APPENDIX

E

SUSTAINABILITY PLANNING PROJECT

FISCAL AND POLICY TECHNICAL ANALYSIS

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

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Collaborative Strategies

SDAN

Introduction, Processes & Procedures

One component of the Sustainability Planning Project was to conduct a fiscal and policy technical analysis of eight promising sustainability pathways (Back Up Support Service, Enhanced Case Worker Models, Training for Future Caregivers, Planning Tools, Planning Consultation, Advocacy, Alternative Housing Resources, and Pooling Resources) of supports and/or services to support positive outcomes for people with I/DD, during times of transition when natural caregivers age. This work builds upon the initial project literature review and community survey findings. SDAN and Collaborative Strategies partnered with researchers from Open Road Inclusive Community Consulting to conduct the analysis.

The analysis was conducted using a qualitative methods, multi-goal and 5-E approach. Qualitative methods center people's experiences, perspectives on, and understanding of the world as opposed to things that can easily be turned into numbers (Ford & Goger, 2021). The researchers used this approach because there is much about the policy and financial considerations for the sustainability pathways that are not yet known and existing numerical data about their use and impact is limited. A multi-goal approach considers multiple and potentially competing objectives of different stakeholders in designing and evaluating policies (Bardach, 2012). A 5-E approach examines multiple aspects of policies including the possible **effectives**, **efficiency**, **ethical** and legal considerations, **evaluation** of alternatives, and **establishment** of recommendations for policy and practice considerations (Weimer & Vining, 2005).

To conduct this analysis, the researchers identified key informants who had deep insight into the use of 8 sustainability pathways, and how states regulate and innovate their systems of support. The key informants were selected from a national network of experts in the developmental disability service field compiled by The National Leadership Consortium on Developmental Disabilities. The informants held leadership positions in nonprofits that focused on advocacy and or service provision, and/or disability related government agencies.

The researchers used semi-structured qualitative interviews to ask questions about the key informants' perceptions of the potential benefits, the policy considerations, financial considerations, and the vision for how states could better support each of the identified sustainability pathways for families especially during times of transition. The experts also recommended policy documents that were then subsequently reviewed.

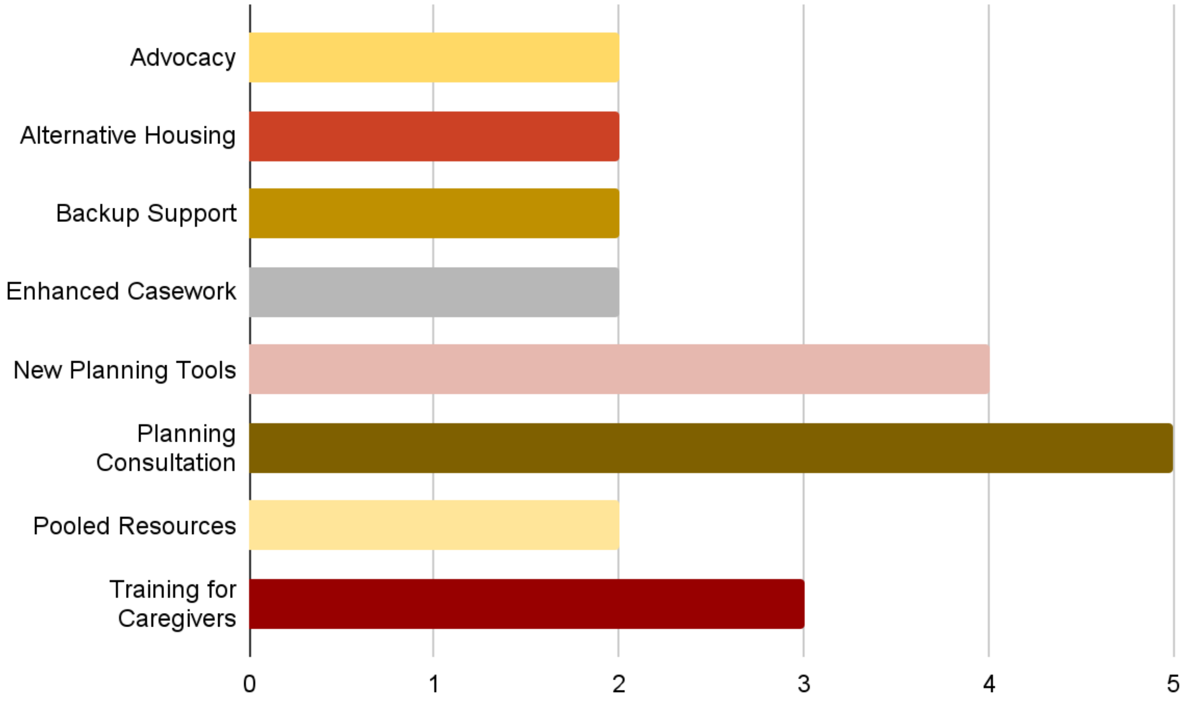
The researchers conducted 9 interviews. The interviews were recorded and transcribed. The transcriptions and documents were analyzed to look for important patterns and themes about the implementation, barriers, effectives, efficiency, and ethical considerations for each sustainability pathway. Content analysis looks at the patterns, themes, or concepts within qualitative data (Patton, 2002). The identity of the key-informants was kept private, and supporting quotes used in the report were de-identified. However, a general description of the key-informants is provided.

Key-Informants Description

Nine key informants with expertise in advocacy, alternative housing models, backup support, enhanced case work, new planning tools, planning consultation, pooled resources, and training for caregivers were interviewed for the fiscal and policy analysis. Key informants represented various local, state, and national organizations, including state government agencies, national advocacy, research, and education organizations, training and consulting firms, and provider agencies. All key informants worked in director, executive, partner, or founder roles and had both substantial tenure and experience in the disability service sector. They worked in eight states, representing the northeastern, southeastern, midwestern, and western regions of the US.

Chart 1 shows the areas of knowledge and experience represented by the key informants. Many people interviewed had professional experience and/or worked in organizations that addressed several key areas of the study.

Chart 1: Expertise of Key Informants



General Findings & Recommendations Across Sustainability Pathways

The experts we talked to believed:

- All the sustainability pathways have the potential to benefit the person with I/DD and their families and save money.
- All the sustainability pathways need to be used with a curiosity and understanding of who the person is, what they want and what they need in their lives.
- People with I/DD and their families are the best people to share with others about what the practices are, how they can be used and how they should be changed as we learn more about them.
- State systems can better support these practices by investing money and other resources to help people learn about these practices, how to use them, and how to make sure families record what they do in a way that meets the state's rules.

General Findings

- All the sustainability pathways have the potential to positively impact the experience of people with I/DD, especially those using self-directed services as natural support providers age.
- Informants believed all could be cost effective by helping to prevent costly physical and behavioral health crises and prevent placement in restrictive congregate care following the loss of a natural support provider.
- Most sustainability pathways did not require major policy changes; however, some required a broadening of interpretation of covered services or other rules with DDA waivers and changes to ensure that policies across different service systems like aging and housing did not contradict one another. Some pathways were already services covered under DDA waivers, but steps needed to be taken to expand the pool of approved vendors for those services.
- Many if not all of the models were integrally connected to other models and required the implementation of some of other models to be in place to work well.
- Many highlighted that though the pathways were likely efficient, arguments for the models should not be based on cost savings. There was concern that when states adopted models specifically to reduce costs, they cut back on investment in the infrastructure needed to make the models work well and the quality of support declined.

- Most of the costs/investment areas and recommendations involved:
    - Investing in understanding the current infrastructure of DDA and other service sectors like aging support, housing, and food benefits.
    - Investing in improving the infrastructure to reach, better communicate and establish ongoing relationships directly with people with I/DD and their families.
    - Supporting infrastructure to support a variety of paths towards implementing the models so that they could ensure the models were adaptable to meet the needs and be culturally relevant to different communities.
    - Investing in expanding access to family and peer-support providers. Peer and family support were seen as the primary path to help families begin the challenging conversations necessary for future planning early.
    - Investing in technology to improve training and communication amongst support staff and investing in technology to support the independence of those using services.
    - Investing in and engaging in cross-system advocacy and collaboration. Cross-system collaboration may involve collaboration with aging services, housing services, and nutrition support. Additionally, connecting people with I/DD and families to outside professionals such as lawyers is also important.
    - Advocating for and investing in pilot projects to explore the sustainability pathways further, identify how they can be successfully implemented and their impact on people with I/DD and families. This information can be used to establish better data about each model.
    - Investing in better infrastructure around self-directed services in general to help ensure that those using self-direction and their supporters who are engaged in innovation are able to stay compliant with shifting rules and regulations.

Findings By Pathway

Alternative Housing

"The affordable housing stock in Maryland is crap."

Introduction & Possible Effectiveness of Pathway

The availability of safe, affordable, and accessible housing is essential to independent living and the continuation of independent living during times of caregiver transition for people with I/DD. The supply of safe, affordable, and accessible housing is insufficient across every state in the United States (NLIHC, 2023). A lack of suitable community-based housing options increases the risk for institutionalized, congregate care for people with I/DD when their natural support providers age. This includes, and may particularly apply to, those who live with family caregivers and are self-directing their services. Once people are forced by circumstance to move into traditional, congregate care, informants noted it is very difficult to transition out, as there is little incentive for provider-based, residential service providers to help someone transition to a new type of service.

The key-informants identified recommendations, potential barriers, and ethical, legal, fiscal considerations for alternative housing options for people with I/DD. Additionally they directed the researchers to review policies and other documents related to "shared living", "affordable housing", "permanent supportive housing", and "811 vouchers" on both the Maryland Department of Developmental Disabilities and the Maryland Department of Housing and Community Development webpages.

Creativity and the expansion of existing alternative housing options were seen as effective and essential sustainability pathways to support the sustainability of self-directed services when natural caregivers are no longer able to provide care. This pathway, however, only works in congruence with other pathways. For instance, enhanced case management may help the person and family connect with housing navigators to identify, explore, and access available housing options. Housing without well trained and well supported caregivers and back-up supports when needed will not be sustained. Effective use of planning tools and planning consultation may help people and caregivers identify what are important considerations in housing options and identify and access needed resources to attain and sustain the housing. Legal consultation during planning may help families identify options for transferring home ownership.

Additionally, under the right circumstances, pooling resources may be a useful strategy in navigating the limited supply of available, affordable housing. For instance, if one family leaves a house as part of an inheritance to a loved one with disabilities, pooling resources during planning may allow for a friend who also uses services to live in the home and share staffing or other needed resources. To address system barriers to alternative housing options that account for the needs and wants of people with I/DD requires advocacy and educating policymakers about the current limits, barriers and untapped opportunities in the existing housing and service system.

Evaluation of Options, Alternatives, and Barriers

Informants identified several housing models that are alternative to institutions, group homes, or other congregate care for adults with I/DD in Maryland. They included shared living, pooling resources, homeownership or home rental, low-income rental assistance programs, including voucher programs, and project/unit-based rental assistance. They also included tools and resources to help increase the availability of safe and affordable housing units in the state, resources to make home modifications, tools and access to professionals to help people identify their housing needs and options and access or sustain housing.

- Housing Support Services are available to those who use DDA waivers to provide 1) Housing Information and Assistance; 2) Housing Transition Services; and 3) Housing Tenancy Sustaining Services.
- Shared Living options involve a host who is generally not a member of the person's family (though siblings may be exempt), opening their home, sharing their lives and providing some needed support with the person with I/DD. This option is not dependent on the availability of affordable housing units.
- There are options for financial assistance for home modifications to ensure existing housing is accessible.
- Maryland also offers general Housing Choice Vouchers and project-based rental assistance to low-income, non-elderly adults with disabilities like the Section 811 Vouchers. There are also Permanent Supportive Housing options though people with I/DD are often not prioritized for this program unless homelessness is imminent.
- Additionally, there are private, state, and federal partnership programs that offer incentives to builders in terms of interest free capital for builders of affordable housing units for people with disabilities in integrated housing complexes or scattered housing across communities.
- Maryland Inclusive Housing provides housing information for people with intellectual and developmental disabilities and their families.

Despite a multitude of paths to alternative housing solutions for people with I/DD and their families, people face many barriers to accessing safe, affordable, and accessible housing especially during times of transition. Specific, identified barriers and challenges included

- Insufficient funding for housing support and navigation specialists in the Waiver programs. Supporting Quote:
    - "*Housing navigation is in our waiver. The harder part is getting the financing for what you need to make the program effective in your waiver.*"
- Conflicting regulations between County, State and Federal housing services and DDA waiver services. Many of the regulations are onerous and limit people with I/DD's options to access affordable housing. Supporting Quotes:
    - "*Developers who make accessible units do not necessarily know to email DD service providers, or brokers. After 30 days they give it to whoever is on the waiting list whether they have a disability or not.*"
    - "*There is housing support to help people move and get set up in a new home, but if someone with a disability applies and is granted that funding and money goes into their bank account, they might get kicked off SSI.*"
    - "*There is some home renovation covered under DDA WAIVER, but you need 3 estimates and then to get it approved. In all the time it takes, you may lose the contractor, or you lose the voucher that would have allowed you to move in the first place.*"
- There are not enough people to provide housing navigation and housing support for the number of people needing that service. Those who do provide housing-specific support often have limited knowledge of the needs and experience of people with I/DD and Maryland DDA regulations. Support brokers, and disability case managers often lack sufficient knowledge of Maryland's housing system and programs. Supporting Quotes:
    - "*The caseload of case managers is too high across the board.*"
    - *"Some who work in housing navigation don't know much about the experience of people with I/DD and may say 'you always have the option of a group home. You won't be homeless.' and not direct them to resources they could use. Many who work in the DD have almost no knowledge of housing support options because housing programs are complicated.*"
- Most counties in Maryland lack affordable housing stock and in rural areas where affordable housing may not be as challenging to find, sufficient availability to direct support providers often limits housing options. Supporting Quote:

    - “*The affordable housing stock in Maryland is crap.*”
    - “*Rural areas may have a better housing stock but lack enough direct support providers to make it work.*”
- Shared-living options are often lacking due to limited availability of host families and for shared living to be sustained there needs to be time spent on training the host family and ensuring a good match. Supporting Quote:
    - “*Shared living can be wonderful, but if states cheap out on the time it takes to ensure and support a good match, it becomes another version of foster care and often doesn’t work out for anyone.*”
- Pooling housing resources can be legally complicated and often requires legal and financial guidance. Supporting Quote:
    - “*Pooling resources isn’t about putting people who aren’t your family in your will. There are other ways. You may leave your house to your son or daughter but write an agreement for a member of another family to share that home and share support staff or other types of resources for a certain amount of time.*”
- Many people with I/DD, their support providers and families are largely unaware of housing support services and how to access them. Supporting Quotes:
    - “*There is the Section 811 voucher, but the application is complicated.”*
    - *“A lot of people with I/DD don't know much about housing vouchers. You can request your voucher stay the same and not go up with rent increases, but you have to request it and if you don’t request it your rent will go up.*”
- Voucher and project-based housing assistance programs have very long waiting lists. Supporting Quote:
    - “*There are some counties with a 7-15 year wait list for project-based rental assistance programs.*”

Ethical & Legal Considerations

The key informants did not think new laws or policies were needed to support alternative housing options for people with I/DD. They noted that there were several existing policies and programs that support alternative housing already included in DDA waivers. They include:

- Maryland has recently included Housing Support Services under DDA waivers which include the Family Supports Waiver, Community Supports Waiver and the

Community Pathways Waiver. These services are time limited and include support to help people identify and navigate housing opportunities, address barriers to housing and obtain housing or remain in a current rented or leased home.

- Shared living is covered in the DDA waivers. In shared living programs, a host who is generally not a member of the person's family opens their home, shares their lives, and provides some needed support with the person with I/DD.
- Maryland has nearly 7 million dollars invested in Section 811 Project Rental Assistance Program. The program provides project-based rental assistance to low-income, non-elderly adults with disabilities and provides interest free capital for builders of affordable housing units for people with disabilities. Some units are integrated across complexes, scattered across the community and some complexes that are less inclusive where 100% of units are for low-income, adults with disabilities.
- Maryland has searchable databases for affordable housing units.
- Maryland also offers options for Permanent Supportive Housing (PSH).
- All housing, for people who access Medicaid funding for their services, must be compliant with the CMS Final Settings Rule, which prohibits that Medicaid funds be used in settings that have "institutional qualities." These settings would include "disability communities" or "farmstead communities" for example.

Cost and Efficiency Considerations

- Policy experts universally agreed that investments to keep people out of institutionalized care had a positive net-return. Even though there are substantive costs for addressing the safe, affordable, and accessible housing crisis, the cost of inaction including the risk of homelessness and institutionalization was higher.
- Areas of cost for supporting alternative housing paths include funding to attract, train, cross train (between housing services and DDA services) and retain qualified housing and DDA case managers.
- Costs also include creating a better infrastructure for property managers and builders to communicate directly to disability service case managers, families, self-advocacy, and support brokers when affordable housing units for people with disabilities become available.
- Investments need to be made to ensure disability waiver related and housing policy related county, state and federal regulations do not contradict one another or make services across systems inaccessible. Taking the time to collaborate, strategically plan and coordinate between disability and housing policy takes time and funding.

- Shared living arrangements have costs associated with recruiting more host families, having sufficient resources dedicated to ensuring the match between the person using services and the host family is a good one and that the host family is sufficiently trained.

- Greater investments to encourage the building of more affordable housing for the community in general and targeted towards people with I/DD is needed to address limits in the housing stock.

Establishment of Recommendations

- **Advocate for pilot projects**. Advocating for greater funding for alternative housing paths is always hard and housing is a high-cost priority. Good data makes arguments more effective, and states are more likely to fund smaller scale pilot programs related to alternative housing paths. Pilot projects can help to establish the potential risk and returns for greater state investments.

- **Work across systems.** Those who work in the social service sector often have an incomplete picture of the service infrastructure. Investing in time and space to collaborate and strategically plan to fully understand the existing programs, rules and regulations related to existing programs and ensuring rules and regulations allow for cross-system support is essential.

- **Establish stronger infrastructure for communication** between those who develop or rent affordable housing allocated for people with disabilities and those within the disability service system.

- People with disabilities and their families are more likely to explore alternative housing options when there are credible messengers of other people with disabilities and or other families who have used alternative housing. This may require **expanding the pool of designated peer-support vendors**.

- **Plan early.** Transition specialists in high school should work with families to consider housing options early and get on waiting lists for affordable housing support early. Wait lists can be many years in some counties and early planning may open new options.

- Those with intimate knowledge of the experiences of people with intellectual disabilities and disability services should be at the table during reallocations of Maryland's Qualified Allocation Plan (QAP). **QAP'**s determine how states allocate their tax credits for affordable housing and may for instance allow for a higher priority for affordable housing units for people with I/DD.

- Ensure investments in alternative housing, such as Shared Living have **sustainable funding** that allows sufficient recruitment, sufficient time to ensure a good match between the host family and the person with a disability and ongoing support.
- In areas with exceptionally limited housing stock **consider working with county zoning boards** to make it easier to apply for **accessory dwellings** that may be prioritized for people with disabilities.

Planning Consultation & Planning Tools

> *"A plan is just a piece of paper unless it's part of an ongoing conversation where people have the genuine intent and curiosity to keep it going. Tools are no substitute for relationships. But good tools can help to reestablish needed trust."*

Introduction & Possible Effectiveness of Pathway

The key informants often discussed planning tools and planning consultation together. Additionally they directed the researchers to review several websites and documents including The Administration on Community Living, DD Coordinators of Community Services Training Matrix, Maryland DDA's, 2024 Procedure Code and Rate Charts, Frequently Asked Questions Document, LifeCourse Nexus, LifeCourse Connect, Quillo, By Their Side, The Maryland Developmental Disabilities Council Handbook on Futures and Estate Planning, and The Arc Center for Future Planning amongst others.

New planning tools involve the development of standard, yet adaptable planning tools to aid families in creating their plans. Planning consultation involves technical counsel and emotional support to families as they develop long-term care plans. Planning consultation involves new training models and tools.

The key informants noted that new planning tools and planning consultation services are highly effective paths for helping to ensure the sustainability of support for people with I/DD during times of caregiver transition. Good tools and consultation provided by trusted people can help families and people with I/DD ask important questions about future planning early, identify and begin to access needed resources which can sometimes take a long time to develop, and avoid worst case scenarios when a natural support provider is no longer able to provide care.

They noted that good planning tools and consultation services included can help to avoid physical, emotional, and behavioral crisis, ease or prevent some of the trauma related to sudden caregiver disruption and prevent unwanted moves into congregate or restrictive settings. Good planning tools may help train future caregivers to deeply know the person they are or will be supporting, what they are proud of, what brings them joy, how they communicate, what their goals are, what they fear and dislike. Deeply knowing the person helps keep people safe and helps to support the continuation of good care. Planning tools and consultation can also help people think about legal considerations like estate planning and connect them to professionals who can help with those processes.

Planning tools used in conjunction with planning consultation facilitated by trusted, credible messengers may help families navigate the emotional barriers to planning. They may also be helpful in helping families begin to learn "*what they do not yet know, but need to know*.", "*feel more confident navigating the alphabet soup of services*" and mobilize "*non-systems based*" support, like others in their Circle of Support, more effectively.

Evaluation of Options, Alternatives, and Barriers

The key informants noted that there are several tools and consultation services that Maryland's DDA system has adopted or promoted on their website which may be helpful in the future planning process.

They include LifeCourse Nexus, LifeCourse Connect, Quillo, and By Their Side advocacy and oversight services. The Maryland Developmental Disabilities Council also offers a handbook on Futures and Estate Planning. Though not yet listed or promoted on Maryland DDA's website, The Arc Center for Future Planning has planning tools, examples of how others planned, urgent or emergency resources, and a database of future planning professionals like facilitators, lawyers, pooled trust experts and protection and advocacy professionals.

Future planning consultation or facilitation could be facilitated by support brokers and/or case managers. However, many noted that family members or self-advocates with lived experience may be the most credible messengers and may be most effective at providing this service.

Though several resources on future planning are included on Maryland's DDA website, people may find it difficult to access these tools. In addition, DDA's Person-Centered Planning manual states that questions about future planning are vital and should be included at all planning meetings, however information about future planning is not necessarily required for a Person-Centered Plan to be approved.

Requiring that information may prompt more people to engage in conversation about future planning earlier, however it would also involve ongoing, direct, communication with people and their families about the changes and training and support for people who review and approve plans. Requiring items in a plan doesn't necessarily mean the planning is sufficient or even person-centered. The plan and consultation must be used as part of an on-going, person-centered conversation that may be facilitated by existing or new tools. The inclusion of items related to future planning on person-centered plans is currently a training outcome for the training required for Maryland DDA Coordinators of Community Services.

There are several barriers that impact the use and potential benefit of new planning tools and planning consultation services. They include:

- New tools and technology often scare people. Most people are not early adopters of new ideas. Any change in planning tools will require frequent communication and ongoing support for use.
- Self-advocates and family members are often exhausted by changing rules and regulations, especially if the immediate value of the change is unclear. Supporting Quote:
    - "*Families and self-advocates are used to not getting what they want and often feel pushed around the system that seems to change what they require on a whim*."
- Planning consultation that involves the use of family and peer support will require more vendors who are trained and approved for this service.
- If consultation is done through case managers, they need more time. Often meeting agendas are full and there is not much time to really listen to the concerns and wants of the person at the meeting. Addressing emotionally heavy conversations, like aging caregivers, requires trust and trust takes time. Supporting Quote:
    - "*You can't just dive into a conversation about a person's potential injury or death or their loved one's potential future injury or death. These are vulnerable conversations that need to be held in the context of trusting relationships. The number of things support brokers or case managers have on their plate is too much. They might not, the way things are now, have room to build the trust needed for these types of on-going conversations.*"

Ethical and Legal Considerations

- The key informants did not necessarily think that new laws would be needed to implement the use of new planning tools or planning consultation. One said, "*There are several good tools out there. I like the Life Course Nexus because it can help people think outside of formal systems*." Though requiring future planning items on annual person-centered plans may require a policy change.
- Future planning and a list of some planning tools and consultation services are already listed on DDA's website.
- Including future planning items within Person Centered Planning is listed as a learning outcome on the latest Coordinator of Community Services training matrix.
- Tools and conversations must be adaptable to be socially and culturally relevant to different communities.

- Family and peer support and planning meetings that may include conversations on future planning are services included under all DDA waivers.
- Maryland has partnered with the Life Course Connect and Quillo to support the future planning process.
- Though there are searchable sites for lawyers with expertise in estate planning, their knowledge of the experience of people with I/DD and their families may be limited. It is important to have lawyers with some knowledge of person-centered planning and supported decision making.

Cost and Efficiency Considerations

- Planning tools and resources would not add considerable costs as many of them are already an option for Maryland families to use and are linked on the DDA's website.
- The key informants believed good tools and good consultation can help to reduce crisis and all noted that reducing the use of emergency rooms, emergency behavioral health services, and congregate care is always worth the investment.
- Better organizing tools and resources on the DDA's website and making sure all links to resources in the person-centered planning guide are active may have a small cost.
- The larger cost goes into creating an infrastructure to better communicate directly with people using services and their families as opposed to having messages filtered through provider organizations or case managers. Creating an infrastructure to support direct and ongoing communication would likely be a higher cost. Supporting Quote:
    - "*90% of the system's communication goes directly to providers and then maybe they give families or people with a disability a flyer or have a meeting. We need to invest in better ways of communication especially for people using self-directed services.*"
- If planning tools have databases to other relevant professionals (like lawyers) there is a cost to ensuring the system is up to date.
- Supporting the training and approval for more peer and family support specialists may also have a larger cost.
- If case managers and support brokers are to include planning consultation in their services more billable hours for planning meetings, and lower caseloads may be needed.
- Time and space to connect with organizations outside of the developmental disability service field such as Area Agencies on Aging, the Administration on Community

Living and Law Groups may be important. One informant noted that traffic on their future planning site increased dramatically when they invested in outreach to other organizations and systems.

Establishment of Recommendations

- **Support an infrastructure to improve ongoing, direct communication** with families and self-advocates that is not always filtered through providers and case managers.
- **Support the recruitment and training of more peer and family support professionals** who are DDA approved vendors. Ensure peer and family support professionals are from diverse communities to help ensure services are socially and culturally relevant.
- For planning tools that can be used across the lifespan, **introduce those tools to families early and often.** Working with professionals in early intervention, Parent's Place of Maryland, or those who work in secondary education transition planning may help to ensure plans and conversations about aging are started early.
- **Invest in communication and connection** with organizations and agencies **outside of the developmental disability service field.**

Enhanced Case Work

"The size of caseloads is too high. Agendas at meetings are too full and people often get bulldozed over. It becomes harder to build the trust needed for hard conversations and to think about anything beyond the most immediate pressing concerns."

"Families sometimes end up with a lot of 'support' and 'management' but very little 'help'."

Introduction & Possible Effectiveness of Pathway

Enhanced caseworker or case management model involves caseworkers having lower caseloads, more time with each client, and training to help oversee waiver service delivery and maintenance of waiver and benefits.

The key informants believed that this could be a highly effective pathway to better supporting the sustainability of self-directed services and lives for people with I/DD during times of caregiver transitions in several ways. These include:

- More time with each person and their Circle of Support would help caseworkers better establish or reestablish trust in the helping relationship. All informants noted that trust was essential to having the sometimes emotionally laden conversations about aging, changing care needs and death. They noted that caseworkers and those they serve are often challenged by the "*tyranny of the immediate*". Due to limited time, caseworkers prioritize immediate needs over long term or bigger picture goals and planning. The enhanced case management model may help circumvent that challenge. Supporting Quotes:

  - "*Conversations about future planning are vulnerable conversations. What's more vulnerable than thinking about your own death and what's going to happen to your child? Case managers need to engage in behavior to establish trust to effectively facilitate these conversations. The model of case management we have now, with their current caseloads, is often not possible.*"
  - *"The size of caseloads is too high. Agendas at meetings are too full and people often get bulldozed over. It becomes harder to build the trust needed for hard conversations and to think about anything beyond the most immediate pressing concerns."*

- Caseworkers with lower caseloads, more training and support may also result in less turnover which would allow for a stronger continuity in conversations about future planning and sustainability. Supporting Quotes:
  - "*It's a tough job. You have so much responsibility and often very little support. Caseworkers are also sometimes the messengers or "the face" of the broader system for families and can be the ones who alert families of unwanted changes, or bad news. This can make establishing trust under the best of circumstances very hard. Not having the time or resources you need to do your job well can be demoralizing."*
- Lower caseloads may also mean that case managers/workers will be better able to support those using self-direction in staying in compliance with current or changing regulations, avoid the suspicion of waste, fraud, or abuse, and prevent resources from being taken away. They noted that families often fear being honest about how they are making things work, what their needs and wants are. This honesty is vital to people's support stability as natural caregivers are no longer able to provide that support. Supporting Quotes:
  - "*We often don't know what problems families are facing or how they are currently making things work. This is important information, but many people and families are afraid that if they complain the system can always make things worse and if they are honest about what they are doing they will be told it's against the rules*."
  - "*People and families using self-directed services must be extra careful to avoid any suspicions of waste, fraud, and abuse for the service model to*

continue. To stay in compliance and avoid that scrutiny they need better information and better support."

- The key informants noted that waiver services do not meet all of everyone's needs who use them. For instance, many people who use DDA waivers also use housing vouchers or subsidies, SNAP food assistance or other types of support that often come with their own case workers. Case workers from different service systems often lack knowledge of the other systems. Enhanced case work may allow for better knowledge of other types of services and lead to more effective support. Supporting Quotes
    - *"For some families, there are so many case workers for different programs or people in their families that they need their own case workers. Families often end up with a lot of "support and management" but very little help."*
    - *"Those who work for instance in housing often know very little about the rules and requirements in the DD waivers and vice versa. That can lead to conflicts and to people not getting information about resources that could really help them."*
- Enhanced case management may also help support better physical and behavioral health outcomes. Supporting Quote:
    - "*I know in behavioral health enhanced case management is sometimes used to reduce an overuse of the emergency room and from what I understand it is very effective*."

Evaluation of Options, Alternatives, and Barriers

- Some key informants believed that an effective strategy to support enhanced case work was to collaborate more closely with Managed Care Organizations (MCO's). They noted they are a sometimes-discounted partner in coordinating and managing quality, person-centered support. Supporting Quote:
    - "*MCOs often get a bad rap because they are insurance companies. From my experience there are many people who work within them that are interested in person-centered care and they can be powerful partners in changing people's experience with services in positive ways*."
- Some key informants suggested that states explore new technology to improve communication, quality of training and reduce the administrative burden for case workers in the current model and in an enhanced model. Supporting Quote:
    - *"Good technology can make case worker's lives a lot easier."*

    - *"It's not always about the amount of training, but does the training align with what we know about adult learning. Using technology in creative ways may lead to better training."*

- Others noted the potential in cross training between housing navigation case workers and waiver case workers. Supporting Quote
    - "*It would be great if housing and DDA waiver services had more knowledge of one another. Case workers could play an important role in this.*"

- Some key informants noted there was strong potential between collaborating and cross training between case workers under the aging waiver and DDA caseworkers. They noted that this could be effective in terms of addressing the needs of the entire household, keeping greater residential stability for longer, and may also be cost efficient. Supporting Quote
    - "*When we look at future planning, we are often looking at dual generations requiring support at the same time. Effective collaboration across aging systems and developmental disability systems may allow for both generations to stay in their home for longer and to find solutions to meet the needs of the family as a whole.*"

The key informants noted at least one major barrier to enhanced casework:

- Many noted that proposed cuts to Medicaid would make reducing caseloads, adding more support, and training for caseworkers very difficult. Supporting Quotes:
    - "*The budget does not currently support caseworkers to have smaller caseloads or fit in more training with their current requirements."*
    - *"If they turn Medicaid into a block grant it would not necessarily be a bad thing. It can allow for more flexibility. If they cut it by 30% though. God, that would be devastating."*

- Others also noted that downward fiscal pressure and workforce challenges may spur innovation, but there must be enough resources to support the infrastructure needed to sustain innovation.

Efficiency & Fiscal Considerations

The primary costs for the enhanced case work model identified by the key informants included:

- Spending on recruitment of new case workers.

- Cost to develop, add, and/or expand existing caseworker training.

- Cost for ongoing, high quality, support, training, and communication. Support and training for caseworkers and communication on new topics needs to be sustained over time.
- Time to collaborate across service systems to understand how caseworks could be cross trained and what policy changes would be needed to work across multiple waivers.

Despite these cost areas, the key informants believed enhanced case management to be a cost-efficient pathway for several reasons. They included:

- Enhanced case management can reduce physical and behavioral health care costs.
- Like all other pathways it has the potential to reduce the unwanted transition into more restrictive congregated settings.
- Enhanced case work may allow for an aging family member and one with a lifelong disability to use one case worker together. This would be more efficient.
- Better training and lower caseloads tend to reduce turnover of case workers which leads to better services and lower cost for the state.

Ethical and Legal Considerations

The key informants noted that enhanced casework that involves working across multiple waivers or service systems may require policy changes.

- Though enhanced case management or casework is not currently a covered service across any of the DDA waivers, it is a model used by Maryland's Medicaid 9 managed care organizations as part of the MOM (Maternal Opioid Misuse) program. This is a 5-year demonstration project funded by the Federal Center for Medicare and Medicaid Innovation. As such it would not be a novel concept for the state.
- If the model of enhanced case work involved working across multiple waivers or multiple service systems, policies would need to be changed so that not all potential funders describe themselves as "funders of last resort. Supporting Quote
    - *"If for instance someone is working across the aging and DDA waiver, they both can't be funders of last resort. If everyone is a funder of last resort then nothing will get funded, or at least it will take a lot of back and forth."*

Establishment of Policy Recommendations

- **Explore and invest in the use of new technology** or new platforms to reduce the administrative burden on case workers and improve the quality of training.

- **Collaborate** with those who oversee case workers from multiple service sectors settings and Managed Care Organizations to determine specific training needs, and policy changes needed to enact enhanced case work.
- **Invest in strengthening the workforce** pipeline for case workers.

Training for Future Caregivers, & Backup Support

"Siblings are often not part of the conversation when parents start to plan when their child with a disability is transitioning out of high school… It's often not until siblings are in their 30s or 40s and getting thrown into positions of caregiving after a traumatic loss of a parent without the needed support and need to support their sibling who is also experiencing a traumatic loss."

Introduction & Possible Effectiveness of Pathway

Training for future caregivers and backup support were also identified as necessary and effective pathways for the sustainability of self-directed services during times of transition. Backup support services involve a service that would guarantee substitute staff are available to support waiver participants when regular staff call in sick or are not able to make their work shift. Training for future caregivers involves the development of training modules and coaching support that help future caregivers understand how to navigate the system and plan for implementation.

- The key informants noted that reliable access to backup support when support staff call out or are no longer available is often a primary challenge for people using self-directed waivers. The challenge is more pronounced when primary natural caregivers like parents are no longer able to provide care. Supporting Quote:
    - *"If people were able to be the employer of note to a back-up support provider agency that would likely ease the anxiety some people have. They know if their staff calls out, at least someone will show up."*
- Some noted that the need for backup provider agencies is partially related to insufficient development of Circles of Supports. Supporting Quote
    - *"You have your Circle of Support, but it's more of a point than a circle. You just have mom and a few people who get on a call a few times a year. Ensuring circles of support are active and engaged is important, especially during times of transition."*
- The key informants noted that supporting future caregivers and engaging them early in the planning process is highly important. Supporting Quote

  - *"Many families start to paint a picture of what life will be like for their child with a disability when they are transitioning out of high school. Siblings, who are expected and may want to support their siblings when their parents no longer can, are often in that same age cohort as their sibling, so it's not always developmentally appropriate for them to be part of that conversation then. However, too often there is a long gap, where they aren't involved at all until crisis hits. Siblings are often not part of the conversation when parents start to plan when their child with a disability is transitioning out of high school. Siblings are often then in their 30s or 40s and getting thrown into positions of caregiving after a traumatic loss of a parent without the needed support and need to support their sibling who is also experiencing a traumatic loss. It would be better for everyone if siblings or future support providers were better supported and involved earlier in the process."*

- Effectively engaging, training, and supporting future caregivers and ensuring reliable and quality backup supports may reduce the chance of crisis, reduce stress for the person and family, promote wellbeing and the sustainability of self-directed services.

Evaluation of Options, Alternatives, and Barriers

- The key informants noted that the other sustainability pathways, especially planning tools, planning consultation and advocacy are necessary to ensure back-up support and training for future caregivers is effective. Supporting Quotes
  - *"Future caregivers need support not only in how to do the right paperwork or provide direct support to their loved ones, but they need to learn how to navigate complicated systems. Parents often spend the entirety of their child's life learning these systems and siblings are often just thrown into it after a difficult loss. They need better access to peer support and advocacy training."*
  - *"Caregivers often face a lot of stress, ensuring people stepping into that position have the support they need is essential. Peer-support is very helpful."*
  - *"Better planning tools and technology that allows for effective communication about who the person is, how they communicate, what brings them joy and how to best support them is essential."*
  - *"There are some settings in which there may be natural, untapped sources of back-up support providers that may widen the person's circle. Faith communities or certain apartment complexes are examples. Good planning consultation may help with this"*
- Effective use of technology may lead to better communication, better training and for some people may reduce some of the need for backup support. Supporting Quotes

    - *"We underutilized technology in our field. For some people, not everyone of course, but for some, good use of technology can reduce the need for some support."*
    - *"New communication and training platforms can help whoever is coming into caregiving be a backup provider or family caregiver to know how that person communicates and who they are…That is essential for effective support."*
- Often funding for DD programs must show clear 1-to-1/activity-to-outcome benefits for the person with a disability. It was noted that when it comes to supporting siblings, especially before they take on a direct role in caregiving, it can be hard to show that connection. Advocating in general and advocating for pilot programs may help circumvent this challenge.

Ethical and Legal Considerations

- There may be ethical and legal considerations for hiring a formal provider agency to provide backup support. It was noted that under self-directed waivers the person (or a designated representative) is the employer of note for their staff. If they partnered with an agency, the staff person may not be able to have both the person, and the agency as their employer. The informants noted that this was not an insurmountable challenge. Changes in waiver policies or networks of families pooling resources to enable staff sharing may help to navigate this challenge.
- Some key informants also noted that *Some who use self-directed services had experiences that impact their trust with provider-based agencies. Establishing trust with backup support providers may take time*." " Supporting Quote:
    - *"They don't trust provider agencies based on some of their lived experience. They don't trust them. That's not their choice."*
- Some people who use DDA services also use psychiatric services. It was noted that psychiatric based services are often reluctant to share medical information due to fear of HIPAA violations, even if the caregiver has formal approval for information sharing. Those in the circle of support need help learning to do cross-systems advocacy.
- Having access to a pool of backup support providers does not mean the support will be 'good'. Especially if they do not know the person. Ensuring all staff, including backup staff are familiar with the person and have an effective way to communicate is essential.
- Training for future support providers is already a covered service under "Family Caregiver Training and Empowerment Service" under DDA's waiver programs, but the pool of DDA approved Caregiver Trainers is limited.

Efficiency & Fiscal Considerations

- Access to reliable backup support provided by an agency, or a network shared with others using self-directed services and well-trained, and well supported future caregivers both were noted to reduce the chance of physical, and behavioral health crisis as well as the need to transition out of self-direction. In this sense both were considered highly efficient pathways.
- Additional costs may rest in ensuring that the planning and communication tools are effective to help backup support providers and future caregivers know the person they are supporting well. This may require infrastructure investment.
- There may be additional costs in supporting future caregivers beyond the covered service of Family Caregiver and Training and Empowerment. Organizations like sibling advocacy organizations offer substantive support for future caregivers. Many chapters are funded through state Developmental Disability Councils but vary in terms of their effectiveness and activity in part based on the sufficiency of their funding.

Establishment of Recommendations

- **Better utilize technology** for planning and training of backup staff and future caregivers. Additionally, better utilize technology to support a person's independence when possible.
- **Encourage engaging siblings, or other future caregivers early** in the planning process.
- Develop a **stronger infrastructure to support** future caregivers. This may involve expanding the pool of approved vendors for the Family Caregiver and Empowerment services. This may also involve investing in infrastructure for sibling (and other caregivers) leadership and advocacy networks.
- **Advocate for pilot programs** to help establish the most effective methods of accessing backup services and supporting future caregivers. The information gathered through pilot programs to advocate for lasting changes.

Advocacy

"Navigating these systems is hard. We need leadership and advocacy programs to educate individuals about how policy and legislation works, how you access services when your needs change and how funding flows across all these programs."

Introduction and Possible Effectiveness of Pathway

Advocacy has been an essential tool in the disability service system and for self-direction. Often led by people with disabilities and their family members, advocacy has been critical in advancing the rights of people with disabilities to be included in their chosen communities and direct every aspect of their lives. Several key informants noted that advocacy efforts are crucial to improving future planning and sustainable support for people with disabilities who are self-directing. This section will focus on possible models to support advocacy as well as critical topics in advocacy that were referenced during interviews with key informants or emerged from background reviews conducted by project researchers. Critical areas of advocacy identified by key informants address sustainability planning for people who are self-directing in several ways.

Housing. Availability and support to access safe and affordable housing is a major challenge for many people with disabilities. It is estimated that more than 70% of people with disabilities live with family members (Hellar, 2010); however, as families age, this becomes more and more challenging. Further, many adults with disabilities would prefer to live outside of their family home, but struggle to find affordable housing in their chosen communities. In several states, people with disabilities, families, and invested stakeholders have led advocacy efforts to

1. Ensure that safe and affordable housing is available and accessible to people with disabilities; and
2. Encourage states to include funding and service definitions for housing navigators in waiver services and self-directed supports.

Centers for Independent Living (CIL) have been leading housing advocacy across the United States for decades. Advocacy efforts include ensuring that housing vouchers are available to people with disabilities, and that developers and builders create accessible houses and apartments. Several CILs also have ACL programs that help people with disabilities identify possible housing in their states. In Oregon, the Developmental Disabilities Council recently funded a project to explore the housing crisis. Led by Community Vision, an Oregon provider organization, a campaign was created to increase affordable and safe housing stock across the state. A report called Access Denied has been making waves in educating people about the current housing crisis and need for additional investment.

State Funded Future Planning Support. Future planning is critical for the sustained wellbeing of people with disabilities, yet, as it has been mentioned throughout this report, many people with disabilities and family members delay planning because they do not have access to (or know they have access to) reliable, credible, planning resources. This is particularly true for resources that are included as waiver benefits and do not require families of people with disabilities to pay out of pocket for expensive consultation and planning support. In several states, including Maryland, state systems have invested in planning tools and resources for people with disabilities and their families. For example, Washington DC has contracted with the Arc of the United States's Future Planning program to offer planning education and support to people with disabilities and families at many different stages of life. The Arc's Center for Future Planning includes comprehensive financial planning support that is for families to consider. Seventeen states, including Maryland, Delaware, Pennsylvania, and Indiana have also invested in LifeCourse Nexxus, a tool that helps people with disabilities, families, and agencies providing services access (among many things) tools for planning at different stages of life.

Sibling Benefits. One key informant also noted that sustainability planning often includes and relies on siblings of people with disabilities to provide needed support, housing, and resources. Although there is substantial evidence that family members who provide caregiving and resource support often need to take time off of work in order to meet their loved one's needs (Anderson et al., 2007; Skufca & Rainville, 2021), siblings of people with disabilities are not eligible for paid leave under the Family and Medical Leave Act. One informant shared this is a real challenge for siblings who have a meaningful caregiving or support role in a person's life, sharing *"siblings are not currently included in family medical leave. That's the biggest one that we hear."* Advocacy efforts to include sibling eligibility under FMLA would greatly benefit people with disabilities who are self-directing their services.

Financial Planning. Benefits counselors, financial planners, or experts who help people with disabilities and their families plan for their financial futures while keeping in mind what is needed to maintain critical benefits such as Medicaid and Social Security Income, are essential for sustainability planning. Experts have recommended that states allow people with disabilities to use Medicaid support for future financial planning with experts, such as benefits counselors, who can guide people to save and maintain their needed benefits. Some states are considering this already; advocacy is one way to encourage state legislators to consider this important option.

Enhance Advocacy Skills. Another way to enhance advocacy for sustainability planning in self-direction is to enhance the skills, knowledge, and connections of advocates across Maryland. Around the United States and Maryland, there are several effective advocacy efforts as well as supports to enhance the advocacy skills and efforts of people with disabilities.

For instance, in Maryland and West Virginia, Expectations Matter, originally a DD Council funded project, is led by people with disabilities, family members, and professionals affiliated with Shared Support Maryland, Inc. Expectations Matter teaches people with disabilities, families, and professionals about person centered planning. People who attend the training learn from people with disabilities about their rights, who is involved in planning, and how to lead their person centered planning processes in ways that work for them. One informant noted that peer to peer advocacy training is "just incredibly important to having really credible messengers.' Expectations Matter training teaches not only about the rights of people with disabilities, but it also teaches people with disabilities and people involved in person centered planning advocacy skills to ensure that people with disabilities are in charge of their plans and lives. Expanding this program could help to ensure that people who are self-directing have needed knowledge about their rights in sustainability planning as well as peer support to develop their advocacy skills.

During the interviews, key informants also noted that existing local and national advocacy and leadership development programs, such as partners in policymaking, could include or enhance future and sustainability planning as an area for advocacy. One informant noted that there is a need for more *“Leadership and advocacy programs that educate individuals how to… navigate systems and how the funding flows and like all of these things about policy and legislation that are so mysterious.”*

Evaluation of Options, Alternatives, and Barriers

The most significant advocacy barrier noted by key informants is the lack of funding that exists to support advocacy. They noted that advocacy movements are largely grassroots and carried out by people who are most impacted by inequity, thus also more likely to be under-resourced. However, as noted, advocacy efforts have been critical in promoting needed policy, regulatory, and funding changes that impact people with disabilities and their families. Support for coordination and streamlined advocacy efforts is essential to ensure advocacy efforts, particularly when they are not funded, have maximum impact.

Further, current federal and state priorities, including the proposed $200 billion in cuts to Medicaid and the lawsuit against Section 504 are urgent priorities for many advocacy groups. While sustainability planning is also urgent, many advocates are prioritizing advocacy for protecting the current benefits that so many people with disabilities rely on.

Finally, although many resources are available to people with disabilities and families (including those mentioned above such as LifeCourse Nexxus and benefits counselors,) they may remain underutilized because people do not know about them. Key informants mentioned that communicating the availability of needed resources has been a challenge in many state systems, leaving many people with disabilities and families feeling unsupported unnecessarily. Lack of or misunderstanding about available resources may lead to duplicative or less effective advocacy efforts, as people may spend precious time developing advocacy campaigns for resources that are available.

Ethical and Legal Considerations

Because advocacy is often underfunded and under-supported, there are agencies, including provider agencies and others, that have begun creating advocacy and self-advocacy groups to promote efforts to enhance services for people with disabilities, including people who are self-directing. While there is not necessarily an inherent conflict in this model, advocates have shared that sometimes priorities and messages can be co-opted to focus on the needs of the agency over the needs of the advocates.

While increased advocacy efforts can help to advance sustainability planning in self-direction, it is important that there are checks and balances in advocacy groups and processes, particularly those that are agency supported, to ensure that people most impacted are leading advocacy efforts.

Efficiency and Fiscal Considerations

Several of the advocacy efforts mentioned in this section have been funded as pilots and DD Councils, which are extremely useful tools in starting and scaling advocacy to a systems level. That said, they are not always ongoing, causing challenges in sustainability for advocacy movements. Similarly, there is a credible chance that some of the federally funded efforts that support the work of advocates will receive fewer funds in coming years due to priorities of current federal administration. For instance, the Self Advocacy Resource and Technical Assistance Center (SARTAC), an ACL funded Project of National Significance was awarded $400,000 per year through 2026. Among many advocacy efforts, SARTAC funds self-advocacy fellowships and provides $5,000 annual stipends to promote the self-advocacy efforts of self-advocate leaders across the field. Currently, there is no clear plan for changes to ACL funding and grant opportunities; however, it is worth considering alternative fiscal avenues for supporting advocacy.

For example, private foundations, funders, and donors may show interest in supporting advocacy in sustainability planning for self-direction. In the 1990s, the start of self-direction is largely credited Robert Wood Johnson Foundation grants offered to 19 states to develop self-determination programs, which evolved into Medicaid-funded programs under section 1915 of the Social Security Act as well as cash and counseling grants in three states that evolved into section 1115 authority of the Social Security Act, which is crucial to the sustainability of self-direction. Coordinated efforts could compel Foundations to invest in sustainability planning for self-direction as it is a service model that is founded on principles of self-determination and human rights of people with disabilities.

Establishment of Recommendations

- **Coordinate, fund (when possible), and offer available support to advocacy efforts that address sustainability planning**, including housing advocacy, financial wellness advocacy, sibling benefits advocacy, and planning support advocacy.
- **Coordinate advocacy efforts across systems and between advocacy groups.** Coordination could be helpful to compel private foundations, funders, and donors to support sustainability planning for self-direction. Focusing on building foundation relationships and approaching with a statewide effort may encourage private funders to support advocacy efforts that promote self-direction.

- **Support advocacy that is meaningfully led by people with I/DD**. Ensuring that advocacy efforts are directly aligned with the needs of people with I/DDs and their families and are prioritized over agency concerns is critical.
- **Create a communication campaign to ensure that people with I/DD and family members are aware of sustainability planning resources that are already available to them,** particularly those that are available for free or covered by Medicaid funds and budgets. In order to focus advocacy efforts, it is important that people with I/DD and family members know what resources are available to them so that they share correct information and focus on gaps in support rather than overlapping requests. A communication campaign may increase knowledge and impact of currently available resources and inform the messages of advocacy efforts.

Pooled Resources

"There are many creative ways families are pooling resources. Not every family has the same means. Not every family has the same values and how they manage their finances. It's one thing to pick me up when I need a ride to the doctor. It's another thing to put me in your will. Families are pooling their resources to start nonprofits to offer their staff more support for instance."

Introduction and Possible Effectiveness of Pathway

People with I/DD and their families have been informally pooling resources, including finances, housing, caregiving, and more before the disability service system existed. Research from the National Leadership Consortium (Gilden et al., 2021) shows that many families continue to pool and share resources that do not utilize formal services (such as pooled trusts, provider agencies, etc.) as a means to plan for and protect their loved one's future. A few reasons for pooling resources outside of formal systems that participants of the 2021 Future Financial Planning (Gilden et al., 2021) study shared included:

- Many people lack access to formalized services. For example, families may share resources while they are on wait lists for support or because they do not meet a specific requirement to qualify for needed benefits.
- Some families are not satisfied with the options available. For instance, decades ago, many families of people with disabilities shared caregiving responsibilities in order to avoid institutionalization for their loved one.
- People with disabilities and families are wary of the capacity of formal options to adequately meet their loved one's needs. Some families worry that their pooled

resources will not be protected, or that they may be lost if regulations or tax laws are changed.

Within Maryland and nationally, there are several options for people to pool their resources, particularly through Shared Living and Pooled Trusts. Shared Living models have been discussed thoroughly in the Housing Section of this report and offer people with disabilities opportunities to live in their chosen communities, access natural supports, and develop meaningful relationships within and outside of their host family home.

Pooled Trusts (or '(d)(4)(C)') are a type of Special Needs Trust[1] in which people with disabilities and families of people with disabilities pool or join sums of money into a trust that is managed by a nonprofit organization. Pooled trusts help people with disabilities have more financial security without impacting their eligibility for needed benefits like SSI and Medicaid. In Maryland there are several nonprofit organizations that manage tens of millions of dollars in pooled trusts (https://specialneedsanswers.com/pooled-trust). Maryland is also one of ten states that allows people over the age of 65 who qualify to establish or transfer money into a pooled trust with no penalty, making it a more flexible option than many means of saving for people with disabilities and their families as they age.

Pooled trusts are a savings option that many families who do not have significant wealth utilize (Gilden et al., 2021). They offer administrative support and protection for families' finances at more affordable rates than traditional trusts. Pooling resources also optimizes individual investments.

Pooled trust funds are distributed to people with disabilities in a way that is agreed upon by the family upon sharing their money. Funds can be used more flexibly than those in ABLE or others accounts for certain living and medical expenses that are not covered by public benefits. In Maryland, when the beneficiary of the pooled trusts dies, the remainder can be designated to remain with the managing nonprofit or must be paid back to the state to reimburse the Department of Mental Health & Hygiene for the cost of the person's benefits.

Evaluation of Options, Alternatives, and Barriers

In Maryland, there are several nonprofit organizations established to manage pooled trusts. Depending on the organization, pooled trusts include a start-up fee to open an account

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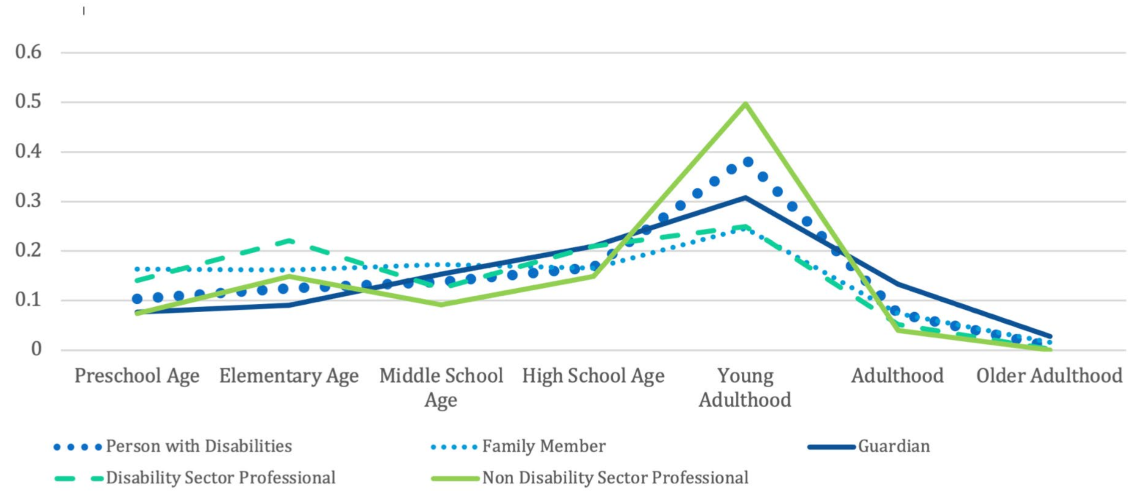
[1] Special Needs Trusts are accounts that people with disabilities and their families can set up so that they can save money for the future while protecting their eligibility for Medicaid and SSI. Special needs trusts are particularly helpful to ensure that people with disabilities have funds they need to cover expenses that are not covered by their benefits, such as education, recreation, and some medical expenses. They are often set up and controlled by a family member of a person with disabilities. There are several types of special needs trusts that are funded and managed differently. Some trusts, such as first-party and third-party trusts, often require families to invest a significant amount of money to qualify for support from financial institutions. Pooled trusts are an option that allow people with disabilities and their families to share resources while saving. More information about Special Needs Trusts can be found at the Special Needs Trust Alliance website at https://www.specialneedsalliance.org.

(usually ranging from $500 to $2,000), and ongoing fees to manage the account based on the amount of money in a person's account. Some organizations also have closing fees that are charged if people choose to transfer their funds. Families who opt to utilize pooled trusts must consider the operations, fees, and policies of the nonprofits that manage the accounts to determine which trust is best for their savings.

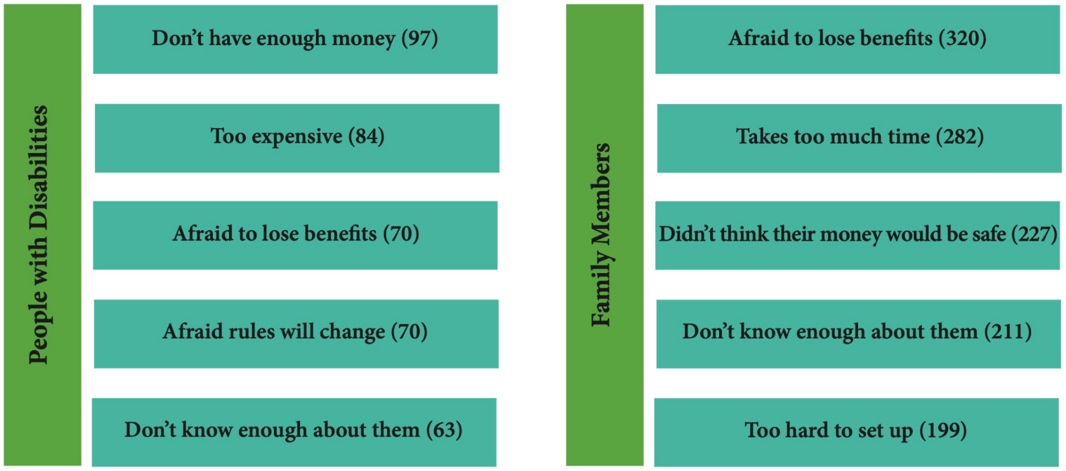
When choosing a pooled trust, people with disabilities and families should consider the values and approaches of the managing nonprofit. At the time that pooled trusts are established, plans for how the funds can be used in the future are also considered. In the case that a family member is no longer available to approve how funds are spent, the managing nonprofit will follow the plan of the family as closely as possible. However, many families fear that managing nonprofits may be overly restrictive or overly flexible with the funds (Gilden et al., 2021). For instance, some families worry that the managing nonprofit will not allow their family members to use funds for important life events because they didn't place the same value on them. Conversely, families fear that the managing nonprofit may distribute funds too liberally at the request of their loved one, which could leave them in trouble if they overspend their accounts and need funds in the future. Finally, many families fear theft or misuse of pooled trusts funds. While the instances are rare, there have been cases when people have taken advantage of and even stolen from pooled trust accounts.

Another major challenge with pooled trusts is that people with disabilities and families do not know about or how to access them. Research (Goodman et al., 2017; Hewitt et al., 2010; Lindahl et al., 2019) has consistently shown that people with disabilities and families of people with disabilities fail to plan for their futures, including their financial futures, because they do not want to (it is unpleasant to think about), they do not have or know where to find resources and education to help them plan, and (in the case of financial planning) they do not believe they have enough resources to make a savings plan.

Key informants confirmed these findings and shared that a major challenge in supporting people with disabilities and families across the lifespan is delayed planning. The 2021 Future Financial Planning study found that most people believe that people with disabilities and their families should start planning for their financial futures in early adulthood (see chart below), however in practice, many people delay planning until they are in crisis.



Similarly, the 2021 Future Financial Planning study also found that of the 35% of respondents who did not have a future financial account (such as a pooled trust account) people with disabilities and families cited fear of losing benefits, mistrust of the rules and regulations making savings accounts possible, lack of financial resources, and lack of knowledge about future financial planning were all barriers to establishing accounts (see Figure 7 from the report below).



People with Disabilities	Family Members
Don’t have enough money (97)	Afraid to lose benefits (320)
Too expensive (84)	Takes too much time (282)
Afraid to lose benefits (70)	Didn’t think their money would be safe (227)
Afraid rules will change (70)	Don’t know enough about them (211)
Don’t know enough about them (63)	Too hard to set up (199)

Figure 7. Top 5 Reasons for Not Having a Future Financial Account

Ethical, Legal, Efficiency, and Fiscal Considerations

While pooled trusts are an essential option for people with disabilities and families to pool resources, they are underutilized in Maryland and across the United States because people do not know about, understand, or trust them. Research shows that training and education are highly correlated with opening and establishing a future financial account (including a pooled trust account) (Gilden et al., 2021); however, the Future Financial Planning study also found that almost ⅓ of people with disabilities and families who responded had no future financial training or education.

Some states, including the District of Columbia, have invested in online planning tools, education, and resources (such as the Arc's Center for Future Planning) that help people with disabilities and families plan for their futures. In Maryland, Benefits Counselors, including Community Work Incentives Coordinators and DORS Benefits Counselors may help people with disabilities and families to learn about and understand their options related to establishing and maintaining pooled trusts. There are also private training and education opportunities that exist, some that are provided by the pooled trust managing nonprofits themselves.

When states invest in this type of training for people with disabilities, families, and service professionals (including provider organizations and case managers), it helps ensure that people with disabilities and families are receiving accurate information to help them plan. For instance, the Illinois DD Council funded (just over $100,000 per year) the National Disability Institute, a leader in research and education promoting financial wellness for people with disabilities, to develop trainers who could provide financial planning education to people with disabilities and families across the state.

Experts have also recommended establishing guiding principles to encourage ethical and person centered practices of special needs trust administrators (including nonprofit managers of pooled trusts). The Alliance of Pooled Trusts is creating a set of standards for managing special needs trusts, including information about who gets to make decisions about the person with a disability's life. Some experts have even recommended that an organization be established to provide oversight or monitoring of special needs trust administering agencies to ensure that people who are managing critical funds for people with disabilities need a set of standards in how they operate and administer savings. (Gilden et al., 2021)

Establishment of Recommendations

- **As a state, adopt standards of practice for pooled trusts that are built on the guidelines and standards being created by the Alliance for Pooled Trusts.**
- **Offer educational opportunities for future financial planning for people with disabilities and their families**.
- **Invest in marketing and communication of pooled trust benefits, opportunities, and options so that families and people with disabilities know that they are eligible**, understand the benefits, and have knowledge needed to set up a trust.
- **Consider investing in statewide training or train the trainer models** so that there are qualified trainers to help people with disabilities and their families navigate complex systems and rules.

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