



NCAPPS

Human Services Provider Agency Toolkit for Self-Determination

Prepared by

Jeffery Keilson

Valerie Bradley

Jami Petner-Arrey

Jane Lawrence

as part of NCAPPS technical assistance



Provider Agency Toolkit

Preface

This guide contains strategies and resources to assist home and community-based human services providers (HCBS) in championing self-determination among the people they serve. Though the ultimate exercise of self-determination is having people direct their own supports, not every individual receiving HCBS services may be eligible for or interested in the self-directed services available where they live. Provider-directed services, such as community-based group homes, structured employment, day programs, or shared living will continue to be part of the array of options available to people needing support. Human services providers, however, can infuse self-determination in every aspect of service delivery by helping people exert greater control over their environments and make choices about their everyday lives. By consistently using person-centered approaches in provider-directed services, people will experience increased autonomy and meaningful participation in their communities.

This resource was created as part of technical assistance by the National Center on Advancing Person-Centered Practices and Systems (NCAPPS). It builds on similar resources developed as a part of technical assistance provided to the state of Colorado.

Introduction

Nationwide, the focus on self-determination and self-direction for people receiving HCBS is growing. In response to advocacy efforts from people with lived experience, states are developing, offering, expanding, and improving opportunities for people to control decisions that impact their lives. In the context of this resource, the following definitions are used:

Self-Determination is the right of all people to participate in and approve of the design of their personal support systems, to fully engage in their communities, and to make choices in their daily lives. The philosophy of self-determination underscores the importance of maximizing an individual's control over their lives; however, the realities of provider-directed services mean that some decisions may be out of reach. If someone lives in a group environment, for example, they may not have the final say over staff hiring decisions since the needs and desires of roommates must also be considered. Nevertheless, people in these settings can become more self-determined by being

supported and encouraged to take charge of short-term and long-term decisions, learn to solve problems, and exercise agency in their lives.

Self-Direction is one vehicle to achieve self-determination. In self-direction, the person with the disability has control over their budget, what services are provided, and who provides those services, as well as other life decisions. Self-direction also places responsibility for the consequences of decisions with the person and their circle of support, including implications on their health and safety. For someone to be successful in directing their services, they need to understand the meaning of self-direction, gain skills to self-advocate, and be supported by knowledgeable and committed support brokers or case managers.

While more people are self-directing some or all of their publicly funded supports, the vast majority of people using HCBS supports are in provider-directed services. Therefore, it is important to find ways that provider agencies can implement strategies that align with person-centered practices and enhance self-determination. Practices that increase the partnership between service providers and the people they support make it possible for more people to experience self-determination by exercising greater decision-making authority over important aspects of their lives.

Expanding opportunities for self-determination is more critical as states, agencies, families, and people using HCBS cope with the disruption caused by the COVID-19 pandemic on provision of essential services, as well as the resulting workforce crisis and increased social isolation and loneliness. The ability to accommodate change, reorient routines, and find ways to stay engaged in communities are greatly enhanced when people can make their own decisions. This goes for all people using HCBS, including people with intellectual and developmental disabilities, behavioral health issues, brain injuries, and older adults. While it will take enduring commitment and time to ensure the growth and sustainability of self-determination, the rewards for the all those involved are tremendous.

Recommendations in this paper are aimed at enhancing self-determination in services provided by human services agencies.

Expanded Self-Determination in Provider-Directed Services

There are significant differences between self-directed and provider-directed services. People who choose to direct their own services generally have control over their individual budget, and who, when, and how services will be provided. In contrast, provider organizations have historically made a wide range of decisions on behalf of the people they serve, including:

- Where people live
- Who people live with
- Hiring staff
- Home furnishings and decor
- Menus, food choices, and mealtimes
- Activities and leisure options
- Individual or group schedules

Provider-directed services generally occur in settings owned or controlled by a provider agency. Some services provided in a person's home may be provider-directed, if the agency providing the support selects the staff or determines the hours that the support will be provided. While the HCBS Settings Rule (2014) requires providers to offer more choices, privacy, and flexibility to people they serve, there are additional ways providers can support self-determination.

What Would Self-Determination Look Like Within a Provider-Directed Environment?

The following are indicators that a provider organization has embraced self-determination for the people they serve:

- The provider agency holds people's preferences in the same standing as applicable regulations and requirements
- People are supported in decision-making regardless of the severity of their disability or level of support needed
- Agencies collaborate with case managers to ensure that people can make informed choices when selecting the agency to provide services
- Major decisions are made collaboratively between people supported (and families/guardians, when appropriate) and the provider agency
- People, with the support they need, make choices such as selecting housemates, how their day is structured, and their circle of support
- People choose how they receive services by having input on schedules, leisure activities, etc.
- Support staff understand the concept of "dignity of risk," and support people's right to make choices even if they disagree with those choices
- The agency supports the communication skills of participants and employs active listening
- Decisions by participants are integral to service provision

- Providers assist people in creating a circle of support to encourage and support decision-making

These characteristics of self-determination should be present in a range of settings, including group homes, host families, supported living, and day and employment supports.

Why Should Providers Support Self-Determination?

Not only is it the right thing to do to support people in making decisions about their lives, there are also federal requirements for providers who deliver Medicaid HCBS. In 2014, the Centers for Medicare and Medicaid Services issued the HCBS Settings Rule. The rule provides support for valued outcomes like choice, privacy, and community inclusion. It stresses that services and supports are based on the individual's experience and choices. For provider-owned or provider-controlled residential settings, people must have:

- A lease or other legally enforceable agreement to protect from eviction
- Privacy in their unit, including entrances lockable by the individual (staff have keys as needed)
- Choice of roommates
- Freedom to furnish and decorate their living space
- Control of their schedule and activities
- Access to food at any time
- Visitors at any time
- Physical accessibility

These rights can only be adjusted if there is justification in the person-centered plan.

Providers play a significant role in moving self-determination and the principles of the Settings Rule forward. Through professional organizations, they can influence the direction of regulation and practices that encourage self-determination. Moreover, the expansion of self-determination by a provider is likely to make an agency more attractive to individuals and families interested in making more decisions about their lives and supports.

A more empowered group of participants can also positively impact direct support professionals in the agency. By reducing the time spent organizing people's schedules and routines, direct support professionals will have more time to support the person in pursuing their interests and making friends and community connections.

Finally, supporting self-determination will improve individual decision-making skills, help families ensure the right fit for their family members, increase the cultural responsiveness of supports, and nurture a more creative and engaging workplace.

How Can a Provider Agency Expand Self-Determination?

There are critical actions agencies can take to create an environment where providers actively encourage people and families to assert greater control over their lives. Some steps include:

Develop a vision for the agency founded on the principles of self-determination that supports each person in making choices for themselves, fosters education and leadership training for people receiving supports, and infuses person-centered thinking throughout the organization. This vision should be developed jointly with stakeholders, including people receiving supports, family members (if applicable), direct support professionals, managers, executive level staff, and Board members. Grounded in the belief that all people can make choices about their supports and lives, this vision should be accessible to all stakeholders.

Develop a plan to implement the vision in partnership with people receiving services and their families. This includes developing agency policies that support self-determination and identifying key administrative and managerial staff to lead implementation. The plan should be guided by a committee with broad representation, including people with disabilities and their families, who will oversee the initiative and advance objectives, tasks, and timeframes. Implementation should be a key part of the agency's overall strategic plan and foundational to ongoing operations. Importantly, the implementation plan should identify potential barriers to successful roll-out, which may include insufficient staff training or reluctance among staff and leadership to take risks. The implementation plan, much like the vision itself, should be shared with all stakeholders for feedback and insight.

Change the organizational culture and enlist administrators and managers as leaders of the change. One persistent challenge of any change strategy is maintaining momentum while anticipating and mitigating opposition. Strategies include:

- Secure support from the Board of Directors or other governing bodies. This may require helping Board members understand the vision, providing individual success stories of improved quality of life, and explaining how the change will enhance the reputation of the agency. This could also be accelerated by adding people with disabilities to the Board, as well as establishing a committee with the explicit mission of promoting more control by people receiving supports.

- Educate and enlist support from all levels of staff, including executive leadership, managers, supervisors, and direct support staff.
- Conduct training in person-centered thinking and planning.

Celebrate successes by sharing positive stories and rewarding progress. Examples include:

- Create an organization-wide learning community to share experiences and best practices.
- Collaborate with external agencies and training consultants to assist with creating a culture of celebration.
- Expand opportunities for managers and direct support professionals to lead culture change efforts.
- Use social media, websites, and all internal communication channels to recognize accomplishments, discuss steps that leadership is taking, and reinforce commitment to the vision on the part of the agency.

Conduct training for family members and guardians on the importance of self-determination, why the agency is moving in this direction, and respond to those who might be concerned about family members making decisions they do not support. Training should assist families in raising their expectations of a person's capacity to exercise more control of their lives. Many families will need to be supported to embrace the change. This can be done by sharing participant testimonials, helping create safety nets, and gradually increasing control as individuals develop skills.

Identify champions within the provider agency who can be trained as change agents to advance the vision. Champions at all levels should be welcomed, including direct support professionals, host families, program directors, managers, and senior staff. The group should meet regularly for ongoing training and brainstorming. Topics may include existing policies or practices that are hampering self-determination, person-centered policies that could be introduced, or ways to adjust the agency's performance evaluation process to include enhancing self-determination as a goal for all staff.

Ensure representation of people with disabilities on the agency's Board of Directors or governing Board to sustain and grow self-determination for people they support. This can take many forms. One option is having at least two people receiving supports as full members of a Board. Another possibility is creating a subcommittee of the Board that includes a broad range of people receiving supports and at least two Board members. This committee would be charged with ensuring that the Board is engaged and supportive of self-determination for people served by the agency. The committee would regularly communicate with the Board on progress and opportunities for learning and improvement.

How Can Providers Collaborate with People they Support?

Develop leadership training for self-advocates. Because many participants have been disempowered for much of their lives, it is common for people receiving supports to defer to staff or families, and to avoid disagreeing with decisions made by others. In addition, people may have had limited experience in making decisions for themselves or being supported to make decisions that carry some risk (and thus opportunity to learn from mistakes). To address these concerns, it is critical to offer training and opportunities to make decisions – starting with day-to-day choices and moving to more significant ones. One useful exercise is helping people develop questions they might want to ask when hiring or selecting staff.

Organize a group of peer mentors to provide decision-making support to people receiving services, and who can embolden people to speak up. Even with training and support, many people rely on peers to understand how to navigate disagreements or express themselves, for example, at a service plan meeting or a meeting with a healthcare professional. Peers can provide invaluable guidance and information, model self-advocacy, and help others gain greater self-confidence.

Identify and train participants to inform agency leadership of issues, obstacles, and questions about the self-determination initiative. People using services are instrumental in facilitating self-determination among peers and in educating agency staff about what is needed. This could involve collaborating with and including people receiving supports on the Board of Directors or committees within the agency, as well as identifying possible mentors. When people using services are included, however, it is absolutely essential that their participation is not an act of "tokenism." Their contributions must be valued and used to better the agency. Agencies can provide guidance to Board members on ways to include participants, ensuring accommodations so they can fully participate in meetings and decision-making.

Create a position to advance self-determination in the agency that is filled by a person with lived experience. This sends a bold statement, both internally and externally, that the agency takes seriously the importance of self-determination among the people they serve. This role, which could be a Vice President of Advocacy and Peer Support, should have real authority and influence. It is also worth noting that people with lived experience may fulfill multiple positions in an agency, including in executive leadership, aside from a dedicated role to support self-determination efforts.

Develop a plan to incorporate participants in the hiring and training of staff by introducing them to the hiring process, seeking their input on essential attributes of staff, and including them in the interview and decision-making processes. If such activities are pursued, limitations on the person's

participation or decision-making role (e.g., an applicant’s ability to pass a background check, the role of the agency in making the final decisions, salary discussions, etc.) should be clearly communicated to avoid confusion.

Ensure documents and information are in formats understood by people receiving supports.

Providers need to develop agency materials and policies in plain language and accessible to agency participants. Materials should also be made available in alternative formats for people with sensory impairments. Contact information should always be clearly stated on materials so people can reach out directly to appropriate staff or providers with questions.

How Can Providers Employ Best Practices to Expand Self-Determination?

Develop and promote best practices on an ongoing basis as the self-determination initiative progresses. Techniques can include sharing videos of individuals speaking about decisions they made and the impact they had on their lives, as well as testimonials by staff and families on the positive outcomes from increased autonomy and decision-making. This might also include surveying people receiving services or hosting focus groups to evaluate the agency’s progress toward reaching its goals.

Create opportunities and strategies to support individuals in making day-to-day decisions and tracking them in their plan. Many people have not been encouraged to make even minor decisions, so choices such as deciding what to eat, how to spend recreational time, and selecting a television program are opportunities to nurture decision-making skills. A component of training for staff and caregivers should also be in supporting and respecting these choices. Staff may also be surveyed about innovative strategies and approaches they are using to advance self-determination. As much as possible, skill-building and increased choice-making should be documented so that progress is clear, and staff can observe when opportunities can or should be expanded.

Support and expand connections people have in their communities. Person-centered planning can help identify the support a person may need to strengthen connections with friends, community activities, and community organizations. Further, to increase choices, many day services should offer a range of activities the person can select from, rather than locking people into defined programming. Expanding connections can also help people using services broaden their interests and contribute to greater decision-making.

Expand the choices available to agency participants to allow them to direct, as much as possible, the services that they receive. This may require the agency to create more flexibility within service delivery, for example, allowing some flexibility in staff hours so that people can receive supports at

times that are convenient to them or to be left alone. It may require agencies to change job descriptions so that staff can more fluidly support people across a range of needs and settings, including in the community. It may also mean that agencies have direct conversations with people about the services available to them within the agency and how they can best mix and match options to meet their needs. This flexibility necessitates thoughtful collaboration with other agencies who deliver supports to the person. When such decisions are possible, people using HCBS gain experience directing their own services and continually progress in self-determination.

Increase the use of supportive technology to enhance opportunities for independence. The applicability of technology to facilitate personal goals should be included in the person-centered plan for all individuals. In addition to increasing independence across settings, provider agencies can enhance staffing and increase cost effectiveness through technology. As a tool to support greater independence, technology offers the person more opportunities to be fully in control of how they spend their time and navigate in the community.

Support and facilitate the person's choice of where and with whom to live, and who is providing their supports. Putting choices regarding where living arrangements and staff in the hands of the individual should be viewed as a basic element of self-determined services. As part of the planning process, people should be helped to understand they have the option of moving or changing provider agencies. In these cases, agencies collaborate with the person and additional agencies, as needed, to support a smooth transition.

How Can Agencies Facilitate Circles of Support?

A circle of support is a person's group of friends and advocates, helping them make decisions about their life. A strong circle of support can enhance quality of life, increase community connections, decrease loneliness and social isolation, and lead to volunteer or paid employment opportunities. To help build a circle of support, provider agencies and staff can:

Identify interests the person wants to pursue. For example, a man with mental health needs and living in a group home may be passionate about World War II. To foster his interest, staff might choose to take him to the library to check out books on the topic or watch a movie on the history of the era. While this is helpful, his interests can also be used to build a bridge to groups in the community that similarly share his passion. A more creative approach could be helping him identify a WWII veteran to share his firsthand experiences. This connection not only decreases isolation and increases emotional mental wellbeing, but may also lead to lifelong friendships.

Identify the kinds of choices the person wants to make and where they feel they need support and assistance from others. While this can be done in less formal ways, there are also formal approaches such as Supported Decision Making – an alternative to often restrictive guardianship that is often addressed through legislation, policy, and practices. Supported Decision Making helps people who need support making decisions, receive assistance through friends, family members, or other trusted confidants. Promoting Supported Decision Making and other alternatives to guardianship may help emphasize an agency’s commitment to people with disabilities living more self-determined lives.

How Can Agencies Help People Make Connections?

Many people need support to meet new people and develop relationships. This is particularly critical for people with disabilities who may experience greater loneliness, social isolation, and limited connections with family members or paid staff. The impact of isolation on mental health and physical health is significant. Numerous strategies can assist people in making connections, including:

- Work with faith-based communities to identify members who could build relationships with people who share their faith and would welcome them into their congregations.
- Work with senior centers, elder housing, and Area Agencies on Aging to identify people who are older and retired who have skills or interests to share with someone. Such relationships could lead to lasting friendships and create connections that could evolve to support someone through Supported Decision Making.
- Identify businesses that encourage their employees to volunteer in their communities. Developing relationships with local businesses could be fruitful in identifying people that might share similar interests with people being supported or who would be willing to develop new friendships.
- Collaborate with local schools and colleges to create an initiative to facilitate connections. For instance, there might be students whose course of study is restaurant management or nutrition who could work with someone interested in learning how to cook.
- Suggest that staff contact their own family and friends to see who might be interested in connecting with someone the agency supports. For example, a person may mention a preference for a particular dish from a local restaurant, which could lead to a connection to a staff member’s family who works there.

Getting to know people who receive services and their interests may allow for natural opportunities to create connections.

Conclusion

For an agency to be successful in supporting people receiving services to have real control over decisions that affect their lives, agency leadership will need to be intentional, creating and enacting a plan for expanding self-determination. This plan should be created in collaboration with people receiving services, family members, agency staff, and potentially interested people from the community, and shared broadly throughout the agency and with full support of the Board of Directors. The plan should be dynamic and should be monitored regularly to evaluate how things are going and what changes need to be made. Small, incremental steps lead to significant changes over time. For many people using HCBS, agencies are a vital force to propel change and to advance the principles of self-determination. Agencies must take active steps to embed self-determination in all aspects of agency culture and service delivery.

About NCAPPS

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) is an initiative of the Administration for Community Living and the Centers for Medicare & Medicaid Services to help states, tribes, and territories implement person-centered practices. It is administered by the Human Services Research Institute (HSRI) and overseen by a group of national experts with lived experience (people with personal, firsthand experience using long-term services and supports).

NCAPPS partners with a host of national associations to deliver knowledgeable and targeted technical assistance.

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Resources

Advocates as Leaders. (2017). My Voice Counts: Supported Decision Making, An Alternative to Guardianship. <https://selfadvocacyinfo.org/wp-content/uploads/2019/06/Support-decision-making-Guide-revised-2018.pdf>

Amado, A. (2013). Friends: Connecting People to Community Members. Research and Training Center on Community Living, University of Minnesota.
https://rtc.umn.edu/docs/Friends_Connecting_people_with_disabilities_and_community_members.pdf

Amado, A. (2013). Friends: Connecting People to Community Members. Activity Worksheets. Research and Training Center on Community Living, University of Minnesota.
https://ici.umn.edu/products/docs/Friends_Activity_worksheets.pdf

Bigby, C., Whiteside, M. & Douglas, J. (2019). Providing Support for Decision Making to Adults with Intellectual Disability: Perspectives of Family Members and Workers in Disability Support Services. *Journal of Intellectual Disability Research*. <https://www.tandfonline.com/loi/cjid20>

Charting the Life Course. <http://www.lifecoursetools.com/planning/>

Carter, E. et al. (2014). Welcoming People with Developmental Disabilities and Their Families: A Practical Guide for Congregations
<https://vkc.mc.vanderbilt.edu/assets/files/resources/CongregationPracticeGuide.pdf>

Davis, K (n.d.). Creating a Circle of Support. Indiana Resource Center for Autism.
<https://www.iidc.indiana.edu/irca/articles/creating-a-circle-of-support.html>

LeBlanc, N. (n.d.). Dignity of Risk and Person-Centered Planning During COVID-19. National Centers for the Advancement of Person-Centered Policies and Practices.
https://ncapps.acl.gov/docs/NCAPPS_Nicole_COVID_DOR_201002.pdf

National Center for Supported Decision Making: Everyone Has the Right to Make Choices.
<http://www.supporteddecisionmaking.org/>

Social Capital: The Real Route to Inclusion. (2014). *Frontline Initiative: A Publication of the National Alliance of Direct Support Professionals*. Vol. 12, No. 1.
https://ici.umn.edu/products/Frontline_Initiative/FI_12_1.

Substance Abuse and Mental Health Services Administration (n.d.). Supporting Choice: Helping Others Make Important Decisions.

<https://easacommunity.org/files/Shared%20Decision%20Making%20Helper%20Workbook.pdf>

The What, When Why and How's of Active Support. https://www.aaid.org/docs/default-source/annual-meeting/active-support-handout-.docx?sfvrsn=db25d365_2