White Paper

A Policy Roadmap for Advancing Disability Rights in Georgia

National Leadership Consortium on Developmental Disabilities

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Executive Summary

The Georgia Landscape

Georgia has established a strong policy foundation for supporting people with intellectual and developmental disabilities (I/DD) in their homes and communities. The state operates Medicaid-funded Home and Community-Based Services (HCBS), has adopted Employment First, increased provider reimbursement rates, and reduced its reliance on large institutions. Yet thousands of Georgians still cannot access the services that make community living possible.

For people with I/DD, the primary HCBS programs are the New Options Waiver (NOW) and the Comprehensive Supports Waiver Program (COMP). These waivers cover costs for personal assistance, respite, employment support, nursing, behavioral services, transportation, and other supports. HCBS help people live, work, maintain relationships, and participate in their communities. They also help family caregivers remain employed and support local provider organizations and direct-care jobs.

Approximately 8,000 Georgians remain on the state's I/DD Planning List, meaning they are waiting for approval to receive NOW/COMP waivers for supports. A DBHDD and Georgia Council on Developmental Disabilities working group estimated **1,217 urgently needed new waiver slots** for those most at risk; they estimate these waiver slots would cost $132 million. However, only 100 waiver slots were approved after the 2026 Legislative Session.

Recently, Georgia legislators have approved more funding for facility-based centers (typically crisis centers) than waiver slots for community-based supports. This trend is concerning to many people with disabilities and their families. Facility-based crisis infrastructure cannot replace preventive community services. A balanced system must respond to emergencies while also investing in assistance, respite, behavioral support, and healthcare coordination that can prevent some crises and institutional placements.

Expanding HCBS is both a disability-rights priority and a fiscally responsible, pro-family workforce strategy. National evidence reviewed in this paper shows that Medicaid HCBS serve more people at a lower average cost than institutional long-term care. Underinvestment does not eliminate costs; it transfers them to families, hospitals, emergency responders, crisis programs, and institutional systems. Six in ten family caregivers report employment consequences related to caregiving, including reduced hours, missed work, or leaving the workforce.

Personal Experiences

The experiences of UnlockGA Ambassadors Daniel Abadie, Kayla Rodriguez, and Patricia Sonnier provide context, highlighting their perspectives and opinions. Daniel's story demonstrates how

support and mentorship create pathways to entrepreneurship and leadership. Kayla's experience shows how paperwork, uncertainty, and years of waiting affect families providing unpaid care. Patricia's story illustrates the burden created by inconsistent information and the expectation that families will remain the permanent plan for meeting every need.

Their stories reinforce several conclusions: support makes independence possible; family labor often conceals unmet need; administrative complexity is a barrier; accessible opportunities can change life trajectories; and people with disabilities must help shape the policies that affect them.

Policy Recommendations

1. **Expand HCBS capacity and reduce the Planning List** through workload-based budgeting[1], funding 1,217 new waivers slots, implementation of the proposed three-tier Planning List, and preventive bridge services.
2. **Continue to strengthen the DSP workforce** through regular rate reviews, workforce data, paid training, credentials, career pathways, benefits, and incentives for rural and specialized services.
3. **Expand competitive integrated employment** by coordinating Medicaid, vocational rehabilitation, education, and workforce systems and increasing supported employment and benefits counseling.
4. **Strengthen self-advocate leadership** through compensated decision-making roles, accessible participation, and accountability for how agencies respond to recommendations.
5. **Improve cross-agency coordination** through a permanent Community Living Council, shared outcomes, and a unified navigation and referral process.
6. **Improve data and accountability** through a public dashboard reporting waiting times, waiver access, delivered services, workforce capacity, community outcomes, and disparities.

Georgia's central challenge is closing the gap between policies that support community inclusion and the scale, workforce, coordination, and accountability needed to make those policies real. The goal is not simply to fund more services. It is to ensure that Georgians with disabilities can live, work, make decisions, contribute, and belong in their communities.

[1] In this paper, "workload-based budgeting" refers to a budgeting approach that estimates funding needs based on the projected number of eligible people requiring services. Applying this approach to NOW and COMP waivers would treat expected growth in urgent service needs as an ongoing budget responsibility rather than solely as a discretionary expansion. The term describes a recommended budget methodology; it does not itself create a legal entitlement or restrict legislative or executive budget authority.

This paper is written by The National Leadership Consortium on Developmental Disabilities and contracted Georgians with disabilities who were paid to contribute to its development, focused on advancing community supports for people with disabilities.

1- Introduction

Home and Community-Based Services, commonly known as HCBS, are provided in a person's home or another community setting as an alternative to institutional care. Depending on a person's eligibility and needs, HCBS may include personal assistance, respite, supported employment, behavioral services, nursing, transportation, assistive technology, and support with daily activities.

For Georgians with intellectual and developmental disabilities (I/DD), the primary Medicaid HCBS programs are the New Options Waiver (NOW) and the Comprehensive Supports Waiver Program (COMP). NOW generally serves people who need intermittent support while living in their own or family homes, while COMP provides more intensive services for people with greater needs.

Because waiver enrollment is capped, eligibility does not guarantee immediate access. When state funding is insufficient, people who are potentially eligible are placed on Georgia's I/DD Planning List. Approximately 8,000 people are currently waiting. For people with disabilities and families, that wait can mean years without reliable personal assistance, employment support, respite, healthcare coordination, or help planning for a future in which family caregivers may no longer be available.

The right to community living holds particular significance in Georgia. The U.S. Supreme Court's landmark 1999 decision in *Olmstead v. L.C.* began here and affirmed that unnecessary segregation of people with disabilities is discrimination. Georgia's 2010 settlement with the U.S. Department of Justice subsequently accelerated the expansion of community services and the transition away from large state institutions. In February 2026, after 16 years of federal court oversight and system reform, the court terminated the settlement's remaining behavioral health provisions and related monitoring requirements. This represented significant progress; however, provisions concerning community-based services for people with intellectual and developmental disabilities remain in effect. The promise of *Olmstead* therefore remains incomplete when people must wait years for support or cannot find workers to provide authorized services.

HCBS are also essential workforce and economic infrastructure. They help people with disabilities pursue employment, education, entrepreneurship, relationships, and leadership. They help family caregivers remain employed rather than becoming the unpaid substitute for an under-resourced

service system. When services are unavailable, costs and responsibilities shift to families, hospitals, emergency responders, and institutional systems.

This paper examines Georgia's disability-policy landscape and offers a practical roadmap for moving forward. It combines policy analysis, research, Georgia-specific evidence, and interviews with Ambassadors Daniel Abadie, Kayla Rodriguez, and Patricia Sonnier. Their stories illustrate how service access, employment, caregiving, administrative complexity, and leadership intersect in daily life.

A central principle connects each section of this paper: support and independence are not opposites. Reliable assistance is often what makes independence possible.

Georgia already has many of the policies and programs needed to create a stronger community-based system. What remains is to ensure sufficient scale, staffing, coordination, and accountability, and to keep people with disabilities at the center of the decisions shaping that system's future.

Waivers, Not Walls! *UnlockGA's recent Initiative,* ***Waivers, Not Walls****, centered on advocacy and action to fulfill the promises of Olmstead, HCBS, and community supports in Georgia. People with disabilities want funds for more* ***Waivers*** *that support people to live and thrive in their chosen communities, not funds for more* ***Walls****, or institutional supports that infringe on people's human rights through segregated and congregate supports.*

While the content developed for this White Paper is not a result of this initiative, its spirit and purpose have influenced the recommendations developed.

2- The Current Policy Landscape in Georgia

Georgia has established policies and programs intended to support the right of people with intellectual and developmental disabilities (I/DD) to live, work, and participate in their communities. These include Medicaid waiver programs that fund Home and Community-Based Services (HCBS)—particularly the New Options Waiver (NOW) and Comprehensive Supports Waiver (COMP)—as well as Employment First and initiatives addressing housing, transportation, healthcare, and family support. However, the effectiveness of nearly every disability policy depends on whether people can access adequate HCBS. Without a funded waiver, qualified workers, and sufficient provider capacity, other community-inclusion policies cannot fully achieve their goals. Home and Community-Based Services

Current policy and progress | HCBS allow people with disabilities to receive support in their homes and communities rather than in institutions. For Georgians with I/DD, the primary Medicaid HCBS programs are the New Options Waiver (NOW) and the Comprehensive Supports Waiver Program (COMP). These waivers may fund personal assistance, employment services, respite, nursing, behavioral support, transportation, and community participation. Georgia's 2010 settlement with the U.S. Department of Justice helped expand these services and reduce reliance on large state institutions. (Georgia Department of Community Health).

Remaining gaps |

Enrollment in Georgia's NOW and COMP waiver programs is limited to the number of slots funded through the state budget and authorized under the waiver. As a result, meeting eligibility requirements does not guarantee immediate access, and eligible people may wait years for services. Even after receiving a waiver, workforce shortages can prevent participants from obtaining all the support authorized in their service plans. These barriers are particularly serious in rural communities and for people with complex medical or behavioral support needs.

Reducing HCBS spending may create short-term savings, but it can transfer costs to hospitals, emergency responders, crisis services, institutions, and unpaid family caregivers. National evidence indicates that community-based services can improve outcomes and reduce unnecessary reliance on more costly institutional care. (CMS Money Follows the Person)

Opportunities | Georgia can strengthen HCBS through predictable multi-year funding, expanded provider capacity, greater participant direction, and public reporting on whether people receive authorized services. A new federal option scheduled for 2028 may also allow Georgia to offer earlier, lower-intensity services to people who do not yet meet an institutional level of care, helping prevent crises while preserving support for people with more extensive needs.

The Planning List

Georgians who are potentially eligible for NOW or COMP but cannot immediately receive a funded waiver are placed on the state's I/DD Planning List. While waiting, they may receive limited state-funded or family-support services, but these programs do not provide the comprehensive and continuing support available through a Medicaid waiver.

Approximately 8,000 Georgians are on the Planning List. A DBHDD and Georgia Council on Developmental Disabilities working group estimated that 1,678 people would develop an urgent need for waiver services over the following year. After accounting for anticipated departures from existing waivers and the Planning List, the working group calculated a net need for **1,217 new waiver slots**. (GCDD's 2026 waiver-needs analysis)

During the 2026 legislative session, the General Assembly approved funding for 500 new waiver slots in the FY 2027 budget. However, Governor Kemp, in an effort to balance the budget due to shortfalls not addressed during Legislative Session, disregarded most of that appropriation, leaving funding for 100 slots. Although each waiver will significantly affect one person and family, 100 slots address only a small portion of the documented need. (GCDD's FY 2027 budget analysis)

Remaining gaps and opportunities |

The Planning List affects every other part of the disability policy landscape. Without HCBS, a person may be unable to work, live independently, access healthcare, or participate in community life. Families often fill the gap through unpaid care, and reduced employment, causing financial strain and increased familial stress. Georgia can respond by treating predictable waiver demand as a recurring **workload obligation** in the state budget, supported by annual reduction targets, adequate administrative staffing, and transparent reporting on waiting times and unmet needs.

The Direct Support Professional Workforce

Direct Support Professionals (DSPs) help people with disabilities manage daily activities, work, maintain their health, and participate in their communities. In 2024, Georgia invested approximately $107 million in NOW and COMP provider-rate increases, which were expected to raise average DSP wages from roughly $10 to approximately $16 per hour. Georgia has also expanded DSP training and certification. (Georgia DBHDD)

Remaining gaps and opportunities |

A waiver cannot provide meaningful access when no qualified worker is available. Recruitment and retention problems continue, particularly in rural areas and specialized services. Georgia can build on recent investments through regular rate reviews, transparent workforce data, paid training, portable credentials, career ladders, benefits, and incentives for rural or complex-needs services.

Employment

Georgia's Employment First Act establishes competitive integrated employment as the preferred outcome for people with disabilities receiving publicly funded services. Supported employment is available through DBHDD and vocational rehabilitation, while the Dignity and Pay Act is phasing out subminimum wages.

HCBS gaps and opportunities |

Many people need job coaching, personal assistance, behavioral support, or transportation to obtain and maintain employment. When a person is waiting for a waiver, or providers cannot recruit staff, employment services may be unavailable. Georgia can improve outcomes by coordinating Medicaid, vocational rehabilitation, schools, and

workforce agencies while expanding benefits counseling, customized employment, and long-term workplace support.

Housing

Georgia supports community-integrated housing through DBHDD residential services, Section 811 rental assistance, and accessibility-modification programs. These initiatives have increased opportunities for people with disabilities to live outside institutional settings. (Georgia DCA Section 811)

HCBS gaps and opportunities |

Housing and HCBS are inseparable. Medicaid generally does not pay rent, while housing programs do not provide the daily support a person may need. Someone may therefore have a home but no services, or an approved waiver but no affordable and accessible place to live. Georgia can improve coordination among housing and disability agencies while expanding rental assistance, accessibility modifications, housing navigation, and integrated housing supported by reliable HCBS.

Transportation

Current policy and progress |

Transportation is available through local transit agencies, state transportation programs, Medicaid, and the Department of Human Services. However, services vary considerably by region, and rural communities may have limited routes, hours, or reservation options.

HCBS gaps and opportunities |

HCBS may help people reach certain services or activities, but waiver transportation cannot replace an accessible public transportation system. Without transportation, people may be unable to use employment, healthcare, or community programs that otherwise exist. Georgia can expand rural and demand-response services, improve cross-county travel, and better coordinate public, Medicaid, and human-service transportation.

Healthcare Access

Medicaid provides healthcare coverage and finances most long-term services for Georgians with I/DD. Georgia has also developed initiatives to improve health-risk screening, individualized healthcare planning, and coordination between disability services and medical providers.

HCBS gaps and opportunities |

HCBS often make healthcare usable. A person may need a DSP to identify symptoms, communicate with providers, arrange transportation, or follow treatment instructions. Without these supports, manageable conditions can become emergencies. Georgia can strengthen disability-competent care, provider networks, care coordination, accessible telehealth, and integration of physical, behavioral, and oral healthcare.

Family Supports

Georgia's Family Support Services program assists eligible people with I/DD who live with their families and do not receive NOW or COMP. Assistance may include respite, information, education, equipment, and other flexible supports. (Georgia DBHDD)

HCBS gaps and opportunities | When HCBS are unavailable, families frequently fill the gap through unpaid labor, reduced employment, financial strain, and interrupted sleep. Family supports are limited by funding, and respite may be authorized but unavailable because of workforce shortages. Georgia can expand recurring funding for respite, navigation, crisis prevention, and aging-caregiver planning while ensuring that family assistance complements, not replaces, each person's right to services, independence, and community living.

The Cross-Cutting Challenge

Georgia has created important community-based programs, but a policy on paper is not the same as support a person can use. Employment requires transportation and job support. Housing requires affordable options and reliable services. Healthcare requires assistance with access and coordination. Families need respite and stability.

Closing these gaps will require sustained HCBS investment, a stable workforce, coordination across agencies, transparent outcomes, and leadership and decision-making opportunities from people with disabilities most affected by these policies.

3- What We Heard from the Disability Community

Three lived experiences of entrepreneurship, family caregiving, and advocacy in Georgia

The following narratives were developed from interviews with UnlockGA Ambassadors Daniel Abadie, Kayla Rodriguez, and Patricia Sonnier. Their experiences, perspectives, and opinions are their own and not representative of those of UnlockGA, GCDD, or other entities. Their stories and experiences are critical to providing important context for how people with disabilities experience HCBS and related processes, infrastructure, and policies in Georgia. Each story is presented independently so that the ambassadors' experiences remain central.

Daniel Abadie: Finding His Voice

For Daniel Abadie, finding his voice has been both a personal journey and a professional calling. Daniel is an UnlockGA Ambassador and the founder of Vivid Vocals VO, a voice-over production company built on the belief that every story deserves to be heard. His path to entrepreneurship began long before he launched his business, with the people who believed in him as he grew up

and helped him develop the skills and confidence to envision an adult life shaped by his own interests.

Daniel describes his childhood as a period of learning, adaptation, and support. His family, friends, teachers, and therapists recognized the challenges he experienced related to his disability, including difficulties with social communication and sensory processing. They offered accommodations while also helping him strengthen the conversational and social skills he would need to build relationships and pursue greater independence. As Daniel grew older, he came to see advocacy as a way of giving back to the people who had supported him. He wanted other disabled people, and the educators, families, and caregivers who support them, to have opportunities, feel less afraid of everyday challenges, and experience a better quality of life.

His interest in voice-over work grew from the broadcasts and characters that captured his attention when he was young. He listened closely to sports announcers, wildlife and history narrators, and animated characters. When he later learned that many voice actors work from home studios as freelance entrepreneurs, he began to picture a career that could combine his interests, abilities, and need for flexibility. Encouragement from his family gave him the confidence to pursue that possibility. Voice-over work could provide income, but it could also help nonprofits, disability organizations, and advocacy coalitions communicate messages that mattered.

In spring 2021, Daniel's mother learned about the Synergies Work i2i: Ideas to Innovation program and encouraged him to enroll. During the eight-week program, Daniel and other disabled entrepreneurs learned how to describe and promote their businesses, understand basic financial concepts and business structures, build websites, develop relationships with potential clients, and connect with mentors. The experience helped Daniel move from having an idea to seeing himself as an entrepreneur with a service of value to others.

One of Daniel's strongest memories is the presentation at the end of the program. In front of mentors and members of the business community, he introduced his voice-over services, explained what his business represented, and described the clients and projects he hoped to pursue. The presentation gave him a chance to practice telling his own professional story, and people in the audience expressed interest in working with him. He also learned to create business cards with a QR code linked to his website and to pair those materials with an elevator pitch that sounded natural and authentic. Just as importantly, he became part of a network of disabled entrepreneurs pursuing businesses in areas such as art, music, environmental services, and greeting cards. Many of those connections continued after the program ended.

Daniel has since used his voice across business, media, and advocacy. His experiences have included disability-focused panels, employment advocacy events, voter education materials with audio description, and audiobook narration related to disability-driven innovation. Community-based organizations and advocacy networks also connected him to his first paid job and gave him

opportunities to learn how disability policy is shaped. Through those experiences, employment, entrepreneurship, and advocacy became closely linked: each offered a way to contribute, build relationships, and challenge assumptions about what disabled people can do.

Daniel also recognizes the barriers that remain. He has encountered an employment landscape in which disabled applicants are too often viewed as risks rather than as workers and innovators. For him, entrepreneurship offers one path around those limited expectations, but individual persistence cannot replace accessible systems, meaningful employment supports, open-minded employers, or public investment. His story shows what becomes possible when a disabled person is supported to develop skills, build a network, take professional risks, and speak for himself. It also demonstrates that inclusion is not simply about being invited into a space; it is about having the safety and opportunity to learn, contribute, ask for what one needs, and challenge barriers without fear of losing the chance to work.

Kayla Rodriguez: The Cost of Waiting

Kayla Rodriguez has spent nearly a decade building a life in advocacy. A Puerto Rican autistic lesbian and non-binary person with ADHD, type 1 diabetes, and other chronic health conditions, Kayla first entered the disability community because they wanted to meet other autistic people. After attending a Disability Day of Mourning honoring disabled people killed by family members or caregivers, Kayla connected with the former Atlanta affiliate of the Autistic Self Advocacy Network. That community became an entry point into advocacy and, over time, into leadership.

Kayla went on to participate in the Bobby Dodd Institute Ambassador Program, Georgia LEND, and Georgia State University's My Voice. My Participation. My Board. program. Their advocacy has included serving in leadership roles with autistic-led organizations, advising participatory research, speaking on national and international panels, and completing a paid communications and policy internship with the Georgia Council on Developmental Disabilities. Yet Kayla's public experience does not remove the need for support in daily life. Their story illustrates how a person can be a skilled, accomplished advocate and still encounter a service system that is difficult to enter and slow to respond.

Kayla first learned about Georgia's NOW and COMP Medicaid waiver programs while interning at GCDD in 2019. They did not apply immediately. The application appeared to require records that would be difficult to locate, and the size of the planning list made the process feel almost pointless. If services were years away, Kayla wondered whether completing the paperwork would make any difference. For approximately four years, those practical and emotional barriers delayed the application. Encouragement from people around them eventually helped Kayla decide that applying was still worth doing, even without any assurance that services would follow.

Kayla submitted an application in late 2023, provided additional documentation, and was formally placed on the planning list in summer 2024. Support from the Bobby Dodd Institute helped Kayla complete an evaluation and communicate the urgency of their needs. Still, the experience of waiting has been defined by uncertainty. Updates generally arrive only when Kayla reaches out, and the answer is often that no new information is available. Each step in the process has seemed to suggest that the waiver might be close, only for the timeline to remain unclear. Kayla worries about contacting staff too often, but also worries that remaining quiet could mean being forgotten.

While Kayla waits, their family continues to provide essential support. Their sister assists with meals, clothing, and personal care, and their mother also helps them manage daily life. Kayla values this support and wants their family members to be recognized and compensated for the work they already perform. The need is not theoretical: unpaid caregiving affects the family's finances, time, and capacity, while the absence of formal services leaves responsibility concentrated within the household. Kayla's waiting is part of why the waiver matters so much.

The waiver also represents a path toward greater independence. Kayla is currently seeking meaningful employment and believes that job development and ongoing employment support could help them find work and remain employed. For someone managing type 1 diabetes, reliable health coverage is also essential. Kayla rejects the idea that Medicaid or waiver recipients are seeking free services or avoiding work. Some disabled people cannot work; others can work when the right assistance is available. In both circumstances, support makes it possible to live safely at home, participate in the community, and build a life that reflects the person's own goals.

Kayla has carried that message into public advocacy, including legislative committee testimony and a press conference. Speaking publicly made them nervous, but the importance of the waiver crisis outweighed that fear. Afterward, Kayla felt more confident that they could do it again. They want more waiver slots, fewer resources directed toward institutional care, and ultimately an end to the planning list. They also want disabled people to be present wherever policy decisions are made–as advocates, advisors, legislators, and other public leaders. Kayla's experience demonstrates why families should not be expected to sustain an under-resourced system indefinitely, and why disabled people themselves must be included in shaping the supports on which their lives depend.

Patricia Sonnier: Turning Family into Advocacy

Patricia Sonnier's advocacy begins at home. She is a wife, a military spouse, a mother of two, a caregiver, a disabled person, and a special education advocate. Her 13-year-old son is autistic, and her 19-year-old daughter has dyslexia and is studying mechanical engineering in college. The ordinary movement of family life is always present in Patricia's work: caregiving, school planning, appointments, paperwork, interruptions, and the constant effort to help both of her children develop confidence in their own voices.

Patricia's understanding of disability systems is also rooted in her own childhood. She received special education services because of her disability and describes herself as being among the early students with an Individualized Education Program who graduated from her school with a standard diploma. That experience allows her to recognize parts of her children's journeys while also understanding that their needs and identities are their own. She does not want to speak over them. Her goal is to help them learn that they are entitled to explain what they need, make choices, and advocate for the lives they want.

As her family navigated education and disability services, Patricia became the person others called when they did not know where to begin. She now leads Sonnier Solutions: Beyond the Carpool Line, through which she helps families understand special education policy and community-based supports. Patricia describes her approach as the opposite of gatekeeping: when she finds a useful resource, learns how a process works, or discovers a strategy that helped her family, she shares it. Her advocacy grew from one family's search for answers into a commitment to make those answers more accessible to others.

The hardest part of that search has not simply been finding information; it has been finding information that is accurate, consistent, and timely. As her son approached the age when transition planning and vocational rehabilitation services become important, Patricia tried to prepare the documentation in advance. She contacted several sources and received several different explanations of what she needed. She has encountered the same contradictions in conversations about NOW and COMP waivers. Each inconsistent answer can mean another call, another form, another delay, and another burden placed on a family already managing extensive care responsibilities.

That burden contributes to caregiver burnout, an experience Patricia believes systems too often overlook. She provides near-constant support to her son while balancing advocacy work and family responsibilities. She is grateful for a spouse whose employment gives their household some flexibility and for friends who recognize when she needs a break and step in to help. She also knows that many families do not have those options. Some parents must leave or reduce paid employment, perform complex care that would otherwise be provided by a trained professional, and continue without compensation or reliable respite. For those families, even a short break can be difficult to arrange.

Patricia's most meaningful successes have come from watching her children speak for themselves. During her son's first visit to the Georgia Capitol, the unfamiliar setting initially overwhelmed him. With time and support, he was able to talk with his representative about an issue important to him. His pride afterward showed Patricia that advocacy could become part of his own story, not only hers. Her daughter's experience offered another lesson in refusing limited expectations. When her daughter was in second grade, Patricia and her husband were told she

might not make it through the next grade. Years later, she graduated in the top ten percent of her high school class, spoke at graduation, and went on to study mechanical engineering. The early prediction did not define her; it became only one small part of a much larger story.

Those experiences shape Patricia's concern about the future. Families often become the default plan for meeting every need, but parents cannot provide care forever. Community-based services, respite, employment assistance, reliable information, and support for independent living are therefore not extras. They are part of creating a sustainable future in which disabled children and adults can remain connected to their communities, pursue their ambitions, and contribute in ways that matter to them. Patricia has seen this in the young adults she knows who want to work, live more independently, and make decisions about their own lives but cannot move forward while waiting for services their families cannot afford privately.

Patricia's story is ultimately about turning experience into shared knowledge and using that knowledge to expand what families believe is possible. She wants policymakers to understand both the strength of disability families and the limits of relying on that strength without adequate support. Resilience does not eliminate exhaustion, and love does not pay for respite, therapies, housing, or skilled care. By helping her children develop their own voices and helping other families navigate the system, Patricia is working toward a Georgia in which no family's future depends solely on how much unpaid care, private money, or persistence they can provide.

Putting It Together: Recurring Themes Across Lived Experiences

Daniel's, Kayla's, and Patricia's stories are distinct. They reflect different identities, roles, goals, and relationships to Georgia's disability service system. Nevertheless, several recurring themes emerge when their experiences are considered together. These themes are not intended to represent every disabled person or family in Georgia, nor should they be interpreted as estimates of how frequently an experience occurs. Instead, they offer qualitative insight into how support, caregiving, service access, employment, and advocacy intersect in the lives of three people deeply involved in Georgia's disability community.

Support and Independence Are Interdependent

Across all three stories, receiving support is not the opposite of independence. It is often what makes independence possible. Daniel's family, educators, therapists, mentors, and professional networks helped him strengthen communication skills, pursue entrepreneurship, and build a public role as an advocate. Kayla's sister and mother provide essential assistance while Kayla waits for formal services that could support employment and compensate some of the caregiving already occurring. Patricia's support has helped her children develop their own voices, enter advocacy spaces, and pursue goals others once doubted they could achieve.

Together, these accounts challenge a narrow understanding of independence as doing everything without help. The independence described by the ambassadors is person-directed: having reliable assistance, accessible opportunities, and enough control to make choices about work, relationships, community life, and the future. When those supports are missing, people do not become more independent; responsibility simply shifts to people and families with fewer resources and fewer options.

"We just need support to live a happy life like everybody else and a successful life."[2]
- Kayla Rodriguez

Families Are Carrying Work the Formal System Does Not See

Family support is central in each narrative, but Kayla's and Patricia's experiences make the hidden labor of caregiving especially visible. Kayla's family provides daily assistance while waiting for a waiver, and Kayla wants that work to be recognized and supported financially. Patricia provides near-constant care to her son and depends on flexibility from her spouse and informal respite from friends. She also knows families who reduce or leave paid employment and perform complex care without compensation, training, or dependable relief.

These stories do not portray families as unwilling to provide care. They show families providing care because of commitment and love, while also absorbing costs that would otherwise fall to a better-resourced service system. The consequences include lost income, caregiver burnout, limited time, and anxiety about who will provide support in the future. Respite, family caregiver compensation, future planning, and community-based services are therefore not secondary benefits. They are part of sustaining both disabled people and the family members on whom the current system heavily relies.

"We're the plan, and we're tired. Help us."
- Patricia Sonnier

Complexity and Waiting Are Barriers in Themselves

The ambassadors' experiences show that a service can exist on paper and still remain practically inaccessible. Kayla knew about the NOW and COMP waivers for approximately four years before applying. The anticipated paperwork and the length of the planning list made the process feel overwhelming and unlikely to lead to timely help. After applying, Kayla provided additional documentation, secured advocacy assistance, and continued requesting updates, yet the timeline remained uncertain. Kayla described feeling responsible for reminding the system, in effect, not to forget them.

[2] Quotations have been lightly edited for clarity and readability without changing their meaning.

Patricia encountered a related problem while seeking transition and disability service information for her family: different sources, and sometimes people within the same organization, offered conflicting instructions. Each contradiction creates more calls, more paperwork, and more opportunities for delay. The ability to navigate such a system depends heavily on time, confidence, organizational knowledge, and access to advocates. Consequently, administrative complexity does not affect everyone equally. A clearer system would provide consistent requirements, proactive communication, understandable timelines, and navigation support before families reach a crisis.

"It is still the single hardest thing right now: trying to find not just any information, but the right information."
- Patricia Sonnier

Opportunities and Networks Can Change Life Trajectories

The stories also demonstrate what can happen when people gain access to well-designed opportunities. For Daniel, the Synergies Work i2i program offered practical business education, mentorship, a peer network, and a setting in which potential clients could see his abilities. Community connections also helped him obtain his first paid job and enter disability policy and advocacy spaces. Kayla's development as an advocate similarly grew through autistic-led community, the Bobby Dodd Institute, Georgia LEND, board leadership, policy work, and public testimony. Patricia transformed what she learned through her family's experience into resources and guidance for other families, while supporting her children to advocate for themselves.

These opportunities did more than teach isolated skills. They expanded networks, expectations, and possible futures. The pattern suggests that investment in accessible leadership development, mentoring, entrepreneurship, employment supports, and paid advocacy can produce effects that continue well beyond a single program. People gain not only knowledge but also relationships, credibility, and opportunities to demonstrate contributions that conventional education and employment systems may have overlooked.

"It made us with disabilities feel pretty confident that we could establish a brighter future for ourselves."
- Daniel Abadie

Lived Experience Must Shape Decisions

Daniel, Kayla, and Patricia have each moved from navigating disability-related barriers to helping shape how others understand those barriers. Daniel uses voice-over work and public advocacy to challenge assumptions about disability and employment. Kayla has served in advisory and organizational leadership roles and has spoken publicly even when doing so felt intimidating.

Patricia shares information with families, engages with policymakers, and emphasizes helping her children tell their own stories rather than speaking in place of them.

Their experiences point toward a model of policymaking in which disabled people and family caregivers are not invited only after priorities have already been established. Meaningful inclusion requires ongoing and accessible roles in advisory councils, boards, legislative conversations, program design, research, and evaluation. It also requires recognizing their time and expertise through compensation when appropriate. Listening becomes meaningful when lived experience influences what is funded, how services are delivered, and how success is defined.

"Include disabled people as part of the conversation when you're making decisions. Nothing about us without us."
- Kayla Rodriguez

From Individual Persistence to Shared Responsibility

Persistence runs through every narrative. Daniel continued developing a business and professional identity in the face of employment stigma. Kayla completed a difficult waiver application, continued requesting updates, and spoke publicly despite anxiety and discouragement. Patricia turned years of systems navigation and caregiving into advocacy for her own family and others. Their persistence is a source of strength, but it should not be the price of accessing ordinary opportunities, accurate information, or essential support.

Taken together, the stories shift responsibility away from individuals having to overcome every barrier on their own. They call for a disability system that responds before families are exhausted, communicates before people fear being forgotten, and invests before talent and opportunity are lost. They also reject stereotypes that disabled people do not want to work, that families already have everything they need, or that support represents dependency. As Patricia emphasized, the opportunity to contribute is a human right. Realizing that right requires shared public responsibility for accessible services, supported employment and entrepreneurship, family caregiver resources, community inclusion, and sustained roles for people with lived experience in decision-making.

The common message is not simply that disabled people and families are resilient. It is that Georgia can build systems worthy of that resilience - systems that recognize people as capable, provide support without unnecessary delay, and make it possible for more people to live, work, lead, and belong in their communities.

"Those who are disabled, those who love and care for those who are disabled, and those with a responsibility to help are some of the most persistent individuals I have ever met."
- Daniel Abadie

4-What the Evidence Shows

The experiences shared by Daniel, Kayla, and Patricia are personal, but the conditions they describe are not isolated. Research on Medicaid long-term services and supports, family caregiving, workforce participation, and community living points to a consistent conclusion: Home and Community-Based Services are not only a disability rights commitment. They are also essential health, workforce, and economic infrastructure. When these services are available, people with disabilities have greater opportunities to live, work, and participate in their communities. When they are unavailable, costs and responsibilities do not disappear; they shift to families, emergency systems, institutions, and an already strained workforce.

HCBS Advance Rights While Using Public Resources More Efficiently

National evidence shows that HCBS have become the primary setting for paid long-term services and supports and are associated with lower average Medicaid spending than institutional services. More than eight million people nationally receive paid LTSS: more than six million in home and community settings and more than two million in institutional settings. This population includes older adults and people who need assistance because of disabilities or chronic illnesses; it is not limited to people with I/DD. Separately, among approximately 5.7 million Medicaid enrollees who used LTSS in 2021, three-quarters received HCBS. Average Medicaid spending was also lower for enrollees using HCBS than for those using institutional services, although differences in individual support needs must be considered when comparing costs.

The difference in spending is also substantial. In 2021, average Medicaid spending was $38,275 per enrollee receiving HCBS, compared with $53,666 for someone receiving institutional long-term care, a difference of more than $15,000 per person (KFF, 2024; KFF analysis of 2021 T-MSIS data).

Long-term evidence suggests that states do not have to choose between serving more people and controlling costs. An analysis of Medicaid spending across 49 states and the District of Columbia found that states that gradually shifted resources toward HCBS served more people while reducing per-person and overall long-term services and supports spending. Gradual rebalancing was associated with approximately 15 percent lower spending over ten years, an 8.4 percent increase in people served, and a 6.3 percent reduction in per-capita spending. By contrast, reducing the share of spending devoted to HCBS was projected to increase long-term costs (Kaye, 2012).

These averages do not mean that every community-based arrangement will be inexpensive, particularly for people with complex medical or behavioral support needs. They demonstrate that institutional care should not be treated as the more economical default. With adequate and

sustained investment, community-based systems can support more people while using public resources more effectively.

Underinvestment Does Not Eliminate Costs; It Transfers Them

When formal services are unavailable, families absorb much of the difference through unpaid labor, out-of-pocket expenses, and lost employment. National research indicates that 78 percent of family caregivers incur out-of-pocket costs, averaging $7,242 annually, or approximately 26 percent of their income. The burden is not distributed equally: Black caregivers spend an average of 34 percent of their income on caregiving expenses, while Hispanic and Latinx caregivers spend approximately 47 percent (AARP, 2021; Caldwell, 2022).

Caregiving responsibilities also affect workforce participation. Six in ten family caregivers report that caregiving has affected their employment. More than half have arrived late, left early, or taken time away from work; 15 percent have reduced their hours or moved from full-time to part-time employment; and others have left the workforce or retired early (National Alliance for Caregiving & AARP, 2020).

These findings reflect what Kayla and Patricia described. Family members provide essential daily support while waiting for formal services, frequently without compensation, reliable respite, or certainty about the future. This arrangement may temporarily conceal unmet need, but it does so by transferring costs to households and relying on families' continued availability. HCBS therefore function as both disability services and workforce policy: they help people with disabilities pursue their own goals while allowing family caregivers to remain employed and economically stable.

Community Supports Function as Prevention

Research also connects unmet HCBS needs with greater stress, poorer health, heavier caregiving burdens, and reduced community participation. When people cannot obtain routine assistance, respite, behavioral support, employment services, or help with daily activities, needs may escalate until families must turn to emergency departments, law enforcement, hospitals, or institutional care. Crisis services are necessary, but crisis infrastructure cannot substitute for preventive community support. A balanced system must be able to respond when a crisis occurs while also investing in services that reduce the likelihood of crisis, incarceration, hospitalization, or institutional placement in the first place.

Programs that help people transition from institutions to community settings have demonstrated that community living can improve people's lives while reducing reliance on higher-cost facilities. Sustained HCBS investment also supports local providers, creates direct-support jobs, and keeps public dollars circulating through communities rather than concentrating resources in institutional systems (CMS, n.d.; Caldwell, 2022; Mathematica, 2025).

Medicaid and the Direct-Support Workforce Are Essential Infrastructure

Access depends on whether a qualified workforce is available to provide authorized services. Research links direct-care workforce shortages and turnover to low wages, unstable hours, demanding working conditions, and inadequate public investment (PHI, 2021). When provider rates and workforce investments do not keep pace with costs, organizations struggle to recruit and retain staff, services become unreliable, and families are again expected to fill the gaps. Funding additional waiver slots is therefore essential, but slots alone cannot produce meaningful access without sufficient administrative capacity and a stable, adequately compensated workforce.

Administrative complexity creates another form of inaccessibility. Kayla's delayed waiver application and Patricia's search for consistent information demonstrate how paperwork, conflicting instructions, limited communication, and unclear timelines can prevent people from obtaining services that technically exist. A right or benefit available only to people with enough time, knowledge, and persistence to navigate the system is not equally accessible.

Limited waiver capacity is not the only barrier to accessing HCBS. Administrative complexity can also make services inaccessible. Kayla's delayed waiver application and Patricia's search for consistent information demonstrate how paperwork, conflicting instructions, limited communication, and unclear timelines can prevent people from obtaining services that technically exist. A benefit available only to people with enough time, knowledge, and persistence to navigate the system is not equally accessible.

Lived Experience Shows How Policy Operates in Practice

The ambassador narratives should not be interpreted as estimates of how often particular experiences occur. Their value is different: they show the mechanisms through which policy choices affect daily life. Their stories illustrate how administrative complexity delays access, how unpaid family labor masks unmet need, how formal and informal support makes independence possible, and how mentorship and accessible opportunities can alter education, employment, leadership, and entrepreneurship trajectories.

The quantitative evidence and lived experiences point in the same direction. People with disabilities achieve greater independence when reliable support, accessible opportunities, and meaningful choices are available. Families are more sustainable when they are not expected to function as the permanent and uncompensated substitute for a public service system. Communities benefit when disabled people can work, lead, build businesses, participate in civic life, and help shape the policies that affect them.

Georgia's central challenge is therefore not a lack of evidence. It is the continuing gap between what the evidence supports and what the state consistently funds and implements. Closing that

gap requires moving from short-term responses to sustained community investment, and from expecting individual families to overcome systemic barriers to accepting shared responsibility for a disability service system that enables people to live, work, lead, and belong.

5- Policy Recommendations

Georgia has made important investments in community-based services, provider rates, employment policy, and disability rights. However, progress remains vulnerable when funding is unpredictable, agencies operate separately, and people with disabilities are not meaningfully included in decisions. The following recommendations provide practical steps for moving from short-term responses toward a coordinated and sustainable system of community support.

1. Expand HCBS Capacity and Reduce the Planning List

Why it matters | Approximately 8,000 Georgians with I/DD remain on the Planning List for NOW and COMP waivers. Without HCBS, people may lose opportunities to work, live independently, and participate in their communities. Families frequently fill the gap until caregiving becomes unsustainable or a crisis occurs.

Current evidence | A DBHDD and GCDD working group estimated that Georgia needs 1,217 net new waivers to address the number of people expected to develop urgent needs over the next year. GCDD has cited an estimated cost of approximately $132 million, although the state should publish a detailed fiscal analysis separating state funds, federal matching funds, administrative expenses, and the projected mix of NOW and COMP services. The General Assembly approved 500 new slots for FY 2027, but the final budget funded only 100. (GCDD waiver-needs analysis; GCDD final budget analysis)

Georgia also approved $409 million for a new 300-bed forensic psychiatric hospital. That facility responds to a genuine forensic-system need, but capital investment in institutional infrastructure should not substitute for community services that can prevent some people from reaching crisis. (Georgia Primary Care Association)

Existing barriers | Waiver growth is treated as an annual discretionary decision, making progress inconsistent. Additional barriers include administrative staffing, provider capacity, workforce shortages, and limited supports for people waiting for comprehensive services.

Recommended policy actions | Georgia should:

- Adopt a workload-based budgeting approach that ties recurring appropriations to validated annual waiver demand.

- Fund the estimated need for 1,217 new waivers, using an updated DBHDD and Office of Planning and Budget fiscal analysis.
- Formally implement and fund the proposed three-tier Planning List, distinguishing urgent need, expected need within one to five years, and future planning, without assuming that the 1,217 estimate represents the Tier 1 population.
- Establish annual Planning List reduction targets and provide sufficient assessment, enrollment, and support-coordination staff.
- Expand bridge services, respite, mobile crisis support, and other preventive assistance for people awaiting waivers.
- Assess whether Georgia should pursue the optional federal Section 1915(c)(11) waiver pathway available beginning in July 2028 to provide targeted, preventive HCBS to some people before they meet an institutional level-of-care standard, without diverting resources from people already eligible for NOW or COMP[3].

Expected impact | Predictable funding would reduce preventable crises, caregiver burnout, emergency-service use, and unnecessary institutional placement while giving families, providers, and state agencies a reliable basis for planning.

2. Strengthen the Direct Support Professional Workforce

Why it matters | Waiver expansion cannot succeed without a stable Direct Support Professional (DSP) workforce. DSPs make employment, healthcare access, independent living, and community participation possible.

Current evidence | Georgia's implementation of the NOW and COMP rate study represented an investment of approximately $107 million in state funds and more than $320 million in total funding. The rate changes increased provider reimbursement by an average of more than 40 percent, creating a stronger foundation for recruitment and retention. (NASDDDS rate-study analysis)

Existing barriers | Workforce shortages persist, particularly in rural communities and services for people with complex needs. Georgia also lacks easily accessible statewide data on DSP wages, benefits, vacancies, turnover, training, and the effect of rate increases on workers.

Recommended policy actions | Georgia should require annual workforce reporting; review rates regularly; measure how reimbursement changes affect worker compensation; expand paid

[3] Federal law, Section 71121, pages 317–318: https://www.govinfo.gov/content/pkg/PLAW-119publ21/html/PLAW-119publ21.htm

training, certification, and career ladders; and consider wage differentials for rural or specialized services. Policy should also support benefits, predictable schedules, and participant direction, including people who recruit and manage their own workers.

Expected impact | A stronger workforce would help people use their authorized services, reduce turnover and service interruptions, stabilize providers, and ensure that new waiver investments translate into actual support.

3. Expand Competitive Integrated Employment

Why it matters | Employment provides income, relationships, purpose, and greater control over one's life. It also allows people with disabilities to contribute to Georgia's workforce and local economies.

Current evidence | Georgia's Employment First Act establishes competitive integrated employment as the first and preferred option for people with disabilities receiving publicly funded services. The Dignity and Pay Act is also phasing out subminimum wages. (Georgia DBHDD Employment First; Georgia General Assembly's Dignity and Pay Act summary)

Existing barriers | Policy commitments do not guarantee access to job development, benefits counseling, transportation, personal assistance, or long-term job coaching. Coordination among schools, vocational rehabilitation, DBHDD, workforce agencies, and employers remains uneven.

Recommended policy actions | Georgia should develop a shared interagency employment plan with measurable targets; expand customized and supported employment; ensure benefits counseling is available before and after employment; provide individualized transitions from subminimum-wage settings; support inclusive employers; and report employment, wages, hours, and job-retention outcomes.

Expected impact | These actions would increase employment and earnings, reduce reliance on segregated services, strengthen Georgia's workforce, and ensure that the Dignity and Pay Act leads to meaningful employment rather than loss of services.

4. Strengthen Self-Advocate Leadership

Why it matters | People with disabilities are experts on how policies work in daily life. Their leadership helps identify barriers that may not be visible in administrative data and ensures that policies reflect autonomy, dignity, and community priorities.

Current evidence | Self-advocates should be in meaningful leadership roles to lead meetings, educate policymakers, develop accessible resources, share personal stories, and influence coalition priorities. Federal Medicaid policy now also requires states to maintain a Beneficiary

Advisory Council composed of people with current or previous Medicaid experience. (CMS Medicaid Access Rule)

Existing barriers | Participation is often unpaid, advisory rather than decision-making, or inaccessible to people who use communication support. Transportation, technology, scheduling, and concerns about public-benefit eligibility can also limit involvement.

Recommended policy actions | Georgia should provide compensated voting roles for self-advocates on Medicaid, DBHDD, employment, housing, and community-living bodies. Meetings and materials should be accessible and provided in advance, with plain language, remote participation, communication support, transportation, and benefits counseling available. Agencies should also publicly explain how self-advocate recommendations were addressed.

Expected impact | Meaningful leadership would produce more responsive policies, improve public trust and accountability, and ensure that disability policy is led by the people it affects.

5. Improve Cross-Agency Coordination

Why it matters | Community living depends on multiple systems. A waiver cannot produce independence without housing, transportation, healthcare, employment, and a qualified workforce.

Current evidence | Responsibility is divided among DBHDD, the Department of Community Health, Department of Community Affairs, Department of Human Services, Department of Transportation, vocational rehabilitation, education agencies, and local systems. The 2026 Georgia *Olmstead* case study identified affordable housing shortages, HCBS waiting lists, and workforce limitations as connected barriers to community integration. (Community Living Policy Center)

Existing barriers | Agencies have different eligibility rules, funding streams, data systems, and performance measures. Individuals and families are frequently expected to navigate these systems independently.

Recommended policy actions | Georgia should establish, or formally charge an existing body to serve as, a permanent interagency Community Living Council. It should include self-advocates and representatives from relevant agencies, publish a shared multi-year plan, establish common outcomes, coordinate transitions between systems, and develop a unified navigation and referral process.

Expected impact | Stronger coordination would reduce duplicated assessments, service gaps, and preventable crises while helping state investments in housing, transportation, employment, and HCBS reinforce one another.

6. Improve Data Collection and Accountability

Why it matters | Policymakers cannot determine whether investments are working without timely, understandable, and publicly available information. Planning List totals alone do not show how long people wait, what services they receive, or whether needs differ across communities.

Current evidence | The federal Medicaid Access Rule requires increased reporting on HCBS waiting lists, access, quality, incident management, and payment adequacy. This gives Georgia an opportunity to build a more transparent public accountability system rather than treating federal reporting as a compliance exercise. (CMS HCBS provisions)

Existing barriers | Relevant information is spread across agencies and reports, and definitions may differ. Data on authorized versus delivered services, workforce capacity, unmet needs, and disparities are not always current or easily accessible.

Recommended policy actions | Georgia should create a public HCBS dashboard reporting:

- Planning List enrollment, priority category, and waiting time;
- Waiver entries, exits, attrition, and time from application to service;
- Authorized versus delivered services;
- DSP wages, vacancies, turnover, and regional provider capacity;
- Employment, housing, transportation, health, crisis, and community-inclusion outcomes; and
- Differences by region, race, age, disability, language, and support need.

The state should publish data definitions, protect individual privacy, invite self-advocate interpretation of findings, and require an annual legislative report and periodic independent evaluation.

Expected impact | Better data would allow Georgia to target funding, identify inequities, evaluate provider-rate and waiver investments, and hold agencies accountable for outcomes rather than program activity alone.

Together, these recommendations would move Georgia from fragmented, crisis-driven responses toward a predictable community-support system. The goal is not simply to fund more services, but to ensure that people with disabilities can use those services to live, work, make decisions, and participate fully in their communities.

6-Advocacy Recommendations

Effective disability advocacy requires more than responding to individual legislative proposals. It requires sustained relationships, accessible policy education, credible evidence, coordinated communication, and leadership by people with disabilities.

The future of Georgia's disability advocacy should be more directly shaped and delivered by self-advocates. People with disabilities who contributed to this paper recommended pairing lived experience with verified evidence, creating paid leadership opportunities, using more varied communication methods, and building stronger partnerships. The following recommendations are intended to advance collaborative advocacy efforts to protect HCBS.

1. Maintain a Statewide Disability Advocacy Coalition

Georgia needs a durable statewide coalition that connects self-advocates, families, providers, disability organizations, researchers, and community partners. A coalition makes it possible to share information, coordinate strategy, respond quickly to policy threats, and present a stronger collective voice.

The coalition should be supported by a clearly identified backbone organization or successor structure responsible for coordination, accessibility, communication, and administration. However, organizational support should not replace leadership by people with disabilities.

Recommended actions

- Establish an accessible coalition charter defining its mission, membership, decision-making process, and relationship to partner organizations.
- Give self-advocates formal voting and leadership roles, including opportunities to co-chair meetings and committees.
- Ensure representation from rural communities, culturally and linguistically diverse communities, people with different disabilities, and people who use varied communication methods.
- Create paid roles for self-advocates as facilitators, speakers, policy reviewers, writers, peer mentors, interviewers, and evaluation partners.
- Develop clear descriptions for paid roles, including responsibilities, hours, compensation, accessibility support, and payment timelines.
- Maintain a shared calendar, contact list, resource library, and regular statewide meetings with virtual participation.

The coalition's success should be measured not only by the number of organizations involved, but also by whether self-advocates have meaningful influence over priorities and decisions.

2. Develop Annual Legislative Priorities

A coalition is most effective when its members agree on a focused set of priorities before the legislative session begins. Without a shared agenda, organizations may respond separately to the same issues or ask policymakers to act without providing a clear path forward.

Recommended actions

- Hold an annual listening and priority-setting process with self-advocates, families, providers, and advocacy partners before legislative planning is finalized.
- Select a manageable number of priorities based on urgency, evidence, lived experience, political opportunity, and potential community impact.
- Develop a short, accessible legislative agenda explaining each issue, the requested action, supporting evidence, and the consequences of inaction.
- Identify the agencies, committees, legislators, and coalition partners connected to each priority.
- Assign leads for policy analysis, storytelling, legislative outreach, communications, and follow-up.
- Create a legislative calendar covering budget hearings, committee meetings, Advocacy Days, crossover deadlines, and final budget decisions.
- Review the priorities during and after the session to respond to changing conditions and document lessons for the following year.

Annual priorities should remain focused enough that self-advocates and partners can communicate the same core requests consistently. Priorities may include HCBS waiver funding, DSP workforce investments, competitive integrated employment, community-based crisis services, housing, transportation, and Medicaid access.

3. Support Grassroots Advocacy and Leadership Development

Statewide advocacy is strongest when people can build relationships with policymakers in their own communities, not only during formal Advocacy Days at the Capitol. Grassroots advocacy should help people understand policy, tell their stories safely, make specific requests, and follow up after a meeting.

Future legislative engagement activities should be co-designed with self-advocates. This process should examine the full participant experience, including issue selection, preparation, meeting requests, accessibility, event-day roles, follow-up, and feedback.

Recommended actions

- Hold structured listening and design sessions with self-advocates before planning Advocacy Days and other legislative activities.

- Expand advocacy beyond the Capitol by supporting meetings in legislators' home districts throughout the year.
- Offer multiple participation options, including in-person meetings, calls, emails, written testimony, short videos, and virtual events.
- Provide plain-language issue briefs, scripts, meeting guides, sample emails, and opportunities to practice before contacting policymakers.
- Use experienced self-advocates as paid peer mentors and advocacy coaches.
- Provide transportation, communication support, interpreters, accessible technology, planned breaks, and flexible participation.
- Help participants complete follow-up messages and maintain relationships after an event.

Leadership development should be connected to real opportunities to act. Training is most valuable when participants can immediately use what they learned in a meeting, public comment, testimony, coalition decision, or community presentation.

4. Strengthen Relationships with Policymakers

Effective advocacy depends on relationships developed before a crisis or budget vote. Policymakers and their staff are more likely to seek information from advocates they know as reliable, respectful, and well prepared.

The coalition should maintain bipartisan and nonpartisan relationships with legislative leadership, relevant committee members, district legislators, agency officials, and legislative staff. Particular attention should be given to policymakers serving on appropriations, health, human-services, employment, housing, and transportation committees. Because committee structures and leadership may change, assignments should be verified through the Georgia General Assembly's committee directory at the beginning of every session.

Recommended actions

- Maintain an updated map of policymakers, committee assignments, staff contacts, districts, and issue interests.
- Schedule educational meetings throughout the year rather than contacting legislators only when requesting a vote.
- Pair self-advocates' lived experience with concise Georgia-specific evidence and a clear policy request.
- Invite policymakers and staff to community events, provider visits, listening sessions, and meetings led by people with disabilities.
- Record questions, commitments, and follow-up needs after each interaction.
- Thank policymakers when they support disability priorities and continue engaging them when positions differ.

- Build relationships with legislative staff, who often play an important role in research, scheduling, and policy development.

The objective should be to make the coalition a trusted source that policymakers contact when they need accurate information about disability and community-living policy.

5. Increase Accessible Policy Education

Families and self-advocates cannot participate fully in advocacy if policy information is overly technical, outdated, or provided too late. Policy education should explain both the issue and how decisions are made, including the roles of agencies, committees, budgets, regulations, and federal Medicaid requirements.

Strong advocacy requires four elements: human rights, lived experience, community outcomes, and responsible use of public resources. This approach can communicate urgency without sacrificing accuracy.

Recommended actions

- Develop a concise message framework with one core message, supporting themes, verified evidence, and clear calls to action.
- Pair personal stories about HCBS, employment, community living, and unmet needs with current Georgia-specific data.
- Maintain a source log and reverify statistics, legislator information, bill status, and budget figures before publication.
- Produce plain-language policy briefs, visual explainers, short presentations, and question-and-answer resources.
- Offer regular policy sessions before and during the legislative session, with recordings and accessible materials available afterward.
- Explain how to identify legislators, contact committees, submit public comments, follow a bill, and understand the state budget.
- Make materials accessible for people with intellectual disabilities, people who use assistive technology, and people whose primary language is not English.

Policy education should prepare people to make their own informed advocacy decisions, not simply repeat messages developed by organizations.

6. Develop Rapid-Response and Story-Based Communication

Policy opportunities and threats can emerge quickly during legislative sessions, agency rulemaking, federal action, or budget negotiations. The coalition needs a rapid-response process that can verify information, approve a shared message, and mobilize advocates without sacrificing accuracy or accessibility.

Recommended actions

- Establish a communication protocol defining who monitors developments, verifies facts, approves messages, creates accessible materials, and contacts partners.
- Maintain adaptable templates for policy alerts, emails, phone scripts, testimony, social media, and calls to action.
- Identify priority audiences, including relevant committee members, legislative leadership, agency officials, coalition members, and the public.
- Use email, text, social media, partner networks, and short-form video to reach people through different channels.
- Include a specific action, deadline, and contact information in every advocacy alert.
- Correct inaccurate information publicly and promptly when necessary.

A rapid-response system should be supported by a consent-based story bank. Storytellers should decide how their experiences may be used, whether their names or images may be shared, and when permission expires. Separate plain-language consent should be obtained for legislative materials, websites, social media, video, audio, and partner sharing. Storytellers should review edited materials before publication and be able to withdraw future permission.

The coalition should also pilot self-advocate-led media, such as a two- to three-minute advocacy video and a podcast-style conversation. Self-advocates should be compensated as hosts, writers, interviewers, narrators, or producers rather than expected to provide unpaid content.

7. Maintain Partnerships and Build Long-Term Sustainability

No single organization can provide every resource needed for statewide disability advocacy. Partnerships can contribute grassroots trust, policy knowledge, research, media reach, legislative relationships, accessibility expertise, and funding. At the same time, relying on one organization or funding source makes advocacy vulnerable to staff changes, grant cycles, and shifting priorities.

Recommended actions

- Create a partner map that includes disability-led organizations, family networks, providers, policy coalitions, civil-rights organizations, universities, community groups, media partners, and philanthropic funders.
- Document each partner's role, geographic reach, relationships, accessibility capacity, and alignment with self-advocate leadership.
- Develop simple agreements describing shared responsibilities, communication expectations, branding, data use, and decision-making.
- Diversify funding through public, philanthropic, organizational, and unrestricted sources while protecting the coalition's nonpartisan mission and self-advocate leadership.
- Validate a potential funder's priorities and restrictions before developing a joint proposal.

- Share resources and credit equitably, particularly when self-advocates or smaller disability-led organizations contribute expertise.

A small learning dashboard should support long-term improvement. The coalition can track paid self-advocate roles and compensation, participation and accessibility feedback, approved stories and communication products, policymaker contacts and follow-up, partner engagement, and responses to calls to action. Qualitative information should also document what participants learned, how strategies changed, and whether self-advocates believed their influence was meaningful.

The dashboard should be reviewed regularly with self-advocates, and measures that do not inform a real decision should be removed. Accountability should strengthen advocacy, not create an unnecessary reporting burden.

Moving the Work Forward

The future of disability advocacy in Georgia will be strongest when people with disabilities lead, organizations coordinate their resources, and personal experience is paired with reliable evidence and a clear request for action.

Maintaining that work will require more than preserving a coalition name. It will require accessible infrastructure, paid leadership, year-round relationships, rapid communication, sustainable partnerships, and an ongoing commitment to **Waivers, Not Walls**.

7. Conclusion

This paper provides a roadmap for advocates, policymakers, agencies, and disability organizations working to advance disability rights and community living in Georgia.

The evidence is clear: Home and Community-Based Services are essential civil-rights, healthcare, workforce, and economic infrastructure. They help people with disabilities live in their communities, pursue employment, maintain their health, and exercise meaningful choice. They also help family caregivers remain employed and reduce reliance on emergency, crisis, and institutional systems.

Georgia has already created much of the framework needed to fulfill this promise. It operates NOW and COMP waivers, has invested in provider rates, adopted Employment First, and developed programs supporting housing, transportation, healthcare, and families. Yet approximately 8,000 people remain on the Planning List, provider capacity varies across the state, and families continue to provide care that the formal system does not.

Daniel's, Kayla's, and Patricia's experiences show both the possibilities created by support and the consequences of its absence. Their stories demonstrate how mentorship and accessible opportunities can open pathways to employment and leadership. They also show how uncertainty, inconsistent information, and years of waiting shift responsibility to people with disabilities and their families. Their persistence is powerful, but persistence should not be the price of accessing essential services.

Georgia needs predictable HCBS funding, a stable DSP workforce, coordinated employment and community systems, accessible information, and transparent public data. It also needs preventive supports that respond before exhaustion or instability becomes a crisis.

People with disabilities must have meaningful, compensated roles in developing and evaluating these policies. They must lead in advocacy, policy, and legislation to place greater authority in the hands of self-advocates. A statewide coalition with a shared legislative agenda, grassroots leadership, accessible policy education, and year-round relationships with policymakers can sustain the work.

Georgia does not have to choose between fiscal responsibility and disability rights or between supporting families and strengthening the workforce. Well-designed community services advance these goals together.

The path forward should be guided by three principles: people with disabilities belong in their communities; support makes independence possible; and those most affected must lead the work.

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