APPENDIX

A

SUSTAINABILITY PLANNING PROJECT

LITERATURE REVIEW

A Roadmap for Future Planning for Adults with Disabilities and the Families, Providers and Administrators that Support Them

Collaborative Strategies

SDAN

As the number of people with Intellectual and Developmental Disabilities (I/DD) living with aging caregivers grows, there is a need to establish continuing caregiving pathways guided by personal choice and control of resources across the lifespan. This review takes a deep dive into the literature (formal and gray) regarding the I/DD community needs and system approaches to later life (adult) sustainability planning in the US and internationally. The review is a component of a broader Maryland Sustainability Planning Project (SPP) that aims to support long-term caregiving (sustainability) planning for people with I/DD as their natural caregivers age and when they can no longer provide support to their person living with I/DD.

Introduction

An estimated 7.3 million people with intellectual and developmental disabilities (I/DD) live in the United States (Larson et al., 2018). About 1.6 million individuals with I/DD receive formal support through their state's developmental disability agency (Larson et al., 2022). Formal support may be administered through Medicaid Home and Community Based Services (HCBS: also known as "waivers") that provide in-home, residential, employment, or other supports that enable persons to live in the community. The number of people receiving HCBS, living with family, increased 143 percent between 1998 and 2018 (Larson et al, 2018). In Maryland, there are two models of HCBS service delivery: the self-directed model and the traditional model (refer to glossary). All Maryland waiver recipients receive case management support through Coordinators of Community Services.

The number of people with I/DD is growing and natural caregivers are aging. The Family Caregiving Alliance estimated 641,000 adults aged 60 + with cognitive and disabilities with that number expected to double by 2030 coinciding with the aging of the baby boomers (FCA, 2016). The Maryland Department of Health submitted a baseline report for fiscal year 2022 on utilization and cost of self-directed services as required by law. The report indicated that the Maryland Department of Disabilities (DDA) had a total of 18,787 active waiver service recipients of whom 2,042 (10.9%) were self-directing their services (Scott, 2023).

The number of people self-directing their waiver services has been steadily increasing. Some believe that the self-direction model allows closer connections to community following CMS guidance with potential cost savings or cost effectiveness (Edwards et al, 2020; CMMS, 2024). In addition, the number of people with disabilities that live with family members has been increasing (Anderson et al., 2018; Anderson et al., 2023) and currently, more than half (62%) of people with IDD receiving a Medicaid-funded service nationally and in Maryland live with their families (Larson et al., 2022). The 2017 FINDS (Family & Individual Needs for Disability Supports Community Report) Survey reports that number higher with 80% of responding caregivers reporting that their family member lived with them (a 5% increase from the 2010 report (Anderson et. al., 2018). The Family Caregiving Alliance report documents a similar number - 75% of people with I/DD living with a family member (FCA, 2016). At the same time, the natural caregiver population is aging: 1 in 10 caregivers is 75 years of age or older. (Anderson et. al., 2018). Furthermore, in 25% of family homes with an adult with I/DD the family caregiver is over 60 years of age (FCA, 2016). Family members (natural caregivers) are essential in coordinating /providing care to their family members with I/DD. As natural caregivers age, continuing pathways for sustainable long-term caregiving need to be established to ensure the continuation of services and supports. Yet most caregivers (54%) report they do not have a transition plan (Anderson, et.al 2018) .

Planning ahead can help guide a person with I/DD to lead a good life as independently as possible. A plan is important throughout all stages of life and especially in the future after the parent or caregiver is no longer able to provide support. Creating future roadmaps also should inform delivery systems and models as more people self-direct their services to optimize choice and control.

5 Overarching Themes

1. People with I/DD are closely connected to / rely on their natural caregiver.
2. This presents challenges and opportunities for later years transition as natural caregivers ages.
3. Self-directed care as an evolution of community based living. As the lifespan of people with I/DD increases (and as many have moved from institutional to community based living), many are likely to outlive their parents, many of which serve as natural caregivers.
4. There is little formal literature linking self-directed practices and later years transition planning.
5. Growing evidence that successful later years transitions planning may help maintain needed services and supports that foster independent living throughout the lifespan.

Methodology

The literature review was conducted utilizing Google Scholar, Marymount University's library database, and PubMed. Additionally, a reverse bibliography was employed to identify additional relevant articles from those found through the search. Major search terms used included "Concerns of Older Caregivers of People with I/DD," "Sustainability Planning for People with I/DD," "Sustainability of self-direction through major life transitions," and "Self-determination for people self-directing with Intellectual disabilities." As this project is focused on transitions that occur as the natural caregiver ages, literature focused on the transition of school-aged children to post-school was not included. The initial search also focused on studies conducted in the United States.

The search yielded around 35 articles. After excluding those articles that did not meet the inclusion criteria (published in English, published within the last 10 years, and focused on transitions/planning for older caregivers), the research was pared down to 18 articles. The majority of those excluded were focused on school-aged transitions. Studies conducted outside the U.S. were originally excluded but the decision was made to include systematic reviews and research studies from other countries published in English that met the other criteria as the information was notable and oftentimes more current than the information available in the United States. Additional articles and resources shared by stakeholders were also reviewed. After further review, nine articles were deemed to specifically address this project's question regarding I/DD community needs and system approaches to later life (adult) sustainability planning. Additional articles and resources providing examples of planning or models for planning were reviewed as part of the project's environmental scan and can be found in the scan appendix.

Findings in the Literature

Needs for Adults with I/DD and Families During Transitions of Care

The initial challenge to starting or documenting a plan is the ability or willingness of the family to start the planning process. Families are likely to fall into three different groups in terms of their readiness to plan; those who are unable or unwilling to make plans because it is too emotionally difficult or they distrust available services; those who have made what they consider to be "plans" but which have not been communicated to key stakeholders (including the person with I/DD and family members); and those who have made plans and these have been agreed by all concerned (Walker, 2018). Difficulties in talking about the future and avoidance of future planning occurs (Anderson-Kittow et al., 2024; Brennan et al., 2020).

For those that have started planning, discussions of future care are vague and aspirational as opposed to providing definitive plans (Lee et al., 2019, Lee & Burke, 2020, Walker et al., 2018). Future planning is often done informally. Families have reported being unsure whether their aspirational plans can be implemented as the plans lacked clarity, detail and specificity (Lee et al, 2019; Lee & Burke, 2020).

Barriers to Planning

Older people with intellectual disabilities and their families are highly aware of the need to plan for when parents can no longer care for their son or daughter at home, but that there are significant barriers that prevent successful transition planning. Numerous studies identified the emotional weight and nature of future planning, uncertainty about the future and inertia as primary barriers (Brennan et al., 2020; Burke et al., 2018; Chiacs et al., 2020; Lee & Burke, 2020). Most parents acknowledged that the need to plan was always in the back of their minds but was often met with a sense of paralysis or inaction due to planning being perceived as too hard to plan (Walker et al., 2018). Balancing overall life demands and lack of time were additional barriers (Burke et al., 2018; Lee et al., 2019; Lee & Burke, 2020). Additional family barriers included lack of communication and/or conflicts with family members (Lee & Burke, 2020) as well as reluctance of family members to engage in the process or to serve as caregivers (Burke et al., 2018). Additionally, parents worried about the burden future care and support roles would place on siblings (Kruithof et al., 2021). Interestingly, most siblings were not engaged in future planning despite the potential for impending caregiving roles. Some caregivers also identified a lack of overall knowledge, which impeded their ability to properly plan (Chicas et al., 2022).

There were also systemic barriers to planning including difficulty in finding reliable information about planning and available services (Chicas et al., 2022; Lee & Burke, 2020), financial concerns (Burke et al., 2018; Lee et al., 2019, Lee & Burke, 2020) and difficulty with system navigation or the absence of systemic supports (Brennan et al., 2020, Lee et al., 2019, Lee & Burke, 2020).

Correlates and Facilitators to Planning

There are some family characteristics that were correlated with increased future planning in the research. Participants who were older, in worse health status, more educated, had greater household income, and unmarried status were more likely to engage in future planning (Burke et al., 2018, Lee & Burke, 2020). However, the severity of the disability or functional ability of the individual was not consistently associated with future planning.

There were several facilitators, primarily related to family communication and social support, that were related to increased likelihood of future planning. This included attending parents training and support activities (Burke et al., 2018; Chicas et al., 2020), networking with other caregivers (Chicas et al., 2020), greater connection to the disability system (Lee & Burke, 2020), and greater family communication (Lee & Burke, 2020). Emergency situations such as eviction and hospitalizations are also associated with engaging in future planning (Chicas et al., 2020).

Domains of Planning

There was limited literature regarding the key domains for inclusion in transition and future plans. One study identified the following domains, presented in the order of how often they were discussed by parents and siblings of individuals with I/DD; housing; legal planning; identification of a primary caregiver or overseer; financial planning; day-to-day care; medical management; and transportation (Lindahl et al., 2019). In another study, caregivers identified navigating the educational, medical, social services, disability services, legal, and financial systems as areas of highest need (Chicas et al., 2022).

The *Charting the Life Course* framework, identified by SPP stakeholders for being a foundational planning tool, was developed by families to help individuals with disabilities and families at any age or stage of life develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. The framework details a series of life domains or pillars of support needs for people with I/DD to consider. The framework has been adopted by 22 states, including Maryland, as part of a community of practice (Grotto et al., 2019).

Promising Strategies

Facilitating family communication emerged as a key to successfully supporting families in future caregiving planning. Explicit family communication may address parental fears and expectations of burdening their children without disabilities, make siblings feel more prepared for the future and decrease the discrepancy between parents' and siblings' views regarding an expected future burden (Kruithof et al., 2021). Identifying and having specific discussions with the person or persons who will become the primary caregiver for the adult with I/DD in the future made it clearer and easier to plan many of the other domains (Walker et al., 2018).

Recommendations and Needs

There is a need for greater support and education for caregivers in creating plans for the future surrounding long-term care of an adult relative with I/DD. Areas of support include:

- Raising awareness and facilitation of planning conversations – A proactive strategy of education and outreach by service providers to start conversations about planning and facilitate family communications could help reduce resistance and emotional barriers to planning. Discussions about the future do need to begin with families early and involve active planning for the future, as opposed to waiting for older parents to seek out this information (Walker et al., 2018).
- Development of planning tools – The diversity of possibilities makes future planning a very complex activity requiring multiple decisions at each step of planning and within each domain of planning about what will be best for an individual. Families need information on what is possible and what their rights are, and support from social services to ensure that transitions allow people to maintain independence while remaining safe and well (Anderson et al., 2024). Additionally planning tools should consider ability, income, language, and culture, and if possible, be customized by age or stage of life (Chicas et al., 2020).
- Support and training for “new” caregivers – Engaging and training future caregivers in advance will better equip caregivers and facilitate transitions.
- Build examples of success – Examples from other families who had made successful transitions could help allay fears based on past negative experiences and give families ideas about how to set up their own solutions without feeling like they have to start from scratch or utilize options that don’t align to their needs.
- Highlight the benefits of future planning – Few studies have examined the benefits of future planning but the limited evidence available suggests positive outcomes for families once they engage in a future planning process (Brennan et al., 2020).
- Acknowledge the value of all levels of planning – While the goal is to have formal future plans with clear communication, even informal plans have value.

Early Identification of Best Practice Models, Emerging Practices and Opportunities for Innovation

A comprehensive review and analysis of best practice models, emerging practices and opportunities for innovation was undertaken through an environmental scan. Details can be found in the scan appendix.

Content and Approaches

- Having the person with I/DD at the center of the community living transition process with a clinical and administrative framework which promotes the emergence of self-

determination and the involvement of individuals with I/DD in their own transition (Longtin et al., 2020).
- Begin discussions about the future early and involve active planning for the future, as opposed to waiting for older parents to seek out this information. Encourage early engagement with the disability service system (Walker et. al., 2018).
- Concerted, systematic efforts towards developing awareness, knowledge and action around future care planning for families caring for adults with intellectual disabilities may be pushing an open door for some families (Brennan et al., 2020).
- Interventions focusing on increasing knowledge about future planning and peer support
- Policymakers should consider increasing the scope of ADRCs to provide information, particularly targeted to younger, low-income, and less educated families

Tools
- "Planning Ahead Cards' helped families to talk about the future and prepare for meetings with social care professionals (Anderson-Kittow et al., 2024).
- Web-based approaches to 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 (Chicas et al, 2022).
- Planning tools need to consider ability, income, language, and culture, and be managed by people motivated by a mission to serve people with I/DD. Planning tools should be customized 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 (Chicas et al, 2022).

Gaps/Considerations

While articles and research outside of the United States were not originally intended to be included in this project, some of the most relevant and recent research came from non-U.S. researchers. Throughout the available research, there was a lack of diversity in study populations, with participants being primarily Caucasian/Western European descent and often highly educated. Additionally, there is limited research available specifically on future planning for those self-directing where there are unique planning challenges.

Conclusions and Next Steps

There is growing evidence that successful later years transition planning may help maintain needed services and supports and that foster independent living throughout the lifespan. The available research supports the conclusion that parents and caregivers know they need to make plans for the future, but many do not want to come face-to-face with the reality that one day they will pass away and their children would need help through others. Initially, it was thought that the project would be centered around raising awareness and identifying key components of planning, but the research findings have elevated the need to also encourage, support and facilitate families to start planning.

The findings from this literature review will inform additional research and analysis as part of this project.

Additionally, we encourage research specifically related to future planning for those self-directing and identification of potential differences in planning domains. Community involvement and representation of all stakeholders should also be prioritized in future research, including caregivers, future caregivers, social services, funding entities, and self-directed individuals.

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