

Lead the life you want with self-determination
and self-direction



Presented by Optum and the Spark Initiative

The Spark Initiative, developed by Optum®, brings together experts from government, nonprofit and private sectors to spark new thinking on major health and human service issues. This report focuses on individuals with intellectual and/or developmental disabilities (I/DD) and is one of a series of four Spark white papers on this topic. Its purpose is to discuss the benefits and challenges of “self-determination” and “self-direction” for individuals with I/DD and their families. It also outlines how both of these ideas can lead to greater fulfillment of an individual’s vision for a good life.

Everyone has a different idea for how they want their life to be. The vision includes goals and accomplishments, as well as dreams and ambitions. For 7.4 million Americans who have I/DD, the opportunity to make their own choices and live the life they want is a passion that drives them every day.¹

What are self-determination and self-direction?

First, it's important to understand what self-determination is. Self-determination means having control in your life. It's a way of making choices based on your preferences, beliefs and abilities. Those choices can then influence your future.²

Everyone should have control over meaningful parts of their lives, without others choosing for them. By thinking with self-determination, individuals can:

- Make their own decisions and plan their futures
- Decide how they want to be part of the community
- Decide how much time they spend in the community
- Decide what type of support they want and need to live their lives
- Have important leadership roles in managing their lives³

Self-determination is more than just an inspired way of thinking. It's living your life your own way. In fact, the American Association on Intellectual and Developmental Disabilities says self-determination is a right, and individuals with I/DD have the same right to self-determination as everyone else. They are "entitled to the freedom, authority and supports to exercise control over their lives."⁴

Making decisions for yourself involves considering what you like or dislike and thinking about all the things you want to do. But you also need to take action.

Self-direction means making action plans for your decisions. For individuals with I/DD, self-direction is the process of designing the supports and services that they want, to live the life of their choosing.⁵ With self-direction, you act on your own behalf to:

- Decide what services or purchases you need
- Make sure services and purchases are funded
- Schedule your services
- Decide who you want to work with or who you want to hire for services
- Resolve problems with your self-directed services⁶

Thinking with self-determination and acting with self-direction can lead to having the final say in how you live your life. For many individuals with I/DD, it brings greater happiness, satisfaction and confidence.

Putting ideas into action

Individuals with I/DD might have certain goals they want to achieve, such as moving into their own home, earning a college degree or starting a career. They might have some ideas on roles they'd like to have in their communities, such as voting, coaching a team or leading a group.

Self-direction can put the right supports in place for individuals to make those goals and achievements possible.

There is a lot of opportunity for individuals to create self-directed plans for themselves. Most states have a specific program to put those plans into action. Usually, the program is called a "Medicaid waiver."



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Often, the state's Medicaid office works with the individual to arrange the available support services through the Medicaid waiver.

There are many different types of supports. What's important is that individuals request the services that will help them achieve their goals.

The people who provide support might be called:

- Personal care assistants
- Personal consultants
- Job coaches
- Service consultants
- Support coordinators

For example, some individuals want to earn a college degree but aren't able to drive to a college campus. In that case, an individual might hire a personal care assistant to give them a ride and help them get to their classrooms. Or, a job coach might support someone at their job as needed to help them understand their work assignments so they can perform the tasks on their own.

Some self-directed programs allow the individual to manage money that is used to pay for the supports. The individual can decide which services they want to pay for and how to budget money for the most helpful supports.

When the program allows the individual to hire helpers or services, it's called "employer authority." And when the individual is in charge of how the money is spent, it's called "budget authority."

Many Medicaid waiver programs have:

- Person-centered planning processes that include an assessment of what you want and need
- Written service plans that outline paid or non-paid supports
- Individualized budgets
- Information and assistance for self-direction



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Challenges to consider

Sometimes family members, friends or guardians make decisions on behalf of the individual with I/DD, without first finding out what the individual really wants. The other people are usually trying to help. But it's important to know that part of self-direction includes the opportunity for the individual to try things — even to make mistakes. Mistakes are part of life. Fixing problems and trying again are also a valuable part of learning through experience.

Anyone who creates a self-directed plan also has the responsibility to point out supports or services that aren't working well. They might need to tell their support coordinator about the problem, or find a new provider.

For example, if a hired personal care assistant doesn't show courtesy, consideration and respect for the individual with I/DD, the individual may use his or her right to end the relationship with the assistant and find a new one. Often, he or she will need to make phone calls or send emails to make the change, sometimes with the help of a friend, family member or support coordinator.

Additional challenges might include a requirement to fill out a lot of forms to begin using the self-directed programs. Sometimes the Medicaid waiver programs can't provide all the supports an individual wants or needs. For example, programs might be limited because of funding or because there aren't enough providers to help everyone who wants certain services.

Some Medicaid waiver programs have waiting lists, and the individual who wants services might have to wait years before their waiver is available.

When designing self-directed plans, individuals also must use good leadership skills. These skills include:

- **Assertiveness** — communicating your preferences, goals and dreams
- **Understanding rights and responsibilities** — knowing the role you have in your self-directed plan
- **Communication** — speaking or using a device or some other means to tell others your thoughts, and also paying attention to the ideas and information given to you by other people
- **Influence** — getting others to understand or act on the ideas you have communicated

To develop leadership skills, individuals and their families, advocates and caregivers might look for online or in-person education programs. For example, the Minnesota Council on Developmental Disabilities created "Partners in Policymaking."⁷ These online courses, which are now available in several states, teach people how to be advocates who protect and advance the rights of those with disabilities.

Even though there are challenges, self-direction offers the benefits of an improved quality of life and greater satisfaction.

What does self-direction look like in the real world?

The movement of self-determination and self-direction has made a difference for individuals with I/DD across the country. Here are some examples.



Part of self-direction includes the opportunity for a person to try things — even to make mistakes.

A self-directed life can include personal care assistants

Santa P., who lives in Las Vegas, Nevada, has a Medicaid waiver. She receives daily services from personal care assistants (PCAs). The PCAs are people that Santa chooses based on who she is most comfortable with, which she says is very important in maintaining her quality of life.

“My PCAs are assisting with the most delicate needs,” Santa says. “The reality is not everyone is compatible with one another. I have found that with self-directed supports, the turnover rate of PCAs is significantly lower, and all parties are much happier.”

She says another thing she likes about the self-directed supports is that she has the flexibility to set her own schedule in a way that fits her lifestyle.

Medicaid pays for the PCA services, and Santa plans for a certain number of PCA hours per week. She says once a year, Medicaid reviewers check up on her PCA services. Generally, the reviewers pay close attention to Santa’s self-direction goals, and they collaborate with her to make the process work.

Santa’s advice is that people need to realize how important their voices are in the self-direction process.

“They need to understand that this is about their lives,” Santa says. “They need to not be afraid to ask questions — lots of questions — to have the courage to say, ‘I don’t like that,’ or ‘That’s not what I want.’”



A self-directed life can include a job coach

Evan N. lives in Atlanta, Georgia. He has a Medicaid waiver and a plan for his supports and services. As part of his plan, a paid personal consultant helps him live a self-directed lifestyle in his own apartment. Also, a paid job coach helps him carry out his work responsibilities.

“I live independently,” Evan says. “I pay bills, rent and everything.” He’s able to do this with his Medicaid waiver, his paycheck from work and family support.

Living on his own has been a dream of Evan’s for a long time. With the help of the personal consultant, Evan lives in a regular apartment complex in the community, with a friend that he chose to live with. The personal consultant helps him shop for food, cook meals and take care of the apartment.

“I cook some days, and some days I have activities,” Evan says. “My favorite things to cook are chicken patties or fish.”

Evan also has a job he enjoys, working five days a week at a community center gym. He checks in visitors with a computer at the front desk and takes care of the exercise equipment. He’s been working there for 18 years. Some days, his job coach is there to review his responsibilities and also to help him and his co-workers understand each other.



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“My job coach helps me to stay on task and encourages me to learn new skills,” Evan says. “Sometimes I get confused or anxious, and my job coach helps to resolve those issues.”

In the community, he serves as a volunteer on the Georgia Council on Developmental Disabilities, which meets four times a year. Evan says he feels lucky to be chosen for the council, and he wants to give his time and talents to inspire others.

Getting the Medicaid waiver was one of the biggest challenges in his self-directed life. He was on a waiting list for 10 years, he says. But Evan has a positive outlook.



“Give independence and a self-directed life a try,” he says. “The worst thing that can happen is you don’t get it right the first time. Keep trying.”

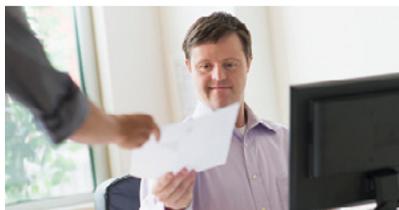
A self-directed life can include family members

Russell L., who lives in Reno, Nevada, is a motivational speaker, writer, poet and an advocate for individuals with autism and behavioral health disorders. He says his success comes from acceptance of himself as a person and his own determination to not let disabilities dictate what he does.

His mom has been his best mentor and role model, helping him create an independent, self-directed life.

“My advice for families and caregivers would be, first and foremost, to listen to the needs and passions of the individual,” Russell says. “Support and love them unconditionally and implement strategies to help assist them down the road of success, with them leading the way.”

A self-directed life can include co-workers



Eric S., who lives in West Jordan, Utah, has a professional career as the Information Specialist for the Utah Developmental Disabilities Council. He works four days a week, creating social media posts, presentations, videos and newsletter articles for the organization.

Part of his job involves participating as the chairman on a national committee that shares information about self-advocacy. Additionally, Eric helps other individuals with I/DD prepare for the annual “Take Your Legislator to Work Day.”

His job is creative and interactive, and he enjoys seeing the end result of his hard work. At the office, Eric’s co-workers provide encouragement and support his ideas for new projects. They proofread the things he writes and help him organize his busy schedule.

“My advice I would give to people with disabilities is to never give up and always get help when you need it,” Eric says. “Try to develop new skills that will help you lead a self-directed life.”



Self-determination is a right, and individuals with I/DD have the same right to self-determination as everyone else.

How to get started

No one knows what works for you and your dreams better than you do. To get started with your ideas about self-determination, consider:

- How you want to live your life
- What you would like to do for work
- The important people in your life who can help you make your vision come true
- How you want to be involved in your community — like volunteering
- What you like to do to have fun and be social
- How you can be healthy
- How you can have an active lifestyle
- Where and with whom you want to live
- Your gifts and talents and how you can share them
- How you strive to become an independent member of your community

To begin creating your self-directed plan, consider some of these questions:

- Do you want a job?
- Do you want to enjoy a hobby?
- Do you want to spend more time with friends?
- Do you want to take a vacation?
- Do you want to have your own apartment or share a home with others?

Often, you can work with a support coordinator at your health plan or state agency to design the services and supports you want in your self-directed plan. Some of the steps might include:



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– Russell L.

- Listing all of your services, including those you plan to buy and the names of the providers
- Listing the costs for each of the supports
- Working on budgeting the money to pay for your service plan
- Hiring, training and managing those who provide your services⁸

Conclusion

Self-determination and self-direction lead to positive changes in an individual's life. This way of thinking, planning and acting does not focus on an individual's disability, but instead focuses on their goals and dreams. The authority shifts from the organizations or communities making services available to the individual who shapes the services to his or her own unique vision for life.

Family, friends, guardians, caregivers and co-workers can be part of the process of designing a self-directed plan. However, the individual's values and preferences must always have the most influence on the final decisions. In a true self-directed structure, individuals are able to awaken their own power and stand for themselves at home, at work and in their communities.

To find out more about the ways Optum and Spark Initiative members are helping individuals with I/DD lead a self-directed life, visit optum.com/resources/library/spark/contact.html.



“My advice I would give to people with disabilities is to never give up and always get help when you need it. Try to develop new skills that will help you lead a self-directed life.” – Eric S.

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