

APPENDIX

C

SUSTAINABILITY PLANNING PROJECT

ENVIRONMENTAL SCAN

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



This environmental scan (scan) is a component of a broader Maryland Sustainability Planning Project (SPP) that aims to support long-term caregiving (sustainability) planning for people with I/DD as their natural caregivers age and when they can no longer provide support to their person living with I/DD.

The scan was completed to identify *Best Practice Models, Emerging Practices and Opportunities for Innovation* related to sustainability planning for older adults with I/DD. The scan explored eight categories (pathways) of supports and/or services (Back Up Support Service, Enhanced Case Worker Models, Training for Future Caregivers, Planning Tools, Planning Consultation, Advocacy, Alternative Housing Resources, and Pooling Resources. This work builds upon the initial project literature review and community survey findings. The pathways were defined as follows:

Back Up Support Service. 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. 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.

Methodology

The scan protocol used predefined keywords that aligned with the eight pathways 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 for the best practices, models, emerging practices and opportunities for innovation related to sustainability planning for older adults with I/DD. Sixty-three resources were identified and reviewed from the scan. Fifty-four resources were included in the scan. Models were included in this analysis if they met a base level of evidence. This included at least one of the following criteria: 1) peer-reviewed (i.e., journal articles), 2) the organization providing information has a record of serving people with I/DD, or 3) accepted best practice.

Eight Pathways Explored

Planning Tools. There is a diversity of planning tools available to assist individuals plan for their future. Evidence for this pathway is supported by federal regulations from the Centers for Medicare & Medicaid Services that specify that Medicaid HCBS programs must use a person-centered planning process for service planning that addresses health and long-term services and supports (LTSS) needs in a manner that reflects individual preferences and goals. A peer-reviewed publication indicated that while advance care planning (ACP) is recommended as a best practice for adults with I/DD; adoption remains low due to that many person-centered planning (PCP) documents lacking content specific to late-life transitions (McGinley et al., 2021). The scan also found evidence for fee-for-service and free-of-charge comprehensive online planning tools. The latter are developed for families to help individuals with disabilities at any age or stage of life and their families develop a vision for a good life, or to assist them in thinking about and planning for their future such as expressing wishes for the future in writing, getting a job and other daily activities or making daily and

major life decisions ([The LifeCourse Nexus](#); [The Arc](#)). There are also free-of-charge quick guides for practitioners supporting people growing older with learning disabilities as part of a person person-centered future planning guide, but they are limited in the information presented ([National Institute for Health and Care Excellence-UK](#)). In addition, utilizing financial tools / resources like [Maryland ABLE](#) can be a resource for people to sustain their services. Based on the nine planning resources and or research articles focused on planning, the following key considerations for planning tools were identified:

- Web-based models should be easy-to-navigate, comprehensive, visually appealing, engaging, and include definitions, explanations, and language that is easy to understand and available in different languages (Chicas et al., 2022).
- Planning should include a diversity of pillars including, but not limited to, living arrangements/ housing, benefits management, community engagement, daily living support needs, decision-making protocols, medical management, financial management, estate planning, and end-of-life considerations.
- Tools should be informed by financial and legal expertise.
- All planning should be person centered.

Alternative Housing: Evidence for this pillar is supported by a publication on designing housing for adults with autism spectrum disorders (Advancing Full Spectrum Housing, Arizona State University) and by qualitative research on the characteristics of inclusive communities for people with I/DD (Stafford et al., 2024). The publication, [Advancing Full Spectrum Housing: Design for Adults with Autism Spectrum Disorders](#), outlines that strategies to advance futures for adults with autism should include engaging people and institutions that direct capital and influence housing policy for housing for adults with autism, increase collaboration and coordination between service agencies and housing agencies at the local, state and federal levels, motivate the real estate community to create housing options that are transit-oriented and accessible to employment, shopping and recreation, as well as increase opportunities for independence and integration and expand both public and private funding for residential services for adults with autism. Stafford's work indicates that inclusive communities for people with I/DD have to plan for human diversity; have people-centered urban governance; aim for equity, accessibility, and ease; plan for connectedness among people, place and nature; and provide vibrant places and experiences.

These findings are backed up by different models of housing options for people with I/DD that incorporate elements of inclusive communities. For instance, the shared housing model, [Fairweather Lodge](#), a housing and employment program that enhances the lives of adults with a mental health disability, helps people reintegrate into the community by providing peer support, a place to live and employment. In this model, the members of the lodge make

decisions as a group and meet regularly creating a system for feedback and problem solving, an example of a people-centered urban governance. The lodge model has only been utilized for individuals with mental illness; however, there is interest in expanding the model to include adults with autism. Another shared housing model, [L'Arche](#), exemplifies human diversity and connectedness among people. In this model, members who have a developmental disability and members who do not live together. "Assistants," individuals who share their life with "core members" (individuals with I/DD) work to build a relationship of mutual care and support among each other, fostering a home life of unity, mutual respect and participation by all members.

There is a diversity of alternative housing approaches to assist individuals in choosing housing options for independent living. Based on the eleven alternative housing models, the following key considerations were identified:

- Housing options should provide opportunities for independence and integration of adults with I/DD and be affordable.
- Shared housing models are affordable, provide opportunities for independence and integration and allow house members to build a relationship of mutual care and support.
- There are numerous shared housing models such as group shared residences, model matchups (a "home provider" shares his/her home with a "home-seeker", who pays rent), L'Arche models (members who have a developmental disability and members who do not live together), or intentional communities (people live together in a community that is built around a shared belief system of care).
- Use stakeholder voices to develop inclusive communities that are planned to foster diversity, have people-centered urban governance, are accessible, allow for connectedness among members and the natural environment (Stafford et al., 2024).
- Engage people and institutions that influence housing policy in the state and foster collaboration and coordination between service agencies and housing agencies at the local, state and federal levels.

Back up Support Services. Evidence for this pillar is supported by one model that advocates for a revised direct-care staff-scheduling system (shift schedules) in community homes serving individuals with I/DD. In this model, the direct-care staffing system compared to staffing systems that used married couples and adaptations of the Teaching-Family Model was superior on measures of turnover, vacancies, number of direct-care employees involved in the care of the persons served and hourly wages (Strouse et al., 2004). There are multiple

models that are not specific to individuals with I/DD that can provide insights. Among these, the use of an on-call pool of aides who can be called in to cover absences in senior center facilities helps reduce staffing costs, maintains consistency of care and manages absences more effectively. Other types of models include companies that offer school age or elder care and could be used to model a new service specific to the needs of individuals with I/DD, or an available pool of advanced nursing, occupational and physical therapy students who want to gain hands-on experience and be considered as alternative /on-call staff. Back up care models that have been used with residents of senior facilities and could be employed for individuals with I/DD include companies that provide paid services through their websites or maintain an on-call pool of aides who can be called in to cover absences.

Based on the ten backup service models reviewed, the following key considerations were identified:

- Ongoing staff development can improve service provision to individuals with I/DD and reduce absenteeism (Friedman, 2021).
- Companies that provide services to other groups (i.e. residents of senior centers, children) can be used as models to develop on-call staff programs to serve adults with I/DD ([Bright Horizons](#), [A New England Nanny](#))
- Advanced nursing and occupational and physical therapy students who want to gain hands-on experience can be considered as alternative /on-call staff ([CareYaya](#)).

Enhance Case Worker Model. Evidence for this pillar is supported by caseworker training models that aim to enhance caseworkers' role with individuals with I/DD. Training case workers on disability-related terminology or Citizen-Centered Leadership training can assist them in developing appropriate interventions for capability development for individuals with I/DD (Saleeby, 2007). While the scan did not find adequate evidence on training case managers on the use of digital tools, a Mobile Health and Rehabilitation (iMHere) platform developed with patients and accessible to individuals with cognitive, motor, or sensory impairments was found to help them manage their conditions and can potentially help caseworkers oversee waiver service delivery (Commonwealth Fund, 2019).

Based on the six enhanced case worker models and research articles focused on caseworker training, the following key considerations were identified:

- Training case workers on disability-related terminology, ACP for individuals with I/DD or Citizen-Centered Leadership training can assist them in developing appropriate interventions for capability development for individuals with I/DD (Saleeby, 2007)
- Use of digital tools/apps can help individuals with I/DD manage their conditions and allow them to securely communicate with their clinicians. Digital tools/apps are helpful for case managers and clinicians to review patients' responses and respond to problems (Commonwealth Fund, 2019).
- Improved communication among stakeholders and the use of a gatekeeper approach can streamline care delivery and reduce redundancy, which allows case workers to manage caseloads more effectively (Green-McKenzie et al., 2004).

Planning Consultation. Evidence for this pillar is supported by ample and diverse planning consultation tools and care support that aim to provide technical counsel and emotional support to families of individuals with I/DD. The scan found that planning consultation resources can be grouped as those provided by certified finance planners (fee for service) and web-based planning models (free). In the first model, finance planners work with families of individuals with I/DD to create a comprehensive plan that includes vision, life, resource, financial and legal planning ([ENABLE](#)). Web-based planning models provide caregivers/families with a framework and tools to organize ideas, vision, and goals, as well as problem-solve, navigate, and advocate for support ([The Arc](#), [The Autism Society](#), [LifeCourse Nexus](#), [By Their Side](#)). The scan also found examples of organizations staffed by parents of people with I/DD that provides individual assistance, workshops, publications, and other resources to help families make decisions about education and other services for their child with I/DD and foster family connection for emotional support ([Pacer Center](#), [Parent to Parent USA](#)).

There are a diversity of planning consultation tools and care support available to provide technical counsel and emotional support to families. Based on the nine planning consultation practices/resources reviewed, the following key considerations were identified:

- Web-based planning models provide a framework and tools to organize ideas, vision, and goals, as well as problem-solve, navigate, and advocate for support ([The Arc](#), [The Autism Society](#), [LifeCourse Nexus](#), [By Their Side](#), [Our Place](#)).
- Traditional certified finance planners can assist people/families with financial planning service. Companies assist with special needs planning to families by creating a

comprehensive special needs plan that includes vision, life, resource, financial and legal planning ([ENABLE](#), [CFP](#)),

- Organizations that provide support to parents of individuals with I/DD by matching parents with other fellow parents who have a child with similar needs with the goal of receiving support and creating new friendships. Organizations that connect parent advocates to “new” parents. Parent advocates assist by distributing informative materials, conducting workshops and training, and providing one-on-one consultation ([Pacer Center](#), [Parent to Parent USA](#)).

Training for Future Caregivers. Evidence for this pillar is supported by several peer-reviewed articles that describe sibling support and sibling leadership interventions that aimed to improve the siblings' understanding of developmental disabilities, increase public awareness of the sibling experience and needs among siblings of individuals with I/DD. Findings indicate that interventions had a significant effect on the siblings' perceptions of social support, increased siblings' sense of empowerment after participating in a leadership program, and increased their motivation to have an impact on systemic changes with the delivery of adult services for their sibling with a disability (McLinden et al.,1991; Dyson, 1998; Burke et al., 2018). Additionally, one article reported that when individuals with autism spectrum disorder showed more severe autism spectrum disorder symptomatology, the support group seemed to provide a buffer against typically developing sibling symptoms of both anxiety and depression (Jones, 2020). A web-based resource, The [Sibling Leadership Network](#), whose mission is to provide siblings of individuals with I/DD information, support and tools to advocate for their brothers and sisters also promotes the siblings' access to support groups through social media to help teenage siblings of people with disabilities connect with peers to talk about their own experience and receive social support.

There is consensus that future caregivers (i.e., siblings) should be exposed to information on how to support the family member with I/DD and what his/her role will be. Based on the ten future caregiver training courses reviewed, the following key considerations were identified:

- Expose siblings to information about how to support the family member with I/DD and what role(s) other family members are able and willing to play, as well as what role the person with I/DD wants them to play, getting involved in care, tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.
- Encourage siblings of persons with I/DD to join online forums and/or social groups to connect with peers to talk about their own experience and receive social support.

- The “Sibling Ambassador Program” intends to increase awareness of the sibling experience and sibling needs among siblings of individuals with I/DD and the public more generally. After completing the program, participants are expected to: teach their communities about the sibling experience; cultivate relationships with other siblings of individuals with IDD; use social networking platforms to share the sibling experience; and establish a sibling support group (Burke MM et al., 2018).

Advocacy. Evidence for this pillar was supported by the common focus that organizations have on enhancing health care services and policies for individuals with I/DD. While these organizations conduct their advocacy efforts differently or have different organization structures, they share similar visions of advocating for equitable policies and programs for individuals with I/DD. For instance, [Maryland Developmental Disabilities Council](#), an independent state agency, advocates for policies and legislation that positively impacts the lives of individuals with I/DD, increasing the knowledge and skills of individuals with I/DD to be effective advocates and leaders. The [Parents Place of Maryland](#), a grassroots organization, staffed primarily by parents, professionals, and community leaders provides resources, support, and information. Notably, the Parents Place of Maryland has a program called LEADers which intends to develop leadership skills among parents of individuals with disabilities and special health care needs. Similarly, [Parent to Parent USA](#), an organization that supports a network of effective Parent to Parent programs provides quality emotional support for families allowing them to create new friendships.

Organizations at the national level focus their efforts on enhancing health care services and policies for children with I/DD. Based on the five advocacy resources reviewed, key considerations include:

- There are numerous advocacy efforts at the state level in Maryland. The [Maryland Developmental Disabilities Council](#) provides training and fiscal support to community partners such as [People On the Go Maryland](#) to support self advocacy efforts and increase knowledge and skills of people with developmental disabilities to be effective advocates and leaders.. The Parents Place of Maryland, a community organization staffed primarily by parents is a grass-roots effort of families, professionals, and community leaders who provide resources, support, and information.
- At the national level, organizations such as [Family Voices](#) promote partnership with families at all levels of health care in order to improve health care services and policies for children with I/DD.

Pooled Resource Services. While limited information was found on pooled resource services in general, there was strong evidence in support of financial trusts. Pooled trusts such as those operated by chapters of The Arc and Third Party Special Needs Trusts from [First Maryland Disability Trust Inc.](#) In the first example, individual accounts are established for each beneficiary, but the accounts are pooled together for investment purposes and a pooled trust manager is responsible for complying with federal and state laws regarding special needs trusts. In the second example, a third-party pooled trust is created by family or friends of the individual with disabilities for that person's benefit allowing the family of the individual with disabilities to "pool" or combine the trust assets with other's assets for investment purposes only.

Based on the three pooled resources models reviewed, key considerations include:

- Supplemental needs trusts funded by family or friends of the individual with disabilities allows the family of the individual with disabilities to "pool" or combine the trust assets with other's assets for investment purposes.
- Third party special needs trusts from [First Maryland Disability Trust Inc.](#) is a supplemental needs trust. A third-party special needs trust provides for the beneficiary's well-being while preserving eligibility for public benefits like medical assistance, waiver programs, and supplemental security income. Two modalities: Third-Party Pooled Asset Trust and Testamentary Trusts.

Sustainability Planning Project: Environmental Scan Summary Table		
Planning Tool /Resource	Summary	Citation / Website
Alternative Housing Approaches		
CHAPS shared housing model	CHAPS, is an example of a nonprofit /private collaboration in Crawford County, PA	https://chapsinc.org/what-we-do/programs-services/overview. Html
Model Match-Up shared housing model	A “home provider” shares their home with a “home seeker” who pays rent. Examples: Homeshare Alliance and Residential Living Options, Inc.	https://www.pa.gov/content/dam/copapwp-pagov/en/dhs/documents/services/disabilities-aging/documents/autism-services/Housing_Options_for_Adults_with_Autism_Spectrum_Disorder.pdf
Fairweather Lodge shared housing model	A housing and employment program: shared decision making and house coordinators /mentors.	https://www.pa.gov/agencies/dhs/resources/mental-health-substance-use-disorder/cdp-fairweather-lodge.html
Model L'Arche shared housing model	Community-based shared living, professional direct support, vocational services, and personalized daily planning connecting to faith, leisure, recreation and social and civic interests.	https://www.larcheusa.org/about/
Intentional Communities model	Community built around a shared belief system. Cohousing incorporates private homes and common facilities. Example: Coho Ecovillage in Corvallis, Oregon.	CoHco Ecovillage https://www.cohocovillage.org/
The Arc policy/ advocacy housing resource	Web-based resource provides information on how and why to advocate for disability housing solutions and resources.	https://thearc.org/policy-advocacy/housing/
Research article	Summary article exploring disability-inclusive sustainable communities.	Lisa Stafford et al The makings of disability-inclusive sustainable communities: Perspectives from Australia. <i>Urban Governance</i> 4 (2024) 113–121.
Maryland Inclusive Housing (MIH) Partnership	Model in development in collaboration with developers/ property owners to set aside units for MIH clients.	https://mih-inc.org/news/mih-shares-its-model-with-groups-around-the-country/
Kelsey Center model	A minimum of 25% of homes are reserved for people with disabilities in accessibly designed building that provide supportive programming for all residents and neighbors.	https://thekelsey.org/learn-center/how-local-state-governments-can-better-ensure-accessible-homes-reach-disabled-tenants/ Learn Center - The Kelsey
Organizational reports	Overview of existing and new residential models and action steps that address the increasing demand for alternative approaches.	https://www.autismspeaks.org/tool-kit/opening-doors-discussion-residential-options-adults-living-autism-and-related-disorders
Main Street Rockville model	An inclusive community development model offering A 70-unit affordable apartment building in which 75% of the units are affordable and 25% are set aside for adults with special needs.	https://mainstreetconnect.org/
Planning Tools		
Research article	Key components of a web-based long term care planning intervention.	Chicas, V et al Identifying key components of a web-based long term careplanning intervention for family caregivers of individuals with intellectual/developmental disabilities. <i>J Appl Res Intellect Disabil.</i> 2022;35:867–877.
Web-based estate planning resource	This resource from the Special Needs Alliance provides information on creating estate plans.	https://www.specialneedsalliance.org/the-voice/developing-an-estate-plan-for-parents-of-children-with-disabilities-a-15step-approach-2/
Transition toolkit	Transition tool kit from school to adult services that could be adapted for later-years transition planning purposes.	https://dsc.uic.edu/wp-content/uploads/2023/12/91-TRANSITION-TOOLKIT-WEB.pdf
Maryland Developmental Disability Council Planning Now tool	Provides information about government benefits, wills, trusts, taxes, and other things to help people plan.	https://www.md-council.org/wp-content/uploads/2018/12/Planning-Now-Guide-2018-4.pdf
The LifeCourse Nexus Web-based resource	The website/tools offer videos and downloadable materials focusing on life stages and exploring areas such as employment, healthy living, housing options	https://www.lifecoursestools.com/about-us/the-lifecourse-nexus/
Special Needs Financial Planning: Fee for service with some free resources.	Website provides a complementary knowledge bank that has planning resources, videos and a housing / transition checklist.	https://www.specialneedsplanning.com/housing-and-transition-checklist-for-people-with-special-needs
Research article	The study examined how states' PCP processes articulate Advance Care Planning (ACP). While ACP is recommended as a best practice for adults with I/DD, adoption remains low.	Jacqueline M. McGinley et al Advance Care Planning for Individuals with Intellectual Disabilities: A State-by-state Content Analysis of Person-centered Plans. <i>Intellectual and Developmental Disabilities.</i> 2021, Vol. 59, No. 4, 352–364
The Arc Build Your Plan ® online planning tool	Future planning tool helps people with I/DD think about and plan for their future.	The Arc Center for Future Planning https://futureplanning.thearc.org/landing
Research article	This study investigated how an ACP program was developed, implemented, and evaluated.	Hille Voss, Anique et al Development, Implementation, and Evaluation of an Advance Care Planning Program for Professionals in Palliative Care of People With Intellectual Disability. 2021. <i>INTELLECTUAL AND DEVELOPMENTAL DISABILITIES.</i> Vol. 59, No. 1, 39–54
Web-based guide	Person-centered planning guide developed by the NICE National Institute for Health and Care Excellence for practitioners supporting people growing older with learning disabilities.	https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/person-centred-future-planning#further-information
Web-based tool	The Dani plan resource is a low cost, fee based planning tool.	The Dani Plan Tool https://daniplan.com/capabilities/
Web-based guide	A care and support planning guide developed by National Voices -UK for anyone who has health care needs over time, or cares for someone who does	https://s42139.pcdn.co/wp-content/uploads/An-interactive-guide-for-for-anyone-who-has-health-and-care-needs-over-time-or-cares-for-someone-who-does.pdf
CMS brief: <i>State Policies and Practices for Planning Across the Lifespan</i>	A collection of resources based on state Medicaid and partner agencies successful approaches for adults with I/DD and their aging caregivers.	https://www.medicaid.gov/medicaid/downloads/Person_Centered_Plan_ning.pdf

Planning Consultation		
The Arc Future Planning Planning web resource	Resources to help create future plans. The Arc Center for Future Planning offers free online trainings about future planning and ways to support people with IDD.	The Arc https://thearc.org/our-initiatives/future-planning/
ENABLE planning resource	Fee based service provides assistance to families to create a comprehensive special needs plan.	ENABLE https://enablesnp.com/special-needs-planning/
The Autism Society web resources	Free future and financial planning resources.	Future and Financial Planning https://autismsociety.org/resources/future-and-financial-planning/
The LifeCourse Framework training tool	Tools for future planning that help guide conversations when planning, problem solving, or working on goals..	LifeCourse Nexus- Foundational Tools: Family Perspective https://www.lifecoursetools.com/lifecourse-library/foundational-tools/family-perspective/
Certified Finance Planner website	Recommended by the Special Needs Alliance It offers a locator tool that helps clients find a financial planner by location and type of planning service.	https://www.letsmakeaplan.org/
By Their Side planning consultation	<i>By Their Side a fee-based service also provides a free future planning resources guide on their website.</i>	https://www.bytheirsideside.org/ https://www.bytheirsideside.org/resources-educational.html
Parent to Parent USA: Family peer support	Connects families with each other for peer/ emotional support. In MD, the Alliance Member is Parent to Parent Maryland.	https://www.p2pusa.org/
Backup Services		
Research articles technology	Discussion of the availability and benefits of using "smart home" technologies and remote support services technologies.	Tassee M and Wagner. Using Technology Solutions to Support Home Health Safety and Greater Independence and Quality of Life J Psychiatria Danubino 2023. Vol 35, Sup 3, pp 87-89, Tasse MJ, Wagner JB and Kim M. Using Technology and Remote Support Services to Promote Independent Living of Adults with Intellectual Disability and Related Developmental Disabilities. Journal of Applied Research in Intellectual Disabilities. 2020; 33:640-647
EAP emergency backup program	Emergency back up staffing support program for Federal staff.	https://www.hhs.gov/about/agencies/asa/foh/bhs/backup-care/index.html#:~:text=Emergency%20Care,regular%20care%20routines%20break%20down
Bright Horizons back up support program	Private company providing backup staffing service for private sector.	https://www.brighthorizons.com/family-solutions/back-up-care
A New England Nanny back up support program	Private company offers corporate backup care program as an employee benefit to its workforce.	https://anewenglandnanny.com/corporate-backup-care-faqs/#:~:text=What%20is%20Pinch%20Hitter?.last%2Dminute%20care%20issues%20arise
ActiPlans: Web-based work scheduler	Scheduler that take into account staff availability, client needs, and last-minute changes.	https://www.actiplans.com/ and https://www.actiplans.com/blog/shift-planning-for-home-care-agencies
CareYaya: Colleges partnership model	CareYaya works with schools of nursing, occupational and physical therapy providing a pool of vetted, experienced caregivers who are college students in the healthcare field.	https://unitedspinal.org/tips-and-tricks-for-the-best-back-up-care-support-plan/ and https://www.careyaya.org/
Research article: On-call pools	Utilizing an on-call pool of aides who can be called to cover absences is an effective strategy in senior facilities.	Slaugh V.W., Scheller-Wolf A.A., Tayur S.R. Consistent Staffing for Long-Term Care through On-Call Pools. Production and Operations Management Vol. 27, No. 12, December 2018, pp. 2144–2161
Research article: Staff development	Providing ongoing staff development, agencies can improve their service provision, reduce burnout and stress by encouraging direct support professional to engage in self care.	Friedman Carli. The Impact of Ongoing Staff Development on the Health and Safety of People with Intellectual and Developmental Disabilities. Journal of Developmental and Physical Disabilities (2021) 33:181–196
Enhanced Case Worker Model		
Interactive Mobile Health and Rehabilitation (iMHere)	Training case managers on using such technology/ apps can help them oversee waiver service delivery.	iMHere: https://www.imhere.pitt.edu/
Research article: Training and education	Integrating persons with disabilities into the healthcare workforce impacts on inclusive and welcoming environments.	Andrew Sentoogo Ssemata et al. Suggested solutions to barriers in accessing healthcare by persons with disability in Uganda: a qualitative study. BMC Health Services Research (2024) 24: 1010. file:///C:/Users/admin/Downloads/s12913-024-11448-4.pdf
Research article: Gatekeeper approach	Improved communication among stakeholders and the use of a gatekeeper approach can streamline care delivery and reduce redundancy, thereby managing caseloads more effectively.	Mary Elizabeth VanGelder et al. An Innovative Case Management Gatekeeper Model for Medicare Surgeries. Professional Case Management. 2013. Vol. 18, No. 3, 112-119
Training: Citizen-Centered Leadership	A 15-week online course focussing on discovery and exploration of what it means to be person-centered and inclusive.	https://citizen-network.org/library/citizencentered-leadership.html
Training for Future Caregivers		
The Arc Sibling Council Web based tool	Information about what is involved in supporting the family member with I/DD and helping siblings plan for the future.	The Arc Sibling Council https://futureplanning.thearc.org/pages/learn/who-are-you/sibling
The Sibling Support Project and Leadership Network	Providing siblings information, support and tools to advocate with their brothers and sisters. The Sibling Support Project, is a program focusing on the future.	Sibling Support Project https://siblingssupport.org/ Resources for Adult Siblings https://siblingleadership.org/resources/resources-for-adult-siblings/
The Sibling Survival Guide	Book providing tips on topics such as how to talk to your parents about plans for your sibling, and a crash course in guardianship, medical & legal issues, and government benefits.	https://www.amazon.com/Sibling-Survival-Guide-Indispensable-Disabilities/dp/1606130137/
Sibling Resources Online Learning Module	Videos to assist siblings with diverse topics such as navigating the system and future planning	https://www.siblingresources.org/course https://www.siblingresources.org/archives
Sibling Advocacy Toolkit	Demonstrates the unique roles that siblings play within advocacy.	https://siblingleadership.org/wp-content/uploads/2014/04/SLN-Advocacy-Toolkit-final.pdf

Research study	Details findings of a leadership and technical assistance support program for siblings.	Burke MM, Lee CE, Carlson SR, Arnold CK. Exploring the preliminary outcomes of a sibling leadership program for adult siblings of individuals with intellectual and developmental disabilities. <i>Int J Dev Disabil.</i> 2018;0:1–8.
Advocacy		
Maryland Developmental Disabilities Council (DD Council)	Training and fiscal support to community partners to support self advocacy efforts and increase knowledge and skills of people with I/DD.	https://www.md-council.org/ https://www.pogmd.org/
The Parents Place of Maryland - Parent peer support model	A grassroots led effort to empower families as advocates and partners.	https://www.ppmmd.org/
Empowering Partners Program	A partnership with The Arc Maryland, POG and The DD Council, supports self-advocacy groups efforts to share centralized discussion topics, activities, and a unified movement.	https://thearcmd.org/empowering-partners/
Pooled Resource Service		
Pooled Trusts by The Arc	Individual accounts established for each beneficiary, with the accounts pooled together for investment purposes.	Database operated by the Arc that run a pooled trust https://futureplanning.thearc.org/professionals?utf8=%E2%9C%93&profession=The+Arc%27s+Pooled+Trusts&state=&_gl=1*1uqqifs*_ga*MTcxNTE2MzAyLjE3MzQ2MzQ2MTY.*_ga_TTHG7VXBGP*MTczMzk3ODE2NS44LjEuMTczMzk3ODQ0NS4wLjAuMA.&_ga=2.158353914.1365255082.1733883889-171516302.1733634616
First Maryland Disability Trust	Trustee services designed to enhance beneficiaries' quality of life while protecting eligibility for public disability benefits.They manage both first-party and third party trusts.	First MD Disability Trust https://www.firstmdtrust.org/who-we-serve/#:-:text=Using%20a%20pooled%20trust%20allows,the%20individual%20with%20disabilities%20only.

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