



Sustainability **PLANNING PROJECT**

2025

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



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FUTURE PLANNING
FOR ADULTS WITH
DISABILITIES AND
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PROVIDERS AND
ADMINISTRATORS
THAT SUPPORT
THEM.**

Letter from **SDAN** Board

SDAN envisions people with intellectual and developmental disabilities living self-directed, fulfilling lives with access to all the long-term services and support they need. We advocate every day to ensure people who self-direct have the resources they need to achieve purposeful and fulfilling lives.

Having a plan that documents how an adult waiver participant will live in the future – where they will live, work, play and pray; how they will receive needed support; and how the costs will be covered is crucial. Yet most people with Intellectual and developmental disabilities nor their families or guardians, have done future planning.

The Sustainability Planning Project documents the needs, challenges and barriers that those within Maryland's intellectual and developmental disability community face as they and their caregivers age. It establishes a much needed roadmap of viable models, practices and policies that can be embraced today in our collective efforts to create sustainability planning pathways for the community.

We are grateful to the many project advisors, waiver participants, family members, providers, support brokers, consultants, national and local experts, and community stakeholders for availing us of their time and expertise. We thank the Developmental Disabilities Administration (DDA) at the Maryland Department of Health for awarding SDAN a DDA ARPA Competitive grant for the Sustainability Planning Project.

We look forward to working with the Maryland I/DD community to advance the action strategies outlined in this report.

Sincerely,

THE SDAN BOARD OF DIRECTORS

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Executive Summary

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 is true for the 20,500 people with I/DD in Maryland who received state support through a medical waiver in 2024. Many individuals with disabilities rely on aging parents or family members as primary caregivers. The majority (62-80%) live with family caregivers, many of whom are over the age of 60. Without proper planning, they risk institutionalization or homelessness when their caregivers can no longer provide support. The future of individuals with I/DD is at a critical crossroad.

THE SUSTAINABILITY PLANNING PROJECT

is focused on exploring later life transition pathways that are critical to supporting independent living for Marylanders with I/DD across the lifespan, with a focus on those who self-direct their waiver services. However, these issues are universal within the I/DD community, making this analysis widely applicable beyond Maryland and those who self-direct. The project has committed to grounding the work in evidence, securing community insights and formulating actionable action strategies. There were four overarching project goals and six overlapping phases of work.

Project Goals

- 1** Explore the needs, challenges, and barriers that those within Maryland's I/DD community face as they and their caregivers age.
- 2** Identify best practice models, existing practices, and opportunities for innovation.
- 3** Discern potential resources needed for creating sustainability planning pathways and pilot projects.
- 4** Deliver a robust roadmap for sustainability planning.



20.5 K

people in Maryland with I/DD receiving DDA waiver services



62% - 80%

of people with I/DD are living with a family caregiver



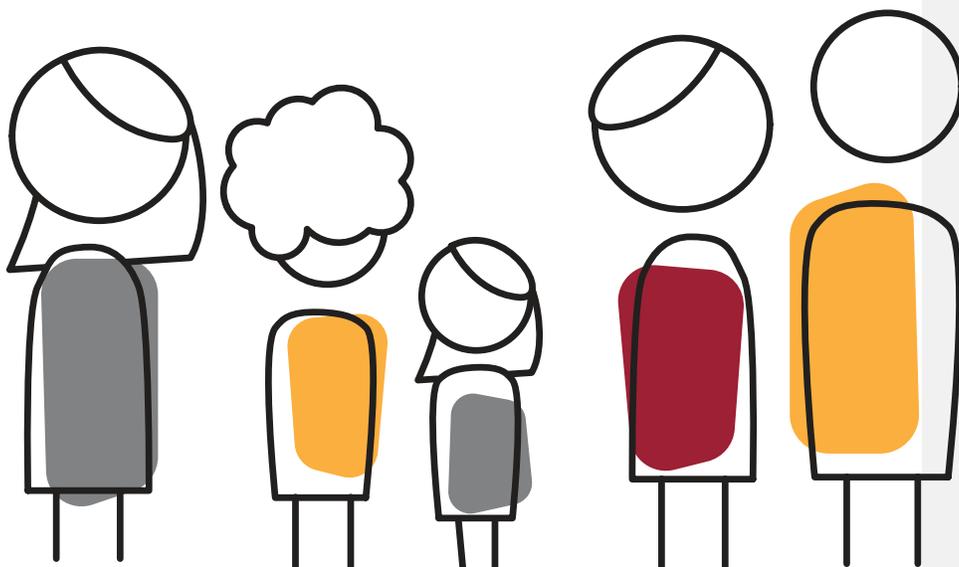
23%

of those caregivers are over the age of 60



17%

of Maryland DDA waiver participants self-direct



Five Strategies for Action

emerged from the synthesis of research findings and analysis. These strategies can be supported by many stakeholders together and independently. They include a focus on readiness and efficacy, providing needed supports that enable participants and their circle of support to move into action, and removing barriers and reducing roadblocks that impede transition planning.

01

Meet Participants Where They Are. Support participants and caregivers in moving from contemplation to action.

02

Increase Access to Planning Tools and Resources. Give caregivers easy to use tools and resources that facilitate the planning process.

03

Support and Elevate Best Practice and Innovative Models. Embrace avenues such as funding, increased promotion, reduction of barriers, and updated policy, that advance inclusive communities.

04

Provide Clarity, Consistency and Stability in Rules and Regulations. Engage stakeholders (including self-advocates and families) in the process, grounding efforts in lived experience while building a culture of mutual trust and respect.

05

Encourage Continued Dialogue, Collaboration and Action by Advocates, Providers, Administrators, Self-advocates and Families. Provide a variety of feedback loops and mechanisms to connect and engage a broad diversity of perspectives and experience.

Key Themes

Assessment of findings throughout the project phases (literature review, survey, environmental scan, listening sessions, key informant interviews, technical analysis), identified core considerations, needs and opportunities of the I/DD community, and policy and fiscal implications that are particularly important in supporting transition planning. These were critical factors in the development of the report’s action strategies.



CORE CONSIDERATIONS underscored in both the literature and community survey	IDENTIFIED NEEDS AND OPPORTUNITIES identified and elevated during the literature review and community survey	KEY LESSONS from the fiscal and policy technical analysis.	FISCAL AND POLICY IMPLICATIONS ground the project road map in the realities of everyday practice
Most caregivers worry about the future: Worry does not translate to future planning.	Improved communication is necessary.	Identified sustainability pathways all have potential benefits.	Neither new funding streams nor policies are required.
There are a litany of barriers and challenges.	Training is needed across the board.	Identified sustainability pathways all have potential benefits.	Sustainability planning is cost effective.
Constantly changing policy and regulation is a top barrier.	A culture of community inclusion and diversity	Person-centeredness is crucial.	Opportunity to embrace innovation and new practices.
Housing, medical management and emotional needs are top areas of concern.	self-advocacy organizations are a resource	Peer-to-peer learning is imperative,	Stakeholder collaboration and engagement is foundational.
Evidence-based strategies exist.	Continuity of care across multiple future caregivers.	Essential for states to support new models and planning techniques.	
	Participant and caregiver needs are interwoven.		
	Streamlined accountability without unnecessary bureaucracy.		

Eight Sustainability Planning Pathways

Eight Promising Sustainability Pathways were selected through a synthesis of the research findings and aligned. These pathways have the potential to benefit people with I/DD and their families, while reducing public spending.



Back Up Support Service. Guarantee substitute staff are available to support waiver participants when regular staff call in sick or are not able to make their work shift. Natural caregivers are most often the ones currently serving as back-up support and will not be able to serve in this capacity in perpetuity.



Enhanced Case Worker Model. Case workers would be provided more time (a smaller case load) and training to help oversee waiver service delivery and maintenance of waiver and benefits.



Training for Future Caregivers. Development of training modules and coaching support that help future caregivers understand how to navigate the system and plan implementation.



Planning Tools. Development of standard, yet adaptable, planning tools to aid families in creating their plans. This could include a suite of resources like transition checklists, sample letters of intents, estate planning templates, guidance for Circle of Care creation, etc.



Planning Consultation. A new service providing technical counsel and emotional support to families as they develop long term care plans. Training modules would likely be a component. Delivery methods still to be determined but at a minimum adding long term planning questions back into the Person centered plan CP and training CCS's to review.



Advocacy. Providing funding for I/DD advocacy organizations to provide coaching, networking, training and peer support related to future planning.



Alternative Housing Approaches. Safe, accessible, affordable housing in the community is essential to independent living, but community-based housing options are extremely limited for people with I/DD. Is there a pathway to support an innovation fund, state committee, or other mechanism to advance best practice /innovative housing solutions?



Pooled Resource Service. An effort to combine more than one person's supply of something (such as money) – or in the case of self-direction, waiver resources (staff, services, etc). Traditional delivery models inherently pool resources.



Acknowledgements

This publication was made possible by the Developmental Disabilities Administration (DDA) at the Maryland Department of Health through a DDA ARPA Competitive grant for The Sustainability Planning Project. Its contents are solely the responsibility of the authors and do not represent the official views of DDA.

[Self-Directed Advocacy Network of Maryland](#) promotes and supports the use of self-directed services (SDS) to protect participant choice and control of services that empower individuals with developmental disabilities to achieve purposeful and fulfilling lives. Formed in 2016 and established as a nonprofit 501c3 in August 2017, SDAN serves as an important network and hub of information for those receiving and administering SDS in communities across Maryland. SDAN has successfully worked with state legislators to inform and advance much needed legislation, developed a state-wide communication and outreach framework that connects Maryland's self-directed community, and brings the voice of lived experience – people living with developmental disabilities, their caregivers and service providers to the decision-making table. The work to date has primarily relied on volunteer board members.

[Collaborative Strategies](#) works to advance community-led solutions to complex problems. We collaborate with nonprofit organizations, philanthropy and community leaders in their efforts to foster the policies, programs and services that enable healthy communities where everyone has the opportunity to thrive. We strive to bring stakeholders and community voices to the table in ways that enable meaningful, lasting results.

This report was prepared by [Marla Hollander](#) and [Jennifer Weber](#). [Kate Kraft](#) served as senior advisor. Research was supported by two research fellows: [Karina Lora](#) and [Mya Mitchell](#). The Technical Analysis was conducted by [Amanda Rich](#) and [Caitlin Bailey](#).

Graphic design services provided by [Verkstad](#). Many thanks to [Liz LaFrance](#), [Ginger Houston-Ludlam](#) and [Lynne Gummo](#) for serving as liaisons to SDAN and the broader Maryland Disability Community.

Project Advisors

Circle of Care Advisors. This group was composed of 20 individuals with I/DD, their caregivers, care coordinators, and support brokers hailing from locations across the state. They identified real-life system roadblocks and core functions, “sustainability planning pillars” for maintaining services and supports that ensure people with I/DD are able to live their best life across their lifespan.

Community Stakeholder Group. This group was composed of subject matter experts and representatives from organizations that support people with I/DD representing a wide range of experience and expertise we believe is needed to inform care practices across the lifespan. Several committee seats were reserved for people with I/DD and their caregiving team. This committee charge was to provide community centered feedback, organizational perspective and insights to the project on an ongoing process. Organizations represented include:

- » Community Services for Autistic Adults & Children (CSAAC)
- » Changing the Lives of Children with Autism (CLCA)
- » Community Support Services (CSS)
- » Choice and Control Maryland
- » First Maryland Trust
- » Maryland Department of Disabilities
- » Maryland Inclusive Housing
- » Montgomery County Transition Work Group
- » People on the Go
- » Self-Directed Advocacy Network of Maryland (SDAN)
- » Service Coordination, Inc
- » Shared Support Maryland
- » The Arc Maryland
- » Visible National Trust
- » Watkins LLC

INTRODUCTION

About the Sustainability Planning Project



The number of people receiving HCBS, living with family increased 143 percent between 1998 and 2018
(Larson et al, 2018)

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.

More than 7 million individuals with I/DD live in the United States (Larsen et. al, 2018). The future of individuals with I/DD is at a critical crossroad, as the nation completes the transition to [Home and Community-Based Services \(HCBS\)](#) and as many caregivers age. The number of adults with I/DD age 60 and up is projected to nearly double from 2000 to 2030, coinciding with baby boomers reaching retirement age (FCA 2016). Natural caregivers, mostly parents, often worry about unknowns such as where their adult child with life-long disabilities will live, work, play and pray; who will advocate for their child; and what kind of vocational, recreation, residential, employment, medical and support services their child will need and receive.

The shift from institutional settings to HCBS aims to provide individuals with disabilities who receive government support more autonomy and opportunities to live in community-based settings with appropriate support. However, this transition requires proactive planning to ensure stable housing, access to direct support professionals, and long-term financial security.

Many individuals with disabilities rely on aging parents or family members as primary caregivers, and without proper planning, they risk institutionalization or homelessness when those caregivers can no longer provide support. Studies indicate that between 62-80% of people with I/DD live with family caregivers, many of whom are over the age of 60 (Larson et. al., 2022; Anderson et.al., 2018). Identifying and implementing pathways for



20.5K

people in Maryland with I/DD receiving DDA waiver services



62%-80%

of people with I/DD are living with a family caregiver



23%

of those caregivers are over the age of 60



17%

of Maryland DDA waiver participants self-direct



sustainable long-term caregiving is essential to preventing crises and ensuring the continuation of services and supports that maintain an individual’s self-determination across the lifespan.

About 20,500 Marylanders with developmental disabilities received state support in 2024 through a Medicaid waiver. The majority of participants utilized “traditional” services, meaning they join an existing program that provides day care, transportation and other services for people with disabilities. However, nearly 1 in 5, or 17%, received that support through the Maryland self-directed service model which provides participants choice, control and authority over their supports and services. Those who self-direct must be willing to take on the responsibility of managing their own service. The number of people choosing the self-direction delivery model in Maryland has been steadily increasing in the past few years.

¹The DDA through its [Waiver Advisory Council](#) is working toward a name change from Traditional Service Model to Community Provider Supported Model and updating the definition to better reflect current practice.

MARYLAND DDA WAIVER PARTICIPANTS BY YEAR AND SERVICE MODALITY

FISCAL YEAR	# OF PEOPLE
Self-Directed	
FY 2021	1,618
FY 2022	2,042
FY 2023	2,777
FY 2024	3,632
Traditional	
FY 2021	16,259
FY 2022	16,754
FY 2023	16,776
FY 2024	16,827

Glossary

For the purpose of this Sustainability Planning Project, the following definitions were used.

Coordination of Community Service (CCS): In Maryland, CCS providers, also known as Targeted Case Management, ensure that individuals and families receive the needed support, training, and services for self-sufficiency, health, safety, and active community.

Circle of Care/Support is a team of people and can include family and close friends, your Coordinator of Community Service (CCS), a Support Broker and staff who know the person with I/DD well. The team helps a person with I/DD identify what they want from life and make it a reality.

Home and Community Based Services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own home or community rather than institutions or other isolated settings. These programs serve a variety of targeted populations groups, such as people with intellectual or developmental disabilities, physical disabilities, and/or mental illnesses.

Later Years Transition Planning is the process of planning for the time when the natural caregiver can no longer provide support. There are two principal components 1) being able to identify a person(s) or method to take on the natural caregiver responsibilities and 2) creating a plan that outlines hopes and provides a roadmap for the future of a person with I/DD disability.

Natural Caregiver(s): The lead, unpaid person(s) who provides support (often to help with decision making, coordination of benefits, and ensuring physical and emotional wellbeing) to a person with I/DD. This person can be paid as staff for other activities. This natural caregiver is often a parent or guardian but could also be a sibling or other relative of the person or have another relationship to the person.

Self-direction is a service delivery model that gives Medicaid waiver participants the opportunity to exercise choice, control, and authority over the services they receive, how they receive them, and who provides them. Individuals hire their own staff and directly manage services.

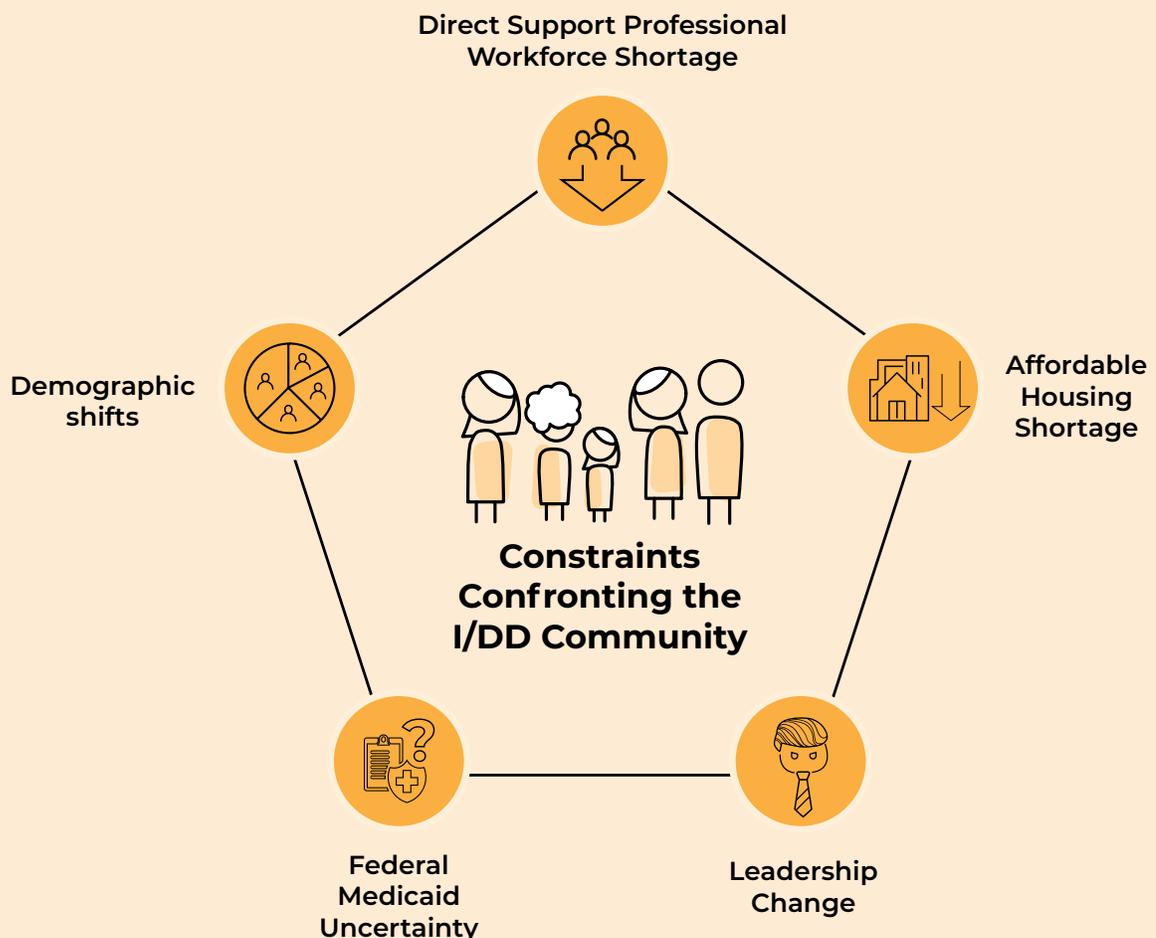
Sustainability: Continuation of services and support across the lifespan, which supports the right for individuals with I/DD to make their own choices and have control over their lives.

Traditional Service Model² provides support and care overseen by licensed or certified provider agencies. The provider handles directing and managing staff and services. These agencies are licensed or certified by the Developmental Disabilities Administration (DDA).

²The DDA through its [Waiver Advisory Council](#) is working toward a name change from Traditional Service Model to Community Provider Supported Model and updating the definition to better reflect current practice.

Environmental, Economic and Political Context

Sustainability planning must also consider the broader environmental and political context of the community. Maryland is in the midst of both a housing and direct support professional workforce shortage, a challenging political and funding climate, and the aging of the first participants receiving HCBS waivers which first became available in 1983.



“

There is much uncertainty in the political climate as it relates to the disability community.”

According to the [Department of Labor](#), there is a current nationwide shortage of skilled direct support professionals (DSPs). DSPs support people with disabilities to participate in their communities. They also provide other services, such as help with activities of daily living. The Maryland Developmental Disabilities Council has documented the problem in Maryland communities and identified solutions to address the shortage in their [Direct Support Professionals Workforce Shortage Think Tank](#) report. Marylanders with I/DD rely on DSPs to live and work in the community, whether through community providers or self-direction. Service providers have high DSP vacancy rates, and people who self-direct their services also struggle to find and keep DSPs. This makes it challenging to meet the needs of people now and expand to serve more people eligible for services, including transitioning youth coming out of the school system, and adults coming off of the DDA Waiting List who are currently eligible for support, but who are waiting for funding to be available.

In addition to a shortage of DSPs, Maryland is experiencing a significant housing shortage as reported in the [State of Maryland Housing 2024](#) report, particularly

affecting low-income residents. This shortage leaves many with I/DD without stable, affordable, and accessible living options. The demand for supportive housing far exceeds the available supply, leading to long waitlists for state-funded programs and group homes. Many individuals with I/DD remain in their family homes well into adulthood, often relying on aging parents for care.

There have been a multitude of administrative, procedural and leadership changes in Maryland in the past five years. The Maryland Department of Health has been engaged in a long-term initiative to move DDA providers and services to a more modernized fee-for service system, transitioning the way they document, track and pay for waiver services and supports. This new system — the long-term Services and Supports Maryland Module (LTSS) — has been implemented incrementally over several years with completion in 2024. The recent and frequent procedural changes, LTSS transition, along with new leadership, has created an environment of instability and uncertainty for waiver participants and providers alike and creates an obstacle to sustainability planning.



There is also much uncertainty in the political climate as it relates to the disability community. At the state level, in January 2025 the [Maryland Governor's Office](#), to address a \$3 billion budget deficit, proposed a reduction of funding for Maryland's DDA in the amount of \$457 million dollar for FY26, with some of the cuts being implemented as early as FY25. This proposal alarmed disability advocates, who feared significant impacts on essential services. In response to the outcry, the administration released a supplemental budget in March 2025, restoring much but not all of the funding for fiscal year 2025. While advocates welcomed the restored funding, concerns persist about the FY26 budget disposition and potential long-term effects of such budgetary shifts on the disability community. At the same time, the federal administration's proposed Medicaid cuts have raised significant concerns regarding impact on people with disabilities, and the future of essential services ([New York Magazine](#)).

Project Overview

THE SUSTAINABILITY PLANNING PROJECT is focused on exploring later life transition pathways that are critical to supporting independent living for Marylanders with I/DD across the lifespan, with a focus on those who self-direct their waiver services. However, these issues are universal within the I/DD community, making this analysis widely applicable beyond Maryland. The project has committed to grounding the work in evidence, securing community insights and formulating actionable action strategies. There were four overarching project goals and six overlapping phases of work:

Project Goals

- 1** Explore the needs, challenges, and barriers that those within Maryland's intellectual and developmental disability community face as they and their caregivers age.
- 2** Identify best practice models, existing practices, and opportunities for innovation.
- 3** Discern potential resources needed for creating sustainability planning pathways and pilot projects.
- 4** Deliver a robust roadmap for sustainability planning.

Project Phases



PHASE 1. CONNECTING WITH COMMUNITY AND

FAMILY ADVISORS to secure feedback and engagement from the broad Maryland I/DD community. Advisors identified real-life system roadblocks, community centered feedback, organizational perspective and insights to the project on an ongoing basis.



PHASE 2. ENVIRONMENTAL SCAN AND LITERATURE

REVIEW to ground the project in science, exploring the evidence base around needs, barriers, challenges and system approaches to later life (adult) sustainability planning in the US and internationally.



PHASE 3. CONDUCTING RESEARCH

to learn about the current experience and needs of the I/DD community in Maryland as well as probe about real and perceived barriers and opportunities. As part of this phase, we fielded an original survey and held exploratory listening sessions with a multitude of stakeholders.



PHASE 4. IDENTIFICATION OF BEST PRACTICE MODELS, EMERGING PRACTICES AND OPPORTUNITIES FOR INNOVATION.

This phase of work explored practices identified in Phases 2 and 3 that are currently being employed and pathways for integrating transformational practices / processes into the Maryland system of support. A policy and fiscal technical analysis was completed as part of this phase.



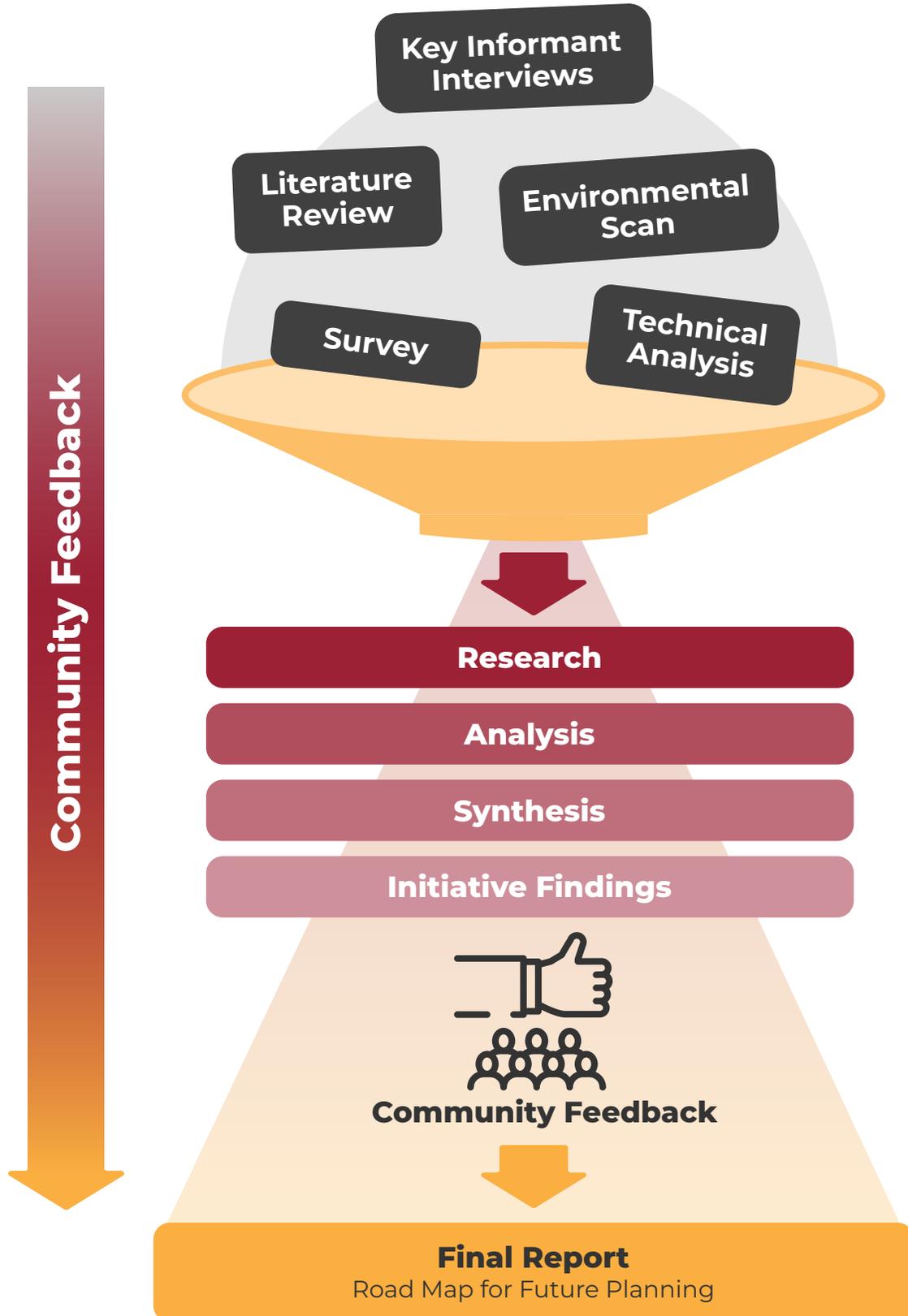
PHASE 5. ANALYSIS / SYNTHESIZE.

Data analysis and synthesis of findings across phases took place throughout the project. Project Advisors were invited to review data and provide feedback during 7 meetings over the course of the project.



PHASE 6. SHARING RESULTS

PROJECT PHASES PROCESS



Key Project Findings

Assessment of findings throughout the project phases (literature review, survey, environmental scan, listening sessions, key informant interviews, technical analysis), identified core considerations, needs and opportunities of the I/DD community, and policy and fiscal implications that are particularly important in supporting transition planning. These were critical factors in the development of the report's action strategies.

Core Considerations

Several underlying factors were underscored in both the literature and survey as fundamental factors informing the future planning process. These include:

- » Most caregivers worry about the future, but that worry does not necessarily translate to future planning.
- » There are a litany of barriers that make future planning challenging. The most pressing being the fear of the unknown or the challenge of planning within constantly changing environments.
- Frequent changes in the administration and requirements of self-direction as well as lack of accountability of administrators create chaos that the participants cannot navigate on their own and the team that replaces the parent/primary caregiver may not be able to navigate either.
- There is a significant amount of time needed to comply with the agency documentation required with each change.
- It is challenging to plan for the changing and evolving needs that occur as the individual and caregiver ages.
- Uncertainty and inconsistency in support leads to a lack of confidence that one can depend on future state and/or federal funding.
- » Caregivers manage multiple areas of care which are of concern in future planning. Housing, medical management and emotional needs are top areas of concern.
- » There are evidence-based strategies that support and advance long term planning but there are barriers to access and utilization.

"Terribly worried about the back tracking of DDA and the fact that nothing they say can be believed. How does one PLAN for THAT?"

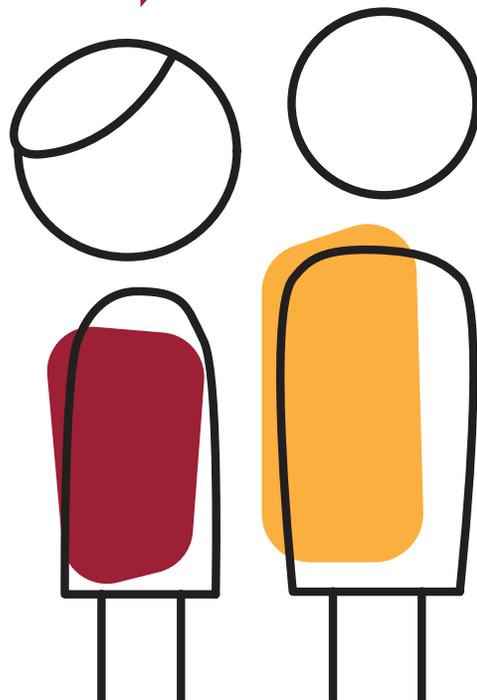
"DDA seems to be making arbitrary changes that impact vulnerable people."

"I'm extremely concerned about my person's future. I thought their services were going well through SDS but now everything is being dismantled. I'm really tired!"

"Rules change with little or no notice. Keeping up with changes and admin is a full time job."

"How can we plan when it seems like DDA policies and the third parties we deal with are in disarray? Our situation has changed very little in the last 10 years. Yet we experience instability because DDA's asks for new clarifications."

"As parents, age 66 and 70, it is so stressful dealing with all the changes in SDS. Hard to plan for the future when rules/benefits seem to change daily."



Identified Needs and Opportunities

Numerous needs, and subsequently opportunities to address those needs, were elevated during the literature review and community survey.

- » Better communication, in more targeted and intentional ways, about the importance of long-term sustainability planning, including participants and their circle of care.
- » New and sustained services and support to facilitate later years transition planning.
- » Training that supports participants, their families/caregivers, and those service providers supporting transition planning.
- » Supporting a culture of community inclusion.
- » Utilizing self-advocacy organizations who are at the center of person centered/ later years transition planning.
- » Supports and planning tools that consider the ability, income, language, and culture of the families.
- » Developing strategies to ensure continuity of care across multiple future caregivers.
- » Iterative planning that considers the future needs of both participants and caregivers as a unit.
- » Collaboration between waiver participants, caregivers, providers and administrators.
- » Support streamlined accountability and oversight practices while protecting waiver participants from unnecessary bureaucratic paperwork.
- » Supporting direct to participant communication from state service systems rather than relying on other information brokers.



Pathway Resources and Fiscal and Policy Implications

It was crucial to ground the project road map in the realities of everyday practice. This included conducting an environmental scan to identify available tools and resources within the 8 identified sustainability pathways, as well as emerging fiscal and policy implications. The following key learnings emerged from this inquiry:

- » All the sustainability pathways have the potential to benefit the person with I/DD and their families and reduce public spending.
- » All pathways must start from the place of curiosity and person-centeredness.
- » Innovation and communication about planning practices is most effective when it comes from other families and other people with I/DD as opposed to primarily professionals without lived experience.
- » Ongoing support must be provided for participants to stay in compliance with policy regulations when using new tools and models.
- » Demand from families and failures in both the quality and capacity of traditional service models are creating pressure for states to support new models for planning and support.

Fiscal and policy implications include:

- » Supporting the pathways does not necessarily require new funding streams or new policies.
- » Support for more comprehensive sustainability planning is cost effective.
- » Communicating to inform participants and policy makers about new models should start from a place of salient benefit, not cost savings.
- » Those who use self-direction are often the ones sparking innovation in support but often do not have much guidance in policy or regulations.
- » Policymakers should meet regularly with waiver participants and family members to understand evolving needs of the community.



Proposed Strategies for Action

Five strategies for action emerged from the synthesis of research findings and analysis. These strategies can be supported by many stakeholders together and independently. They include a focus on readiness and efficacy, providing needed supports that enable participants and their circle of support to move into action, and removing barriers and reducing roadblocks that impede transition planning. Each strategy for action is paired with several implementation tactics.

Five Strategies for Action

01

Meet Participants Where They Are. Support participants and caregivers in moving from contemplation to action.

02

Increase Access to Planning Tools and Resources. Give caregivers easy to use tools and resources that facilitate the planning process.

03

Support and Elevate Best Practice and Innovative Models. Embrace avenues such as funding, increased promotion, reduction of barriers, and updated policy, that advance inclusive communities.

04

Provide Clarity, Consistency and Stability in Rules and Regulations. Engage stakeholders (including self-advocates and families) in the process, grounding efforts in lived experience while building a culture of mutual trust and respect.

05

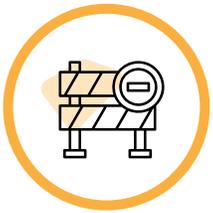
Encourage Continued Dialogue, Collaboration and Action by Advocates, Providers, Administrators, Self-advocates and Families. Provide a variety of feedback loops and mechanisms to connect and engage a broad diversity of perspectives and experience.

ACTION STRATEGY ONE

Meet Participants Where They Are

01

SUPPORT PARTICIPANTS AND CAREGIVERS IN MOVING FROM CONTEMPLATION TO ACTION.



Address institutional barriers to action and planning especially instability in support systems and procedures.



Provide coaching and mentoring to participants and their families and Circle of Care team members.



Provide training for case managers and support brokers that builds trust and efficacy in later years sustainability planning.



Explore using positive language to frame the planning process that focuses on a successful future, not on death or illness.



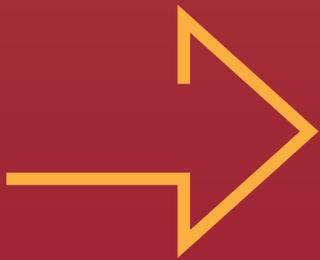
Provide avenues for peer support.



Include opportunity to consider future needs for both participants and their caregivers.



Integrate transition and later years planning questions into current assessments and standards of care and support, such as during the PCP implementation process.



MENTOR RESOURCE

Maryland's Family Supports, Community Supports and Community Pathways Waiver programs all include a service titled Family and Peer Mentoring Supports. This is an existing support that could be positioned to use for sustainability planning. Family and peer mentors explain community services, programs, and strategies they have used to help individuals receiving waiver program services achieve their goals. Mentors foster connections and relationships, which help participants and their families build resilience. This service enables a person- and family-centered matching of individual and family needs to others with similar experiences and could be utilized to help families tackle sustainable planning.

ACTION STRATEGY TWO

Increase Access to Planning Tools and Resources

02

GIVE CAREGIVERS EASY TO USE TOOLS AND RESOURCES THAT FACILITATE THE PLANNING PROCESS.



Create a digital library of best practice planning resources for those ready to plan.



Ensure peer support mechanisms are in place: Begin with promoting and expanding the existing peer mentoring support that connects participants and family members to peer mentors with similar experiences.



Establish a consultative resource provided by experienced professionals that participants and caregivers can utilize.



Provide training and onboarding for future caregivers.



Provide training for CCS's, support brokers and peer mentors: Training needs to be consistent and accountable.

ACTION STRATEGY THREE

03

Support and Elevate Best Practice and Innovative Models

EMBRACE AVENUES SUCH AS FUNDING, INCREASED PROMOTION, REDUCTION OF BARRIERS, AND UPDATED POLICY, THAT ADVANCE INCLUSIVE COMMUNITIES.



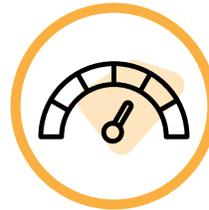
Study impact of the day-to-day administrator role established by the Maryland legislature in 2022 as a key pathway for non-family to play a key long-term coordination role.



Account for upfront investment in training, communication and promotion to support new model implementation.



Support emerging strategies that reduce barriers to sustainability, such as the Maryland Inclusive Housing partnership with developers.



Support an interagency workgroup to optimize disability forward housing.



Engage with economists to perform cost-benefit analyses that support funding.



Support investment in ongoing system innovation.

ACTION STRATEGY FOUR

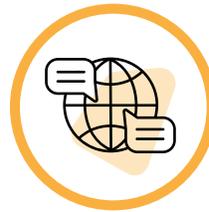
04

Provide Clarity, Consistency and Stability in Rules and Regulations

ENGAGE STAKEHOLDERS (INCLUDING SELF-ADVOCATES AND FAMILIES) IN THE PROCESS, GROUNDING EFFORTS IN LIVED EXPERIENCE WHILE BUILDING A CULTURE OF MUTUAL TRUST AND RESPECT.



Provide a consistent framework in plain language that documents processes and expectations for all involved. Include a glossary of key terms, phrases and acronyms.



Engage in dialogue with CMS, state administrators, National Association of State Directors of Developmental Services and self-advocates and other community stakeholders to optimize efficacy and efficiency.



Develop strategies and improve direct and frequent communication with individuals and caregivers through trusted sources.

ACTION STRATEGY FIVE

Encourage Continued Dialogue, Collaboration and Action by Advocates, Providers, Administrators, Self-advocates and Families.

PROVIDE A VARIETY OF FEEDBACK LOOPS AND MECHANISMS TO CONNECT AND ENGAGE A BROAD DIVERSITY OF PERSPECTIVES AND EXPERIENCE.



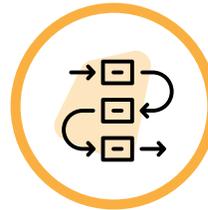
Support grassroots demand for best practice models, emerging practices and opportunities for innovation.



Support communication efforts about the importance of and resources for later years sustainability planning.



Invest in collaboration and infrastructure support for new models. This may facilitate collective ownership and proactively address potential concerns.



Establish a sustainability planning work group to advance the Sustainability Planning Project road map.



Ground development and delivery of activities in person-centeredness.

Project Activities

The section includes an overview of the landscape scan (literature review and community survey) conducted to identify the needs, challenges, and barriers that those within Maryland's I/DD community face as they and their caregivers age. It also provides a summary of the environmental scan and technical analysis conducted to Identify best practice models, existing practices, and opportunities for innovation and discern potential resources needed for uptake. All project activities together, informed the development of the 5 Action Strategies outlined in this roadmap report.

LANDSCAPE SCAN

The initial challenge to starting or documenting a plan is the ability or willingness of the family to start the planning process. From the literature review, families tended 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 that had been agreed by all concerned. One key finding that emerged from the literature review was that the emotional weight and nature of future planning, uncertainty about the future and inertia were primary barriers. Most parents/primary caregivers acknowledged the need to plan but found it emotionally challenging to take the next steps regardless of the tools available.



“Most parents/primary caregivers acknowledged the need to plan but found it emotionally challenging to take the next steps regardless of the tools available.”

Conversely, activities that promoted family communication and provided social support supported development of transition plans. Some examples included parent training and support activities, networking with other caregivers, greater connection to the disability system, and greater family communication.

To capture more specifically the landscape and needs within Maryland, we surveyed individuals with I/DD and circle of care/support team members on their current level of transition planning, challenges and barriers for later years transition, and what they see as opportunities for supporting successful transition planning. Several important learnings emerged from the 362 responses, which included over 350 written comments in addition to the qualitative survey question responses.

BY THE NUMBERS

362

Survey Responses

82%

Natural caregivers
(50/50 paid/unpaid)

83%

Receive waiver services
71% self-direct

6% Other family member

6% Support broker or CCS

2% Person with I/DD



71%

of individuals with I/DD
currently live with family

29

Average Age of
person with I/DD

63

Average Age of
Caregiver

76%

WHITE

9%

BLACK

7%

LATINO



Ethnicity



71%

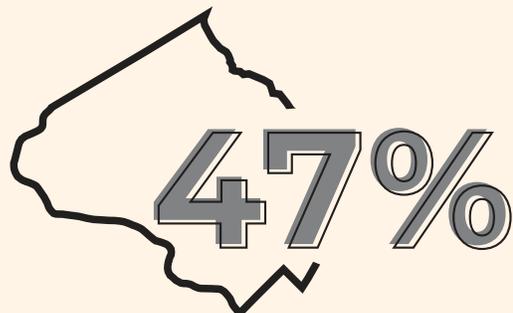
Highly educated
with bachelors,
graduate, doctorate or
professional degrees.

37%

Households
having incomes
< \$96,000

33%

Households
chose not to
disclose.

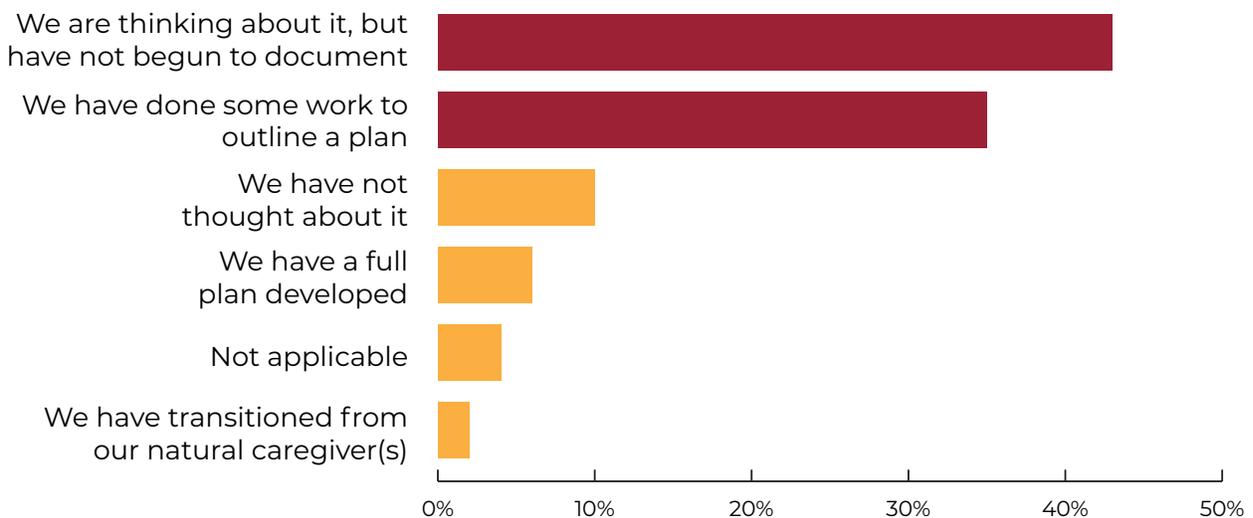


From Montgomery County
18 other counties represented



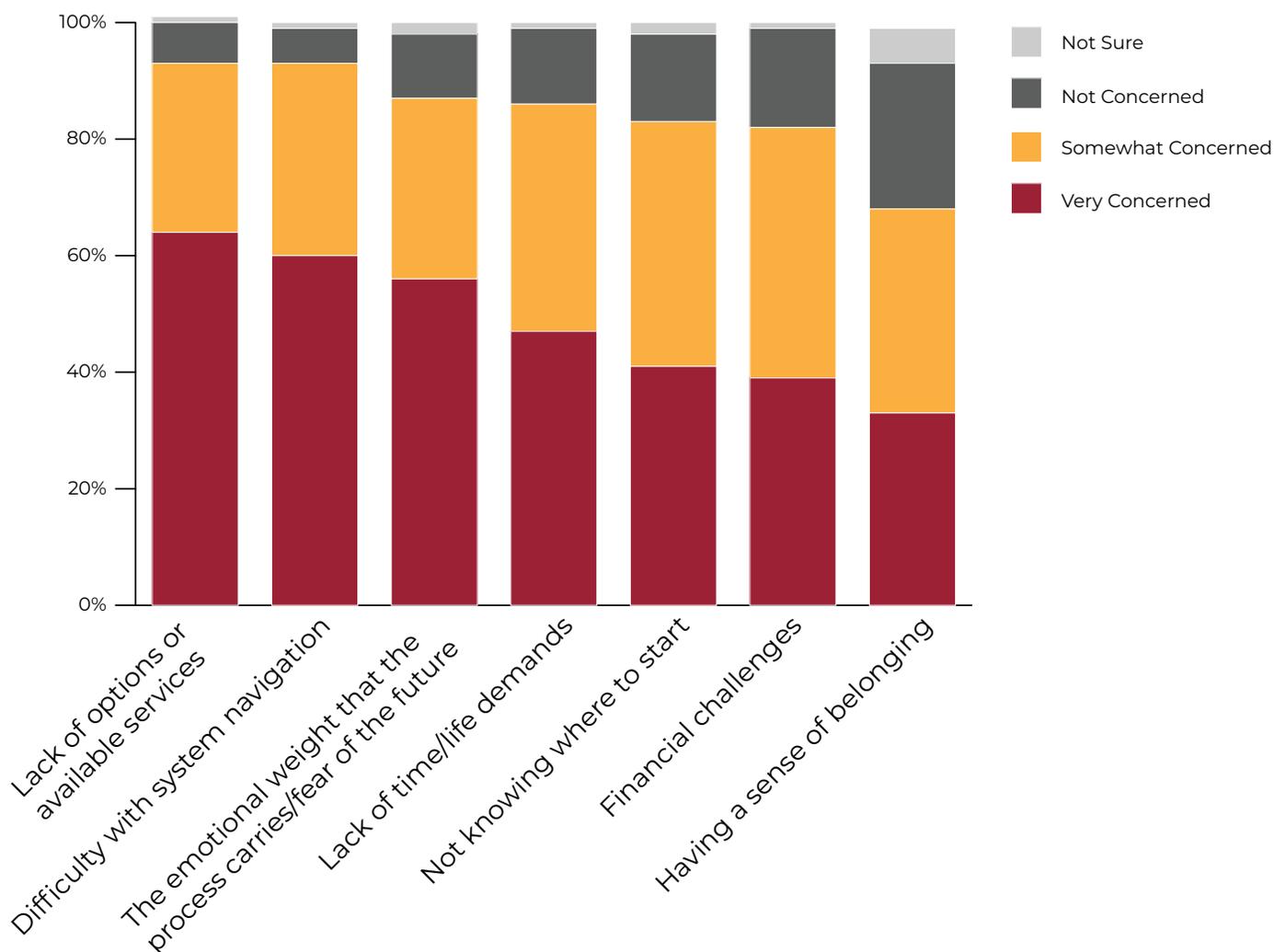
Few survey respondents had completed a transition plan. Consistent with the literature review findings, while many of the primary caregivers were thinking about planning or had done some initial planning, only about 6% had a full transition plan developed. Additionally, while family members were most likely to be identified as the next caregiver, over one-third of respondents did not have anyone identified for this critical role.

TO WHAT EXTENT HAS THERE BEEN LATER YEARS TRANSITION PLANNING FOR THE PERSON WITH I/DD?



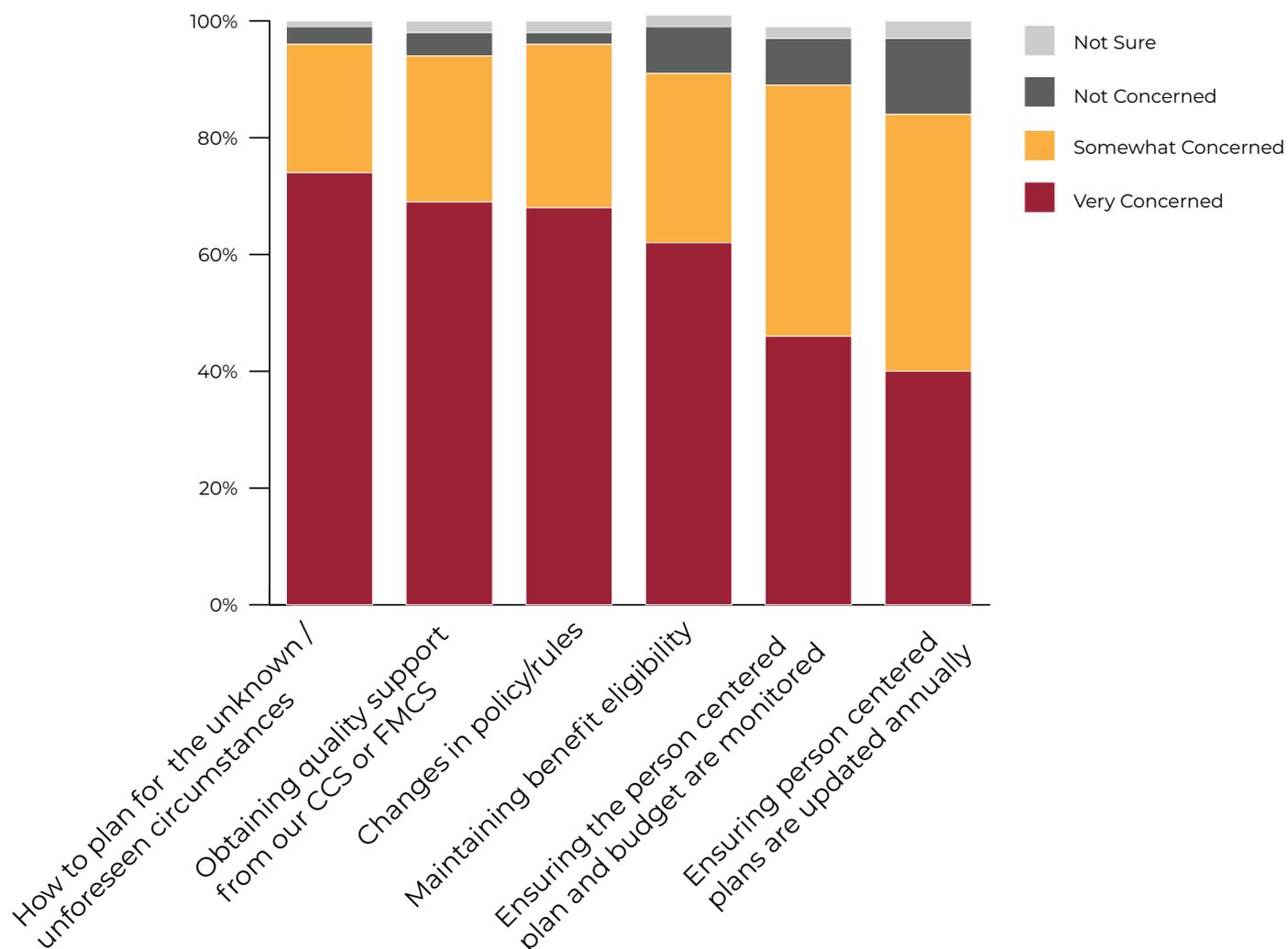
Numerous barriers and challenges to developing and implementing transition plans were identified across the following categories, family considerations, personal or systems considerations, plan management, managing services and staff, and optimizing health and wellbeing. Top barriers to developing a plan included worries about the burden of future care on siblings, lack of services and challenges navigating the system, and the emotional weight of planning.

THE FOLLOWING IS A LIST OF POTENTIAL BARRIERS TO STARTING LATER YEARS TRANSITION PLANNING RELATED TO PERSONAL OR SYSTEM CONSIDERATIONS. PLEASE INDICATE THE DEGREE TO WHICH THIS HAS BEEN A CONCERN FOR YOU.



Top perceived challenges to implementing a transition plan included difficulties in planning for an unknown future, including concerns that there are changes in rules and policies that may not align with the plan developed, maintaining high quality staff and ensuring the individual’s life is lived with joy and happiness.

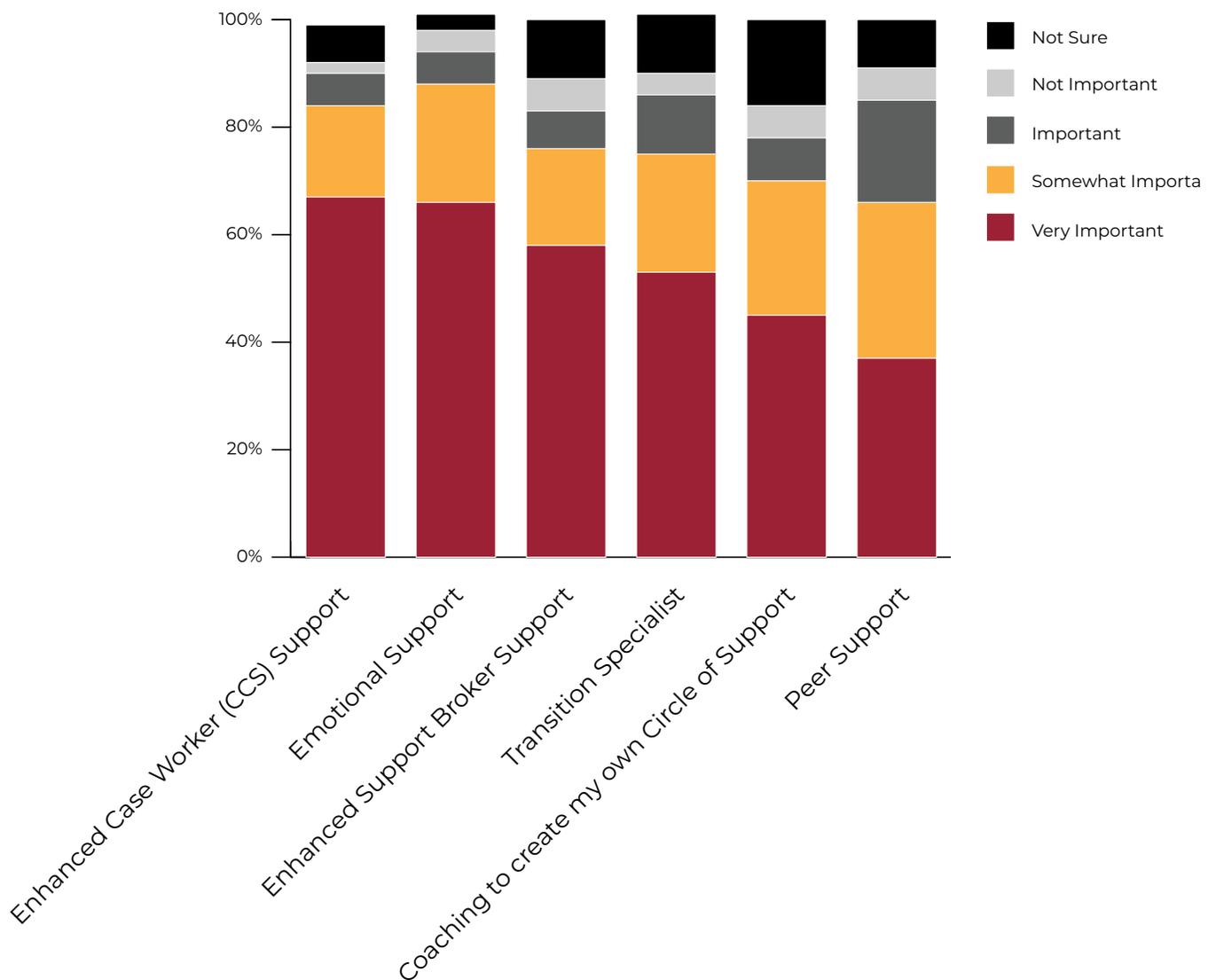
THE FOLLOWING IS A LIST OF POTENTIAL CHALLENGES IN IMPLEMENTING A LATER YEARS TRANSITION PLAN RELATED TO PLAN MANAGEMENT. PLEASE INDICATE THE DEGREE TO WHICH THIS HAS BEEN A CONCERN OR YOU ANTICIPATE IT WILL BE A CONCERN.



While respondents showed high confidence in the barriers and challenges to developing and implementing transition plans, there was an increase in uncertainty when asked about what is needed to support successful transition. Those supports that rose to the top often aligned with identified challenges, giving insights into possible solutions. Aligning with concerns about the burden of future care on siblings, training for future lead caregivers was identified as a top transition planning need.

Additionally, building on the identified emotional weight of planning, two-thirds of respondents identified having enhanced support from case workers and emotional support as being very important for successful transitions.

HOW IMPORTANT IS EACH OF THE FOLLOWING TECHNICAL SUPPORT RESOURCES TO ENSURE SUCCESSFUL LATER YEARS TRANSITION PLANNING AND BEYOND?



Multiple service-oriented resources were deemed important to ensure successful later years transition planning, with emergency back-up staffing leading the list, followed by housing models and financial support.

The available research and survey findings support the conclusion that parents and caregivers know they need to make plans for the future but translating that into action is challenging. While raising awareness and facilitating key components of planning are needed, these findings have elevated the need to also encourage, support and facilitate families to start planning.

Best Practice Models, Existing Practices and Opportunities for Innovation

Eight sustainability pathways were selected through a synthesis of the research findings and aligned with *The Charting the Life Course* framework domains. The framework has been adopted by 22 states, including Maryland, as part of a community of practice. These pathways were the focus of further exploration focusing on best practice models, existing practices and opportunities for innovation. There were three distinct, but overlapping activities employed for this component of the project.

01

The first, an **environmental scan** that further identified and explored a multitude of best practice models, existing practices and opportunities for innovation across the eight sustainability pathways.

02

The second, an **activity** conducted with project advisors to consider **feasibility** of the eight sustainability pathways across two domains: ease of implementation (how easy or hard this would be to accomplish) and impact if implemented (how beneficial would this be).

03

The third, a **technical analysis** to identify policy and fiscal implications of using the eight identified pathways.

Eight Sustainability Planning Pathways



Back Up Support Service.

Guarantee substitute staff are available to support waiver participants when regular staff call in sick or are not able to make their work shift. Natural caregivers are most often the ones currently serving as back-up support and will not be able to serve in this capacity in perpetuity.



Enhanced Case Worker Model.

Case workers would be provided more time (a smaller case load) and training to help oversee waiver service delivery and maintenance of waiver and benefits.



Training for Future Caregivers.

Development of training modules and coaching support that help future caregivers understand how to navigate the system and plan implementation.



Planning Tools.

Development of standard, yet adaptable, planning tools to aid families in creating their plans. This could include a suite of resources like transition checklists, sample letters of intents, estate planning templates, guidance for Circle of Care creation, etc.



Planning Consultation.

A new service providing technical counsel and emotional support to families as they develop long term care plans. Training modules would likely be a component. Delivery methods still to be determined but at a minimum adding long term planning questions back into the Person centered plan CP and training CCS's to review.



Advocacy. Providing funding for I/DD advocacy organizations to provide coaching, networking, training and peer support related to future planning.



Pooled Resource Service.

An effort to combine more than one person's supply of something (such as money) – or in the case of self-direction, waiver resources (staff, services, etc). Traditional delivery models inherently pool resources.



Alternative Housing

Approaches. Safe, accessible, affordable housing in the community is essential to independent living, but community-based housing options are extremely limited for people with I/DD. Is there a pathway to support an innovation fund, state committee, or other mechanism to advance best practice / innovative housing solutions?

01

Environmental Scan

(FULL DETAILS FOUND IN APPENDIX C)

The environmental scan protocol used predefined keywords that aligned with the eight pathways and recommendations from stakeholders with expert-content knowledge and on-the-ground implementation expertise to identify relevant studies, best practices, models, emerging practices and opportunities for innovation related to transition planning. All eight pathways had supporting evidence through published research or accepted best practices and tools. Examples were included in this analysis if they met an evidence threshold of meeting at least one of the following criteria: 1) peer-reviewed (i.e. journal articles), 2) organization providing information has a record of serving people with I/DD, 3) accepted best practice. Sixty-three resources were identified and reviewed: Fifty-four were included in the scan.



PLANNING TOOLS

Web-based planning tools come in all shapes and sizes. These are a few that were identified in the scan. While having a resource is good start, having peer support, guidance from a trained professional and access to the future resources one's need are critically important to successful planning

- » [The Arc Build Your Plan ® online tool](#)
- » [Life Course Nexus Planning Resources](#)
- » [Maryland Developmental Disability Council Planning Now Tool](#)
- » [The Dani Plan](#)
- » [Special Needs Alliance planning resource](#)
- » [Maryland ABLÉ resource](#)

02

Feasibility Exercise

(FULL DETAILS FOUND IN APPENDIX D)

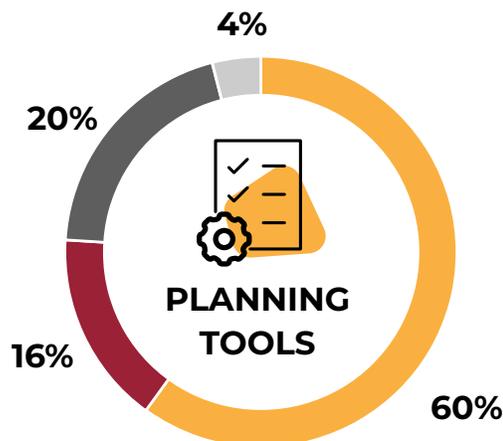
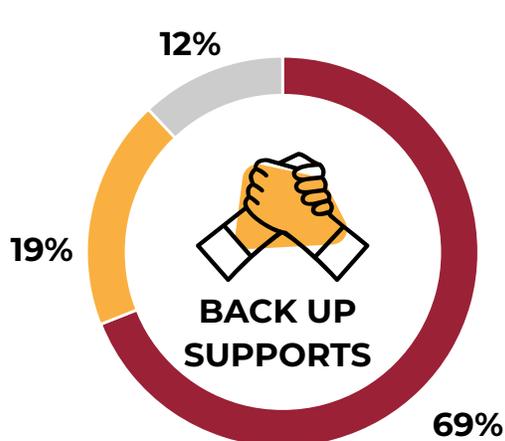
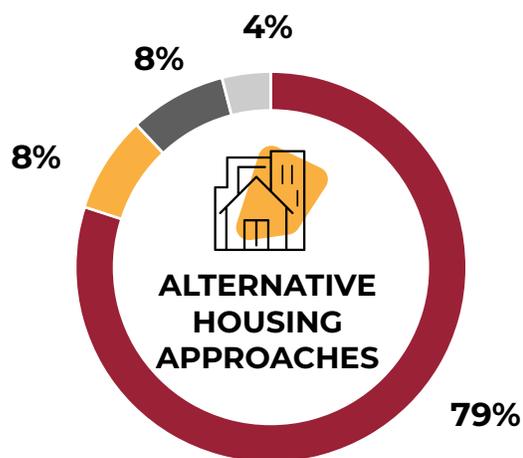
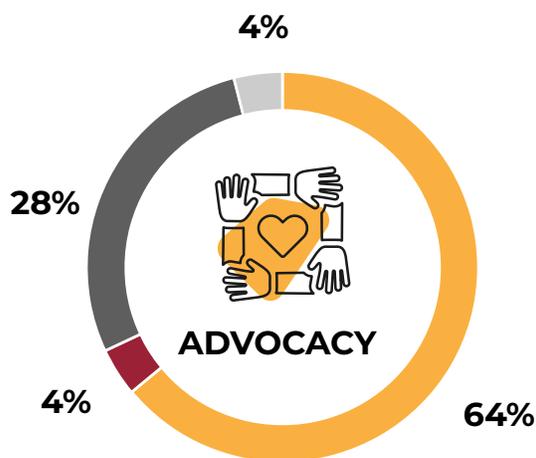
This activity explored the feasibility of implementation of the eight sustainability pathways across two domains:

» **Ease of implementation** (how easy or hard this would be to accomplish)

» **Impact if implemented** (how beneficial would this be)

- High Impact/
Easy to Implement
- High Impact/
Hard to Implement
- Low Impact/
Easy to Implement
- Low Impact/
Hard to Implement

The activity was completed by 26 project advisors. The Advocacy and Planning Tool pathways were viewed as high impact and easy to implement activities. Respondents noted that it is important to measure the impact of advocacy efforts. They also noted that any planning tools should be created with support from financial and legal expertise and be maintained to match current policy. Backup Support and Alternative Housing Approaches pathways were seen as high impact, but hardest to implement activities.





High Impact/Easy to Implement
Contains efforts that are typically the most beneficial and could be completed quickly and efficiently. These are easy to accomplish and of high impact.

Q1

High Impact/Hard to Implement
Contains efforts that may be worth doing, but should be done after those in quadrant 1 are completed. They are more difficult to accomplish but high impact.

Q2

Low Impact/Easy to Implement
Contains activities that may or may not be worth the resource. They would be easy to accomplish, but likely low impact.

Q3

Low Impact/Hard to Implement
Contains solutions that are not worth the time nor the effort and should not be considered. They are hard to accomplish and likely low impact.

Q4



03

Technical Analysis

(FULL DETAILS FOUND IN APPENDIX E)

The technical analysis explored the policy and fiscal implications of the eight identified sustainability pathways. The analysis relied on interviews with key informants and document reviews. Key lines of inquiry were about 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.

There was general agreement that sustainability pathways were important and had the potential to positively impact the experience of people with I/DD, 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; and increase the likelihood that people have the support they need to continue to meaningfully contribute to their chosen communities. Most pathway models did not require major policy changes; however, some required a broadening of interpretation and allowance of covered services or other rules with DDA

“There was consensus that policy makers should meet regularly with participants and families to understand the evolving needs of the community.”

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; however, steps needed to be taken to expand the pool of approved vendors for those services and/or to increase communication with people with I/DD, families, and service providers about their availability. There was consensus that policy makers should meet regularly with participants and families to understand the evolving needs of the community.



Recommendations from the fiscal and policy analysis include:

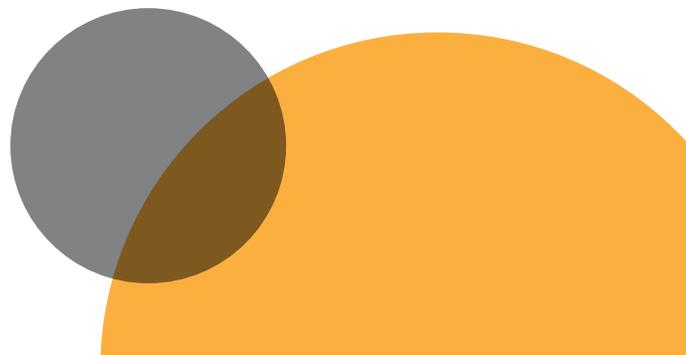
- » Investing in cross-system collaboration to understand the current infrastructure of DDA and other service sectors like aging support, housing, and food benefits and collaborate across systems.
- » Investing in improving the infrastructure to better reach, communicate directly with, and support people with I/DD and their families. This may involve expanding access to family and peer-support providers.
- » Advocating for and performing pilot projects to explore the pathway models further, identifying how they can be successfully implemented, and evaluating their impact.
- » Committing to better supporting those using self-direction and their caregivers who are engaged in innovation so that they are able to stay compliant with shifting rules and regulations.
- » Meeting regularly with people with I/DD and families involved in self-direction to stay informed of their evolving needs and to share how changes in policy, waivers, service definitions, and budgets are responsive to current and future needs.
- » Investing in peer support between people with I/DD and their families will ensure that communication about available services, policy changes, waiver changes, rules, regulations, and best practices in sustainability planning is shared by people with lived experience who understand the complexities of the system and can establish trust with people self-directing.

FISCAL AND POLICY CONSIDERATIONS BY SUSTAINABILITY PATHWAY

Pathway	Potential Efficacy	Main Policy Considerations	Main Fiscal Considerations	General Recommendations
ALTERNATIVE HOUSING	Safe, affordable, and accessible housing is essential to independent living and the continuation of independent living during times of caregiver transition.	New policies are not necessarily needed as all DDA waivers include Housing Support Services and people with I/DD qualify for non-DD specific affordable housing options. Shared Living is also a covered service.	Lack of affordable and accessible, community-based housing drives some people into expensive congregate care, making alternative housing models cost efficient.	Include planning for accessing affordable housing in transition planning starting in high school as affordable housing programs have long wait lists.
	There is currently a lack of community-based, accessible, and affordable housing making alternative housing options a highly effective and important pathway model.	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 examples	Core investments alternative housing models come from supporting infrastructure to cross-train and communicate between DDA, case managers, and housing navigation services and supporting host families in shared living.	Invest in working across systems to ensure those who work in the I/DD sector have a full understanding of state housing options, infrastructure, and programs, and vice versa.
PLANNING CONSULTATION & PLANNING TOOLS	Good planning tools shared by trusted people 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.	New policies are not needed as Person Centered Planning is an identified outcome for CCS training and peer and family support is a covered service under the DDA waivers.	Good planning and consultation can reduce the risk of physical and behavioral health crisis during times of transition and to some extent, are already in use. As such there is not a high fiscal investment.	Start planning consultation early and introduce planning tools early and often in consultation and mentorship services.
		Many planning tools including Life Course Connect and Quillo are in use in Maryland and linked within the DDA website.	Financial considerations include improving infrastructure to reach and communicate directly with people with I/DD and families and expanding the pool of approved peer and family mentorship vendors.	Support the recruitment and training of more approved peer and family support professionals to provide ongoing consultation. Ensure all planning training and tools are grounded in person-centered thinking.

Pathway	Potential Efficacy	Main Policy Considerations	Main Fiscal Considerations	General Recommendations
ENHANCED CASEWORK	Enhanced casework would allow for smaller caseloads and for the caseworker to spend more time with each person and their circle.	Enhanced casework would involve adopting enhanced casework models that use a single caseworker working across different waiver services. New policies or service definitions may be needed to allow for the service.	Enhanced casework is cost efficient as the investment in additional supports would likely lead to better outcomes for people with I/DD and their family during times of transition.	Consider using new technology to reduce the administrative burden on caseworkers and improve the quality of current training and support models for caseworkers.
			Enhanced casework increases efficiency; one caseworker may be able to support a person with I/DD and an aging caregiver under different waivers.	
	Enhanced Casework would likely help to decrease caseworker turnover and burnout and as such lead to more effective services and supports during times of transition.		Primary investments involve recruiting new caseworkers and re-training and supporting current caseworkers	Consider creative ways to strengthen the workforce pipeline and support for current caseworkers (e.g. incentives, flexibility in hours, work from home, etc.) in order to attract and retain quality workers.
TRAINING FOR FUTURE CAREGIVERS & BACKUP SUPPORT	Reliable access to backup support when service staff call out or are no longer available is often a primary challenge for people using self-directed waivers.	Some who use self-directed services have had experiences that impact their trust with provider-based agencies. Establishing trust with backup support providers may take time.	Support for future caregivers and backup support providers may reduce the chance of crisis during times of transition and as such be a cost-effective option.	Better utilizing person-centered technology may reduce the need for backup support for some people, improve the mobilization of informal circles of supports and help to prepare future caregivers.
	Supporting future caregivers and engaging them early in the planning process is highly important.			
	The efficacy of both pathways requires that training and resources are effective and accessible. Training and resources must also be up to date on current compliance and requirements.	Training for future caregivers is a covered service under DDA waiver programs but requires a sufficient pool of DDA approved trainers.	Primary costs rest in ensuring communication tools across people providing support are effective and person-centered.	Engage future caregivers especially siblings earlier in the planning process.
		Changes to self-directed waivers may be needed to ensure the person can be the employer of note for the provider agency.		Increase approved training and resource hubs for current and future caregivers so that they can remain apprised of policy or regulatory changes and understand compliance standards.

Pathway	Potential Efficacy	Main Policy Considerations	Main Fiscal Considerations	General Recommendations
ADVOCACY	Training and support for families and people with I/DD to navigate service systems, coach and mentor others in future planning is a pathway model that supports all others. As such it has it a highly effective, foundational, pathway model	Family and peer mentorship is a covered service under DDA waivers and model advocacy training programs are already in existence. As such no new policies are needed.	Though programs and policies are already in place to help support advocacy and training, a broader commitment to supporting advocacy organizations in general and supporting a train-the-trainer model of advocacy training may expand the capacity that exists within the current pathway.	Support the communication and connection of families with advocacy organizations and resources so that they stay apprised of key advocacy opportunities and coordinate efforts behind important issues
				Support the coordination of efforts across advocacy organizations to help promote greater private investment in advocacy building capacity.
POOLED RESOURCES	Families have addressed limits to formal systems of supports through pooling resources and have found it to be a potentially effective path to support sustainability during times of transition.	Families often pool resources outside of formal systems in order to plan for and secure their loved one's future.	Pooling resources is an underutilized pathway due to lack of information and misinformation that leads to mistrust, and a lack of knowledge of how to access legal and financial support.	States should adopt practice standards building upon the Alliance for Pooled Trusts to ensure standards and ethics that promote person centered approaches and protect people and their finances.
	Formal pooled resource options, such as Pooled Trusts, have helped families with limited incomes plan and save for the future while benefiting from increased return on investment of pooled resources.	There are legal pathways to formally pool resources like pooled trusts and shared living models allowed within the state system.	Investment in creating more accessible marketing, training, and tools for people to learn what pooling resources may look like and how to connect with legal resources would support the expansion of the pathway.	Supporting the development and communication of accessible information on what is needed for people to stay in compliance with state rules and regulations while pooling resources is important. Some existing planning tools address this.



Methodology

Stakeholders and community feedback is essential in developing effective community programs and policies, ensuring they address real needs and priorities.

By engaging those directly impacted, policymakers can create more inclusive, sustainable, and widely accepted initiatives that foster trust and collaboration. This project enlisted advisors to provide continuous input throughout the project through two advisory bodies. Feedback was provided on key components such as identification of selected sustainability pathways, survey design and distribution, feedback on research findings and development of recommendations. Each advisory group met four times during the course of the project with other opportunities to provide feedback and insights virtually.

- » **Circle of Care Advisory Group** composed of people with I/DD, their caregivers, care coordinators, and support brokers, was charged with helping identify real-life system roadblocks and core functions “sustainability planning pillars” involved in maintaining services and supports needed to ensure people with I/DD are able to live their best life across their lifespan.
- » **Community Stakeholder Group**, composed of subject matter experts and representatives from organizations that support people with I/DD was charged with providing community centered feedback, organizational perspective and insights to the project on an ongoing process. They were also charged with helping to identify real-life system roadblocks and ensure connections to the broader Maryland’s I/DD community.

Advisors were invited to provide feedback on the preliminary recommendations during a community meeting. The meeting was hybrid in-person/virtual to maximize participation. At that meeting, interactive activity stations were provided to capture advisor feedback on key findings and the preliminary recommendations (action strategies). The preliminary recommendations were revised based on feedback and then advisors were provided one additional feedback loop before finalizing. Small stipends/gratitude gifts were offered to advisors to thank them for their time and contributions.

A literature review (Appendix A) was conducted early in the project 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. 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. 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.

A survey (Appendix B) was designed and fielded to better understand respondents current level of transition planning, identify needs, challenges and barriers for later years transition, and prioritize opportunities for successful transition planning. The survey included a mix of quantitative (multiple choice, ranking) and qualitative (open answer) methods. The survey design was informed by DiClemente & Prochaska's Stages of Change behavioral model as well as recent sustainability planning surveys fielded by researchers at the University of Minnesota and participant directed advocates of Georgia. The survey was administered in English and Spanish. Waiver participants, their natural caregivers, other family members, and support brokers were invited to take the survey. The survey was developed in Survey Monkey and emailed via the SDAN Network, with supportive

outreach by the Stakeholder and Family Circle Advisory Groups. To ensure broad outreach, these advisors were encouraged to circulate the survey to their networks. The survey was open from 6/28- 8/31/24 to optimize response rate. The survey included 42 questions and took 15-20 minutes to complete. Participants had the opportunity to self-identify, but during analysis all responses were de-identified. A total of 354 surveys were submitted.

An environmental scan (scan) (Appendix C) was completed to identify best practice models, emerging practices and opportunities for innovation among the eight pathways that emerged during the literature review and community survey. The scan protocol used predefined keywords that aligned with the eight models and recommendations from stakeholders. Google scholar, PubMed, and Scopus were used to search for keywords. An iterative process and reverse reference search were employed to refine and select relevant studies, and web-available information. Sixty three resources were originally identified and reviewed with 54 included. Resources not included were deemed to lack relevance upon review by the project team. Information was considered strong evidence when it met the following criteria 1) peer-reviewed (i.e. journal articles), 2) organization providing information has a record of serving people with I/DD. Information was considered emerging evidence when it met the following criteria 1) source of information seemed recent and innovative.

A feasibility activity (Appendix D) was conducted for the eight pathways. This activity explored feasibility of

implementation across two domains: ease of implementation (how easy or hard this would be to accomplish) and impact if implemented (how beneficial would this be). Project advisors were provided a 4 square matrix and asked via survey to assign a quadrant to each of the eight categories. Twenty-six advisors provided feedback.

A fiscal and policy technical analysis

(Appendix E) was conducted by independent researchers from Open Road Inclusive Community Consulting. They embraced a 5-E approach that examines multiple aspects of policies including the possible effectiveness, efficiency, ethical and legal considerations, evaluation of alternatives, and establishment of recommendations for policy and practice considerations (Weimer & Vining, 2005).

The researchers conducted semi-structured interviews with nine key informants who had deep insight into the eight sustainability pathways and an understanding of how states adapt their systems of support over time. 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. Key lines of inquiry were about their perceptions of the potential benefits, the policy considerations, financial considerations, and the vision for how states could better support each of the identified practice models for families especially during times of transition. The experts also recommended policy documents that were reviewed.

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