabilities, challenging behaviour as measured by the Scales of Independent Behaviour-Revised, Adaptive Behaviour Section (SIB-R; Bruininks, 1996), adaptive functioning as measured by the Waisman Activities of Daily Living Scale (W-ADL; Maenner et al., 2013), and whether or not the care recipient was a Medicaid waiver participant.

2.2.1 | Focus group procedures

Each focus group had a moderator, note taker, and two digital recorders. Focus groups ranged from three participants in the smallest group to eight participants in the largest group. A focus group guide (Appendix A) was developed based on previous in-depth interviews eliciting domains of future planning (Lindahl et al., 2019) and piloted with key stakeholders prior to use. Pilot testing revealed that the focus group procedure was adequate, and no changes were made to the focus group guide.

Each focus group lasted 60–90 min, with the vast majority lasting 90 min. At the start of the focus group, the moderator presented and navigated through two available LTC planning websites: Plan Your Lifespan (planyourlifespan.org) and The Arc's Center for Future Planning (https://futureplanning.thearc.org/) to focus group participants. Plan Your Lifespan is an evidence-based LTC planning tool designed for aging individuals. Center for Future Planning is a LTC planning tool designed specifically for adults with intellectual disabilities and their family caregivers. Participants were asked the following: what they liked and disliked about the websites; ways in which it could be improved for use as a LTC planning website for themselves and for their relatives with intellectual or developmental disabilities; hardest and easiest aspects of LTC planning; and to describe domains of future planning that their family had already addressed. Prompted domains included housing, health management, legal management, financial management, direct caregiving, and transportation (Lindahl et al., 2019). Participants were encouraged to give suggestions for an adapted online planning tool focused on individuals with intellectual or developmental disabilities, including what they would like to see on the planning tool to make the planning process more manageable.

2.3 | Data analysis

Interviews were recorded and transcribed verbatim by a HIPAA-compliant transcription company and uploaded into NVivo 11 (Qualitative Data Analysis Software | NVivo, n.d.). Two trained research staff members coded the transcripts independently and reviewed coding together using the constant comparative method to make sure that their coding aligned (Glaser, 1965). If there was disagreement between the researchers' coding, the researchers discussed the disagreement until a consensus was reached. Codes were combined under unifying themes. For example, several codes—namely 'care transition challenges', 'categories that are hard to plan', and 'long term care planning barriers'—were combined under the unifying theme, 'Perceived barriers to long term care planning'. In another example, the codes 'website suggestions around accessibility' and 'website suggestions around communications or behavior information' were combined under the unifying theme, 'Suggestions for long term care planning tool: Accessibility'.

Major themes were then discussed with the rest of the research team. The team took note of the major barriers, facilitators, and suggestions for a planning tool that were common across focus groups and participants. The grounded theory approach was used to collect and analyse focus group data. This approach involves the generation of themes and hypotheses through review of transcripts (Khan, 2014). The major themes became the initial nodes used to code transcripts. After going through the first round of transcripts, these nodes were further developed, with the addition of subcategories, to better encompass the themes and feedback from the caregivers. Eleven nodes were analysed.

Credibility of the focus groups was established through member-checking, by sharing the results and conclusions with several focus group participants. We also triangulated these findings with concurrent surveys conducted with family caregivers recruited from the same health systems, community-based organisations from which participants in this qualitative study were recruited.

2.4 | Human subjects research

This research study was considered exempt by the Feinstein Institutes for Medical Research of Northwell Health's Institutional Review Boards.

3 | RESULTS

3.1 | Sample

We conducted focus groups with 49 caregivers of individuals with intellectual or developmental disabilities. Of the 49 caregivers, 12 lived in Delaware, 10 lived in New York, 18 lived in Ohio, 7 lived in Pennsylvania, and 2 lived in Texas. The mean age of caregivers in our sample was 55.9 (Table 1). Caregivers were predominantly female, white, had a yearly household income of over $75,000, and most had at least some college education (Table 1). The participants also provided demographic information about their relative with intellectual or developmental disabilities. The mean age of relatives with intellectual or developmental disabilities was 22.7 years. Nearly 70% were recipients of a Medicaid Home and Community-Based Services (HCBS) Waiver (Table 1).

TABLE 1 Characteristics of family caregiver focus group participants and their care recipients with intellectual or developmental disabilities

	Sample size	
Variables	**Caregiver (n = 49)**	**Individual with intellectual or developmental disabilities (n = 49)**
Age (M ± SD, range)	55.9 ± 6.1 (45–74)	22.7 ± 6.6 (7–40)
Gender, N (%)		
Male	10 (20.4)	29 (59.2)
Female	39 (79.6)	20 (40.8)
Race, N (%)		
White	38 (77.6)	37 (75.7)
Black or African American	7 (14.3)	7 (14.3)
Asian	2 (4.1)	3 (6.1)
Other	1 (2.0)	2 (4.1)
Missing/unknown	1 (2.0)	
Ethnicity, N (%)		
Hispanic	2 (4.1)	-
Non-Hispanic	43 (87.8)	
Missing/unknown	4 (8.2)	
Education, N (%)		
Less than high school	0 (0)	-
High school diploma or GED	3 (6.1)	
Some college	6 (12.2)	
Associate's or bachelor's degree	26 (53.1)	
Graduate or professional degree	13 (26.5)	
Missing/unknown	1 (2.0)	
Income, N (%)		-
Less than 20,000	0 (0)	
20,000–74,999	13 (26.5)	
75,000–99,999	3 (6.1)	
100,000–199,999	24 (49.0)	
200,000 or more	7 (14.3)	
Missing/unknown	2 (4.1)	
State of residence, N (%)		
Delaware	12 (24.5)	12 (24.5)
New York	10 (20.4)	10 (20.4)
Ohio	18 (36.7)	18 (36.7)
Pennsylvania	7 (14.3)	7 (14.3)
Texas	2 (4.1)	2 (4.1)
Medicaid waiver, N (%)		-
Yes	34 (69.4)	
No	10 (20.4)	
On waitlist	3 (6.1)	
I don't know	2 (4.1)	
ADL/IADL Independencea (mean ± SD, range)		
Total score	-	18.1 ± 10.7 (0–33)
Raw score		1.1 + 0.6 (0–1.9)
Number of problematic behaviours (mean ± SD, range)	-	2.6 ± 2.2 (0–8)

TABLE 1 (Continued)

	Sample size	
Variables	**Caregiver (n = 49)**	**Individual with intellectual or developmental disabilities (n = 49)**
Presence of at least 1 problematic behaviour		
Yes		39 (79.6)
No		10 (20.4)

aWaisman ADL Score: Sum for total score; lower score = severe disability. Raw score is average of resources: 0 = does not do at all, 1 = does with help, 2 = independent or does on own.

Scores on the W-ADL Scale showed that individuals with intellectual or developmental disabilities needed some assistance with activities of daily living, while the responses from the SIB-R indicated the presence of problematic behaviours, with most (about 80%) reporting at least 1 problem behaviour while the average number of such behaviours was 2.6 (Table 1). Results from these caregiver proxy questionnaires indicate that the individuals with intellectual disabilities the caregivers reported on need constant supervision and support. Additionally, only 34.7% of caregivers felt that their relative with intellectual or developmental disabilities could be left unsupervised.

3.2 | Nodes to be used in LTC planning tool

In the focus groups, caregivers described their LTC planning process and what they hoped the online LTC planning tool would look like. From this discussion, different nodes were identified. There was a total of 1215 different references pulled from the transcripts that mapped to a specific node. These nodes included: perceived barriers to LTC planning, perceived facilitators to LTC planning, and suggestions for a LTC planning tool: infrastructure, accessibility, financial,

TABLE 2 Total number of references for each coded node across all focus groups of family caregivers of individuals with intellectual or developmental disabilities

Node N = 11	Number of references N = 1215 N (%)
Perceived barriers to LTC planning	234 (19.3)
Perceived facilitators to LTC planning	205 (16.9)
Suggestions for LTC planning tool—infrastructure	96 (7.9)
Suggestions for LTC planning tool—accessibility	33 (2.7)
Suggestions for LTC planning tool—financial	17 (1.4)
Suggestions for LTC planning tool—housing	25 (2.1)
Suggestions for LTC planning tool—government benefits	9 (0.7)
Suggestions for LTC planning tool—organisation of resources	154 (12.7)

Abbreviation: LTC, long-term care.

housing, government benefits, and organisation of resources (Table 2).

3.2.1 | Perceived barriers to LTC planning

Caregivers experienced different barriers when developing LTC plans for their relative with intellectual or developmental disabilities. Some caregivers identified a lack of overall knowledge, which impeded their ability to properly plan. Caregivers did not begin the LTC planning process because of the emotional weight that the process carries. Many caregivers in the focus groups expressed fear about the future and its uncertainty as a reason for why they have not started the LTC planning process.

> I think the reason that we aren't going further is because I feel disorganized. I don't know – and this is so unlike me because I'm a planner and I have everything planned out. Well, I don't know how to plan this out. (Parent, female, DE)

> And so even though I'm a transition specialist and I can tell everybody else what to do, at this point, I'm like I don't know how to do this. Now, talking to Terri, she's given me some ideas to talk to people. But it's just so frustrating because it isn't this nice clear plan. We don't have a lot of family here so we're on our own and we want – we do have – she is her own guardian but we have things set up and we do wanna do that supported decision making but we still haven't done that yet. And, yeah, it's like, okay, I need to be me, to walk me through what do we do now for this next step. (Parent, female, DE)

3.2.2 | Perceived facilitators to LTC planning

Caregivers described different facilitators that helped encourage or motivate them to create LTC plans. Facilitators to LTC planning included networking (caregivers speaking to other caregivers), support groups, or emergency situations (i.e., eviction, hospitalisation). Some caregivers identified specific people that facilitated planning activities.

I started to learn by going to parent meetings. I hadn't a clue. And I found out about the waiver at parent meetings. I found out when they had the guest speakers come in and talking about supplemental needs trusts and guardianship and just by starting early enough, and if your kid is in a special program, and hopefully you're in a general education program, you're SEPTA is going to have speakers come in. (Parent, female, NY)

So if you're under long-term care – I have this fabulous caseworker under long-term care who calls me every couple weeks, wants me to put up the – put the phone up to Bridget so she can talk to her, asks me if I have any needs. (Parent, female, DE)

3.2.3 | Suggestions for LTC planning tool: Infrastructure

The comments that were coded under the node 'Infrastructure' are comments that did not necessarily fit into the other nodes, such as comments about the web-tool layout, its function, and how it is disseminated.

Some caregivers discussed how to make the planning tool look more visually appealing to visitors, such as keeping the tool's layout simple, engaging, and applicable, while using a warm, welcoming tone in the language used. Caregivers made it clear that they wanted the layout of the LTC planning tool to be easy for anyone to understand and interpret.

So I think one immediate thing – and it's simple – is how the website looks, right? If you come across a page and it doesn't look interesting, you're just going to move on. It has to look professional, engaging. (Parent, female, PA)

Caregivers suggested the information found on the web-tool be printable, in case they want to show the information to others, such as doctors. They also expressed that the LTC planning tool should be available on an app as well, so that caregivers could fill out information and find information without requiring use of a computer to do so.

Female speaker: It might be nice to have an app even, too. Because people are – it sounds crazy, but a lot of people really get away from email and websites now. They're more into an app and a text [laughter].

Female speaker: End up on their phone. Yeah.

Female speaker: So, in order to – I mean, you could have a – obviously, have a web – if they maybe have a

smaller version where you could just click on the app and look in – ask questions or look at questions.

Male speaker: You should have a Facebook page or other social media influence. (Parents, Female and male, PA)

Others made comments about the management and/or development of the LTC planning tool. They felt as though passionate people who share a similar experience will be more likely to provide accurate, current information.

It needs to be run by a passionate group of people, whether they're parents, caregivers. (Parent, female, DE)

So, with that said, it's gonna have to be someone who knows the story and how important it is to keep a site up and running and to have it current. And that's just the bottom line because – I have years and years invested in this now. (Parent, female, DE)

Further, some commented on the ability to edit or input information into the LTC planning tool. The LTC planning tool should be interactive so that caregivers are able to input information about their relative, such as the doctors they visit and being able to upload important documents, such as an individualised education plan.

But I think the planning document where it prompts you – the kid's name and then the doctors and then you can upload the IEP. (Parent, female, NY)

I like the idea of – well, the first website that you showed for the elder care, the – almost like a Google forms kind of a format of filling out your specific information and then – well, kind of the same, having someone in the know sort of look it over and maybe a personal phone call or some sort of – (Parent, female, NY)

Apart from suggestions on the infrastructure of the tool, the LTC planning tool suggestions that were most talked about included accessibility, financial, housing, government benefits, and organisation of resources.

3.2.4 | Suggestions for LTC planning tool: Accessibility

Focus group participants had suggestions for ways to make the tool accessible for all people (e.g., pictures, translations, colour schemes, voice-overs). Comments regarding accessibility included providing definitions, explanations, and using appropriate language so that the

tool is easy to understand, avoiding the use of jargon, acronyms, or medical language.

> There's so many things out there that you might have to put a little blurb that if you click on it, it explains what that particular item means. Because I talk to parents all the time – I saw, I don't know, 100-and-some of them this week – and they don't know the most simple terms and their children are older than mine. So sometimes we really have to be conscious of where people are in the process and what they've been exposed to. (Parent, female, PA)

> Like it needs to be really simple for parents to be able to go to, look at. And then if it's like a click – one or two clicks here, if you're clicking down five clicks away, most times folks are not going to read that. They're going to be overwhelmed with that. So, it has to be something they can get to really easy. (Parent, female, OH).

Further, the tool should be accessible to individuals with intellectual or developmental disabilities and caregivers who come from different backgrounds and socioeconomic statuses. Translations should be available to improve accessibility to non-English speaking caregivers. If an individual with intellectual or developmental disabilities uses the LTC planning tool, then caregivers suggested that the LTC planning tool have pictures, videos, and voice-overs to make using the LTC planning tool easier for this group of people.

> So when you do build this LTC planning tool, it's going to have to be ADA compliant. So that means that if – believe it or not, if they're blind, they'll be able to – any soft copy will be automatically transcribed in braille. Or if the person has a disability with speech, they'll be able to operate that LTC planning tool and get the information. So I mean, that's benefit. (Parent, male, PA)

> I mean the other thing though, I think they could probably be struggling with – for what we said is how complete do you make this? Do you want it to be accessible and, of course, that means the reading levels should probably be maybe seventh grade. You know what I mean? Do you want it to be accessible for people because the people who need it the most are the people opposite of us? (Parent, female, NY)

3.2.5 | Suggestions for LTC planning tool: Financial

Caregivers perceived finances to be a large hindrance to LTC planning, and suggested ways in which the tool could be helpful with financial

planning. This was talked about extensively as it was one of the biggest concerns in the LTC planning process. Quotes and comments that encompassed the financial planning aspect were coded under this 'Financial' node. Caregivers want the LTC planning tool to include information that explains options for financial planning and resources so that they may look for help if they need it.

> But under each thing, under financial, there is a link that you can hit that goes to almost like a separate little booklet but it's part of the website. It's a separate part of the website that will explain things to you. So here are your options financially. (Parent, female, DE)

> I'd like to know what the steps are toward getting a special-needs trust, which we basically had one set up years ago but we never really utilized. But we're looking at an ABLE account and – how to take those first steps. (Parent, male. PA)

3.2.6 | Suggestions for LTC planning tool: Housing

Caregivers made comments about finding housing options and resources. Some caregivers identified having a 'housing' section on the LTC planning tool with pertinent information that would be helpful to their LTC planning. Housing was of huge concern for caregivers. They worried about with whom or where their relative will reside in the future. Caregivers suggested that the LTC planning tool have resources and information about other housing opportunities, such as group homes or nursing homes, and information on ways to pay for housing.

> There's a lack of affordable housing for everyone. So I would suggest that on the housing tab that you would have links to the housing authorities for the states so that people can get on that. How do you get a Section 8 housing voucher? (Parent, female, PA)

> What are my living options? If she's under – she or he's under DDDS, what are the options? Shared living? Community living? Group Homes? Mary Campbell – parents don't know all that. They don't know their options out there. (Parent, female, DE)

3.2.7 | Suggestions for LTC planning tool: Government benefits

Many caregivers struggled with navigating through the Medicaid and Social Security systems. A lot of caregivers talked about the troubles they had with finding centralised information about the waivers that they could receive for their relative with intellectual or developmental disabilities. Bundled into these difficulties included trying to figure out

how to receive social security benefits. Caregivers suggested that the LTC planning tool should have descriptions on how to apply for Social Security Disability Insurance or HCBS Waivers.

> And understanding the waivers. Like how do the waivers work? (Parent, female, PA)

> Well, what's confusing about the other website is I don't know if there's a drop-down menu for each of those and that would be helpful. I think a drop-down menu would at least – if it said financial. So, for example, my suggestion was going to be that there be something put on there about benefits and Medicaid, Social Security. (Parent, female, NY)

3.2.8 | Suggestions for LTC planning tool: Organisation of resources

Caregivers gave specific suggestions regarding the inclusion of community resources in the LTC planning tool, such as resources that are age based, directed at finding medical resources, how-to and step-by-step guides, individualised resources (based on disability), and location-specific resources.

Comments included suggestions about the organisation and layout of the resources on the LTC planning tool.

> I think it's also – we're talking about these tabs and categories. Having subcategories and maybe having some type of focus group about what they look like, like transportation, like how to get there by car access to – how to get your driver's license. He's talking a lot about legal, power of attorney, different things, just having subcategories and creating some type of group where you could come up with those categories. (Parent, female, PA)

> So I think you have your person centered plan where the parents can fill in everything. But under each thing, under financial, there is a link that you can hit that goes to almost like a separate little booklet but it's part of the website. It's a separate part of the website that will explain things to you. (Parent, female, DE)

Caregivers expressed interest in wanting to know more about early intervention services, and finding medical resources such as doctors, dentists, and healthcare agencies, etc. (Finding Medical Resources).

> And the other thing too I think that should be on the tab is that there should be a link to medical providers who have experience dealing with this population, because that is also a problem in the adult world. (Parent, female, PA)

> For me, I think I want contacts. I want just agencies' numbers to contact, then I can go – so I can go to contact that person, get additional information, get information from that person for this particular reason. (Parent, female, NY)

> And I think it's important, like you said, that they be vetted, like maybe vetted through other organizations specific to a disability, maybe a Downs Syndrome organization who has a recommendation, or autism. Someone who has a recommendation of what they would recommend versus just kind of pulling something out of the Yellow Pages-type thing. (Parent, male, PA)

Finally, there were suggestions for grouping resources based on location (e.g., state, town, geographical area) and having a database to find resources based on where you live (Location Specific).

> And then if it's gonna be a national website, of course, you break it down for the states. Even in Delaware, maybe break it down to the counties because it could make a different of where you're living. (Parent, female, DE)

> Yeah, the website would – you can write this where if you live in Delaware, all the resources would be in Delaware. If you live in Pennsylvania, all the websites should be linked to websites. So you can write that query when I type in their basic information and then it should list all the state's resources. (Parent, female, DE)

> Or if you're moving, it'd be a connection to where you're moving to. If you were moving somewhere else, you would be able to type in that location, and at least get some kind of information about what's going on there… (Parent, male, OH)

4 | CONCLUSION

This national qualitative study of caregivers of individuals with intellectual or developmental disabilities found that caregivers continue to struggle in three areas needed to create LTC plans. Caregivers identified navigating the educational, medical, social services, disability services, legal, and financial systems as areas of highest need. Further, the expressed difficulty in finding reliable information to guide them in creating a LTC plan and knowing how and when to start the planning process. Ensuring accessibility is taken into account was important to caregivers. They stated that LTC planning tools need to consider ability, income, language, and culture, and be managed by people motivated by a mission to serve people with intellectual or developmental disabilities. Caregivers also pointed out the need for

planning tools to be customised by age or stage of life and suggested including information on financial and residential planning and integrate information on state and federal benefits like Medicaid and Social Security.

Creation of LTC planning tools is critical as more people with intellectual disabilities age-in-place in family homes. Changes in population demography, health policy, and cultural preferences continued to result in family caregivers assuming caregiving responsibilities for longer periods of time as more people with intellectual or developmental disabilities age-in-place in family homes: life expectancy of people with intellectual disabilities is increasing (Coppus, 2013); an estimated 71% of the estimated 7.4 million people with intellectual disability in the United States live in the home of a family member (Zablotsky et al., 2019); and nearly 60% of family caregivers may be over the age of 60 (Braddock, 1999); the availability of institution-based LTC services is decreasing (Watts, 2020); and families and self-advocates prefer to remain in community settings (McConkey et al., 2006).

Creating tools that overcome barriers to long-term care planning are critical. As echoed in our study and multiple previous studies, navigating the multiple systems to meet the needs of and subsequently plan the LTC of an individual with intellectual or developmental disabilities is overwhelming. Barriers cited by our participants echo that of previous studies: Though parents of people with disabilities worry about what will happen to their son or daughter when they are no longer able to provide care, many older family caregivers do not create long term care plans due to perceptions that they were still coping well; lack of confidence and available information about housing and other LTC options; and disparate funding and systems support (Innes et al., 2012). Unsurprisingly, the participants in our study did not begin long term care planning unless there was an emergency—such as a family caregiver becoming ill or a loved one being evicted—which is consistent with previous studies (Burke et al., 2018).

Evidence shows that families who received education around future planning and supports are more likely to engage in creating LTC plans (Burke et al., 2018). And while a general internet search for LTC generates multiple potential resources, a systematic review of internet use among family caregivers of people with intellectual or developmental disabilities found that (1) caregivers find the volume of information on the internet overwhelming; (2) internet-based searches are challenging and time-consuming to identify relevant information; and (3) misinformation or negativity is problematic (Caton et al., 2019). Consequently, integrated and curated LTC planning tools, such as The Arc's Center for Future Planning (The Arc's Center for Future Planning, n.d.) and University of Northwestern's Plan Your Lifespan (Lindquist et al., 2017; Ramirez-Zohfeld et al., 2021), are valuable. These interventions break down complicated decisions, present the range of LTC options, present curated information to learn more about these options, helps the viewer explicitly state their own values and preferences, and then prompts them to create a more concrete plan. For PlanYourLifespan, the tools also encourage individuals to share these preferences with others (Lindquist et al., 2017).

Unfortunately, creation of comprehensive LTC planning tools is also challenging. First, caregivers underscore a need for more support and educational resources across a wide variety of caregiving domains, including medical management, financial planning, and residential planning (Lindahl et al., 2019). Second, participants in our study requested that a tool include information on both broad categories of services as well as reflect local resources, a reflection of how services for people with intellectual or developmental disabilities are subject to federal, state, and sometimes county-level regulations and eligibilities. Third, tools that describe what is needed may not reflect the reality that there is an uneven availability of certain services by state and by region of the country. Consequently, even when families are eligible for LTC services, there may be insufficient providers to deliver those services. Finally, participants expressed the need to develop tools that are accessible to and account for differences in ability, race, ethnicity, and language.

Wide accessibility of interventions and those that account for racial, ethnic and language differences is critical. Compared to people without intellectual or developmental disabilities, people with intellectual or developmental disabilities are more likely to live in poverty or belong to minority backgrounds (Emerson, 2007; Heller & Factor, 2008). Accounting for diversity is particularly important given the significant disparities in access and health care outcomes by race, income, language among people with intellectual or developmental disabilities (Magaña et al., 2016).

A major limitation of this study was the lack of inclusion of perspectives of individuals with intellectual disabilities in our results and reliance on proxy responses. Proxy responses may have variable degrees of reliability with index subject reports depending on the subjectivity of the perception measured and the personal relationship of the proxy to the index (Nelson et al., 1990). The family caregivers in this study were primary caregivers of individuals with intellectual or developmental disabilities who had relatively low Waisman Activities of Daily Living Scores and had at least 1 problematic behaviour, reflecting a cohort with higher needs and impairment, and consequently more challenging to engage in discussions around LTC planning. While separate focus groups were held with individuals with intellectual disability, the information gathered from the focus groups were not included in these results. Individuals with intellectual disabilities who participated in the focus groups had a range of needs that were not amenable to full participation in a focus group setting and would have been more amenable to semi-structured interviews. This highlights important methodologic considerations researchers should make when conducting research with this population.

Another limitation of the study is the relative lack of diversity of our participants with respect to race, education, and income, despite efforts to recruit from large health systems serving diverse groups of individuals with intellectual or developmental disabilities. Findings may not be generalizable to some racial or ethnic minority groups or low-income caregivers and further research should be conducted to over sample caregivers of intellectual disabilities from diverse backgrounds who may be less connected to health care or social services.

In summary, LTC planning is challenging yet critical for family caregivers of people with intellectual or developmental disabilities. The COVID-19 further exacerbated the importance of long-term planning due to extra responsibilities placed on caregivers. In our study, family caregivers stated that they would engage in LTC planning with the availability of accessible planning tools with curated resources that covered the full range of LTC planning domains and reflected federal and state variations in eligibility and availability of services. Wider availability of existing tools or creation of new tools reflective of these needs may promote LTC planning among family caregivers of people with intellectual or developmental disabilities.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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