



How did the Partnership for Community Living start?

The Partnership grew out of concern for the future of people with disabilities. State and federal budgets are shrinking at a time when demand for services is growing. How can we work together to sustain the supports people need over time while making room for more people?

The Vision Statement and Action Agenda of the Partnership For Community Living was developed after three days of meetings with a group of active and knowledgeable parents, family members, self-advocates, providers, disability advocates, DHR and DCH staff, and legislators. These meetings were facilitated by Val Bradley and Gary Smith of Human Services Research Institute, and Steve Eidelman, Exec. Director of The Arc of the United States. The topic was "Working Toward a Sustainable Future for Georgians with Disabilities". It was organized and coordinated by The Arc of Georgia and co-sponsored by the Governor's Council on Developmental Disabilities and the Georgia Advocacy Office.

The Partnership for Community Living is: Georgians working to ensure people with disabilities have *real* friends, *real* educations, *real* homes, *real* jobs, *real* lives. It outlines a new system of supports and services for people with disabilities. It envisions real change in the system, one that promotes and supports good lives for people with disabilities.

JOIN US IN CREATING THE PARTNERSHIP FOR COMMUNITY LIVING!

Founding Members

The Arc of Georgia

Governors Council on Developmental Disabilities

Georgia Advocacy Office

People First

**CDAG
Community Developers Assn
of Georgia**

Georgia Options in Community Living

Albany Resource Center

Atlanta Alliance on Developmental Disabilities

Georgia Community Supports and Solutions

The Jessamine Place

disAbility Link

Institute of Human Development and Disabilities

Division of Mental Health, Developmental Disabilities and Addictive Diseases

Department of Community Health

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PARTNERSHIP FOR COMMUNITY LIVING

The Partnership for Community Living is: Georgians working to ensure people with disabilities have real friends, real educations, real homes, real jobs, real lives.

VISION AND PRINCIPLES ***Nothing About Us Without Us!***

Community living means:

- People have genuine friendships and relationships.
- People are fully included in school and have real learning opportunities throughout their lives.
- People control their lives, including where and with whom they live and who supports them. People assume responsibility for their choices.
- Support services are separated from housing. People can change providers without having to move.
- People have opportunities for competitive work, self-employment.
- People have opportunities to contribute to their communities through volunteer work and civic associations which interest them.
- People are not segregated from others in the community in housing, school, work or play.
- People have typical life experiences.
- People have choice and control over use of their resources.
- Community living applies to all people with disabilities, with appropriate supports to ensure safety and opportunities for success

Our work is:

- Advocating with people over time to achieve the above outcomes.
- Collaborating with each other so that our collective strengths make the outcomes achievable.
- Maintaining a clear vision about desirable and sustainable futures.
- Improving what works while changing what does not work.
- Making opportunities for continuous learning.
- Making decisions through open dialogues with all stakeholders.
- Welcoming leadership from all stakeholders, especially those who have personal experience with disabilities.
- Creating systems change that embraces person-centered work with optimism.
- Valuing diversity and becoming more culturally competent.
- Renewing ourselves and our communities as we create these opportunities for everyone.

OUR ACTION AGENDA

Nothing About Us Without Us!

- Set expectations that person-centered and self-directed supports become the norm.
- Ensure people have choice and control over their lives while requiring accountability for quality and funding.
- Ensure people have a means of communication and transportation to facilitate active participation in personal and community life.
- Make no decisions affecting people's lives without self-advocates, families or independent advocates at the decision-making table.
- Confront issues of equity and waiting lists; make and implement plans for addressing them.
- Provide information about services and the system to people and families.
- Work with education agencies to document and plan for future needs.
- Make major investments in community provider capacity.
- Increase reimbursement rates to providers while raising expectations for community living.
- Improve the workforce through training, better pay, and better working conditions to reflect their high value and the importance of their roles.
- Develop, implement and maintain alternatives to institutional care, not only because people deserve real homes, but also because we can no longer afford a dual system.
- Retain all savings from institutional downsizing and closures in order to serve more people and to build community and provider capacity denied by the expense of dual systems.
- Retain and redirect institutional expertise into the community.
- Collect data on the following: Who is being served? What services are they getting? How much service do they need? What do services cost? What are the outcomes?
- Make decisions based on the data and share data with all stakeholders.
- Create a competent rate-setting mechanism for individualized budgets.
- Communicate our agenda clearly and consistently with all partners, community members, stakeholders, policymakers, legislators, and the Governor.
- Create catalysts for change in communities throughout the state.

We support the principles of the Olmstead Planning Committee Report.

**Join us in creating the
PARTNERSHIP FOR COMMUNITY LIVING!**

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Person-Centered and Self-Directed Support

Introduction: One of the reasons there has been general dissatisfaction with the service system and its traditional providers is that people served have no control over their lives, including where they live, who lives with them, where and how they spend their days, and who provides their often very intimate support. Services emphasize groups and programs, not individuals. This one-size-fits-all approach rarely works well for people. Nor is an ISP (Individualized Service Plan) the answer: even if “the team” establishes meaningful goals, the details of a person’s life reach far beyond a plan. They encompass how supports are managed and delivered every day, every minute of the day. They require commitment to a positive vision of respect for the person, and for what is possible in all details of the person’s life.

Person-centered support: The term “person-centered” has been around a long time. People and providers accept and use the term while engaging daily in policy and practice that not only do not reflect person-centered principles, values and strategies, but also undermine them. The following chart gives some examples of what person-centered support IS and IS NOT:

WHAT PERSON-CENTERED SUPPORT IS	WHAT IT’S NOT
Harry and Ray know each other and agree they’d like to try sharing a home to stretch their financial resources.	Harry and Ray are assigned to two different group homes because each house has a vacant “bed.”
Marie is a loner who loves animals and nature. Her staff assist her to get a job maintaining hiking trails and filling bird feeders at a nature center.	Marie is required to attend a day center, where she is frustrated by the noise of a large group and indoor activities in which she is not interested.
Harry and Ray are invited to meet two applicants for a position in their home. They ask questions and later state which person they prefer. They spend time coming to agreement. After checking references and other requirements, the provider hires the person they want.	Staff are hired by the provider and rotated through different group homes, depending on staffing needs. Persons served have no say in who works, what the schedule is, and often don’t know who is coming until they arrive.
Sue and Martha share a home. Each has an individualized support plan (ISP) which states her goals and preferences. A staff schedule is developed that works for both. When one staff is absent, the provider sends a trained substitute, known to the person served, who keeps the schedule on track.	When one staff is absent or another event disrupts the schedule, one or both person’s plans are canceled to accommodate the provider. This may mean both stay home, or one person’s schedule is given priority with the other person tagging along. (This may even include a long wait in a doctor’s office.)
Alice rents a home with one other person. When she decides to ask a different provider for services, her current provider works with her and her housemate to design a plan that is agreeable to all.	When Alice decides on a different provider, her current provider immediately asks her to move out, even though her name is on the lease.

The Partnership for Community Living believes that ALL services should be person-centered, and that services which are not person-centered are obsolete. Though the current system does not incentivize person-centered support, it does not prevent providers from taking this approach. Both providers and policy makers are challenged to understand this different way of thinking and to reconfigure resources and services to make person-centered services the norm. Much technical assistance and capacity-building are needed before this paradigm shift can occur. Most importantly, people need to move beyond rhetoric and be willing to learn about and embrace the vision of person-centered support, while knowing it will not always be implemented perfectly.

Self-directed support (self-determination): The term “self-directed support” or “self-determination” is more recent and implies that the person (or family acting on behalf of the person) controls allocated resources, including recruiting, hiring, scheduling, supervising, and firing support workers (e.g. acts as an employer), while also controlling decisions about all other services and all aspects of daily life. The Partnership for Community Living believes the autonomy of the person served is paramount, while acknowledging that people need support to express and maintain autonomy. When family members act on behalf of the person served, safeguards are needed to protect the person’s autonomy to the highest possible degree.

The Center for Medicare and Medicaid Services (CMS) defines three levels of self-direction, suggesting that some people may wish to manage every aspect of their care, while others may prefer to delegate the management of one or more aspects. In every case, however, the base is person-centered – that is, supports focus on one person at a time and strive to do with that person what he/she would do for him/herself if disability were not present. The three CMS levels are as follows:

- **Service Choice – This is the person-centered approach described above. We can do this now.** The person served has opportunities to interview and approve staff and make other decisions about daily life, but does not supervise staff or manage funds that pay staff salaries. A provider agency is responsible for quality and accountability.
- **Service Responsibility – This level requires systems change, and the state should proceed to revise waivers so that it can be accomplished.** The person served (or family) may decide to supervise some services, such as being an employer of staff, but delegate other services, such as managing the budget, filing government reports, paying taxes, etc. The person (or family) is responsible for staff performance and quality, rather than a provider agency.
- **Budget and Service Responsibility – Full self-determination. This paradigm shift also requires systems change.** The person served (or family) manages an allocated budget, acts as employer for staff, files required documentation, makes all decisions and ensures quality and budget accountability. The person may still choose to hire a fiscal intermediary and purchase other services as needed. An independent service broker is available to assist in finding and maintaining supports.

The following chart gives examples of what self-determination IS and what it IS NOT:

WHAT SELF-DETERMINATION IS	WHAT IT'S NOT
Above all else, Jenny needs and wants stability in her life. When she and her family create an individual budget with her support coordinator, they allocate an extra \$2.00/hour for staff wages in the hope of decreasing turnover. This means Jenny’s family will need to provide weekend care in order to balance the budget. All agree that this is the best solution.	Asking Jenny to sign off on a budget prepared by a provider who insists on keeping all staff wages on the same scale and who does not want the family to provide care.
James has been going to self-determination meetings, where he is learning to express his desires for his life and his dissatisfaction with current services. His provider listens and works creatively with James and others to enable him to have more control over his life. When James makes a mistake, all team members come together to find a win-win solution.	James’ provider gives him more freedom but requires him to call at certain times to report his activities. They write an ISP goal stating “using self-determination, James will call his provider at 9:00 AM and 9:00 PM to report his activities.”
Tom’s family manages his supports under a self-determination waiver. Tom repeatedly says he wants to work with a landscaping company. With the help of a support coordinator, his family researches the effect a job could have on his benefits. Although they worry, they realize how important a job is to Tom’s well-being, and they decide to support him in this goal while working with the system to manage his benefits in the best possible way.	Tom’s family refuses to let him get a job because they fear his benefits will be affected. They refuse to learn the facts about work and benefits, citing their authority under self-determination.