



# Sustainability **PLANNING PROJECT**

2025

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

# 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.**



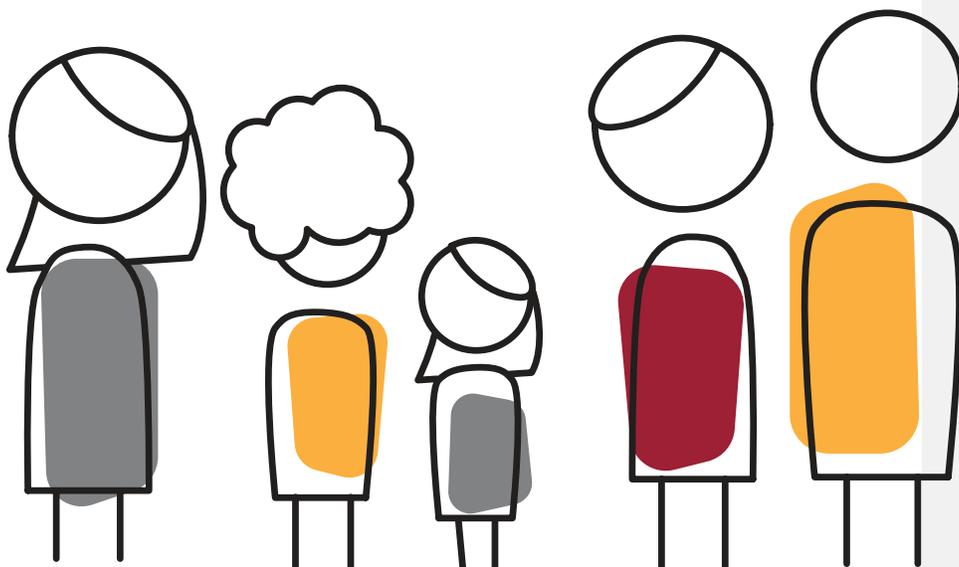
This is true for the 20,500 people with I/DD in Maryland who received state support through a medical waiver in 2024. Many individuals with disabilities rely on aging parents or family members as primary caregivers. The majority (62-80%) live with family caregivers, many of whom are over the age of 60. 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.



<b>CORE CONSIDERATIONS</b> underscored in both the literature and community survey	<b>IDENTIFIED NEEDS AND OPPORTUNITIES</b> identified and elevated during the literature review and community survey	<b>KEY LESSONS</b> from the fiscal and policy technical analysis.	<b>FISCAL AND POLICY IMPLICATIONS</b> 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.



**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?



# 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

Self-Directed Advocacy  
Network of Maryland,  
Inc. (SDAN)

[info@marylandsds.org](mailto:info@marylandsds.org)

[www.marylandsds.org](http://www.marylandsds.org)