



What Is Self-Determination and Why Is It Important?

 A National Gateway
to Self-Determination

Self-Determination: What Is It and Why Is It Important?

The purpose of the Gateway to Self-Determination Project is to “scale-up” efforts to promote the self-determination of people with disabilities. This publication was developed to help communicate, through the stories of people with disabilities, what is meant by self-determination and why it is important that people with disabilities receive the supports they need to live self-determined lives.

Quite simply, being self-determined means making things happen in a person’s own life, instead of having others do things to, or for them. People who are self-determined know what they want and how to get it. They choose and set goals, then work to reach them. They advocate on their own behalf, and are involved in solving problems and making decisions about their lives. They don’t have to do everything for themselves, but instead, they make or cause things to happen in their lives that improve the quality of their lives.

The Developmental Disabilities Act describes “self-determination activities” as “activities that result in individuals with developmental disabilities, with appropriate assistance, having: the ability and opportunity to communicate and make personal decisions; the ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports, and other assistance the individual receives; the authority to control resources to obtain needed services, supports, and other assistance; opportunities to participate in, and contribute to their communities; and support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.”

In this publication, you’ll hear people with disabilities talk about what self-determination means to them. You can also go to the website for the project (<http://www.aucd.org/ngsd>) and see a multimedia collection of video segments of the participants. Brad talks about self-determination as “being able not only to be independent, but to be able to make the decisions necessary to live the



Photograph by Diane Guthrie

life of my choosing to the fullest.” Mitchell points out that, “No one should make choices and decisions without the person with a disability being involved. People should be allowed to hear every option and they are entitled to their own opinion, and should not be influenced by others. Planning, having an idea of what you want to be, is important for self-determination.” Mia says, “It takes a lot of work to be self-determined in whatever you are doing especially if you’re living on your own or learning to live an independent life. It’s a lot of work and it can be a lot of fun. It’s good to have your eyes and ears open around other people – parents, sisters, friends – that love you the most.”

Kathy emphasizes that being self-determined does not mean you do everything on your own. In discussing the importance of her support person, Michelle, in her life, Kathy says Michelle, “has been really supportive, but also she has been a long-time friend who has been involved in encouraging people with disabilities to be the best that they can be in our community for many years.” According to Mia, the “team” of people that support her to live a self-determined life includes her parents, siblings, people in the community, employers, and a long-term mentor who heads an agency providing adult supports.

People become more self-determined not only by gaining skills in areas like goal setting, problem solving, decision making, or self-advocacy, but also by using supports—from friends, family members, and neighbors, to technology and education—that enable them to be the actors in their lives and make things happen for themselves. Jenny and her family, Lara and her parents, and Jessica and her mother are moving toward being more self-determined as these young women become older. Being self-determined takes planning, a vision for the future, and knowing how best to use resources that may be available or finding out a way to obtain needed resources to build a self-determined life.

The contexts and environments in which a person lives, learns, works, or plays are also important to promoting self-determination. Many such environments limit the opportunities people have to make choices and participate in decisions. For example, the lack of public transportation can create a barrier to living a more self-determined

life. According to Kathy, “I am not able to drive. There is no easy way for me to get places without taking a bus or a very expensive cab ride. Of course, I can get rides from friends and co-workers, but I try to be independent and get places on my own.” Jenny and her family live outside of town and are not close to public transportation which limits Jenny’s participation in activities when one of her parents is too busy to drive.

Sometimes the biggest barrier to self-determination is the attitude of other people. Scott talks about his concern with the assumption that people make about his level of understanding, without getting a chance to know him. He says, “It is easy for people to assume that I cannot do certain things, or I don’t understand what is happening in my life, since most of my disabilities are physical.” He also mentions another barrier, self-doubt. He tells us, “I am my own worst barrier to being self-determined. Sometimes I don’t believe I can do something, so I don’t always put forth the effort.” A positive self-awareness and self-knowledge as well as positive attitudes about one’s abilities and strengths, as Scott mentions, are important parts of being self-determined.

In the following pages, you’ll hear Brad, Kathy, Scott, Jenny, and others whose personal experience with disability has taught them what it means to be self-determined, discuss the importance of self-determination in their lives. Research has shown that people who are more self-determined have more positive employment and independent living outcomes and report that they have a higher quality of life. These stories will discuss self-determination in the contexts that, generally, reflect a higher quality of life; having a good job, living in one’s community, having friends, and other varied contexts.

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Self-Determination and Community Inclusion

Too often, people with disabilities have too few choices about where and with whom they live. Being more self-determined enables people to have more of a voice in living in their own communities. Here is what people had to say about it.

“I believe it is important for everyone to be able to thrive in their environment and be a part of the community.”

Brad

Brad

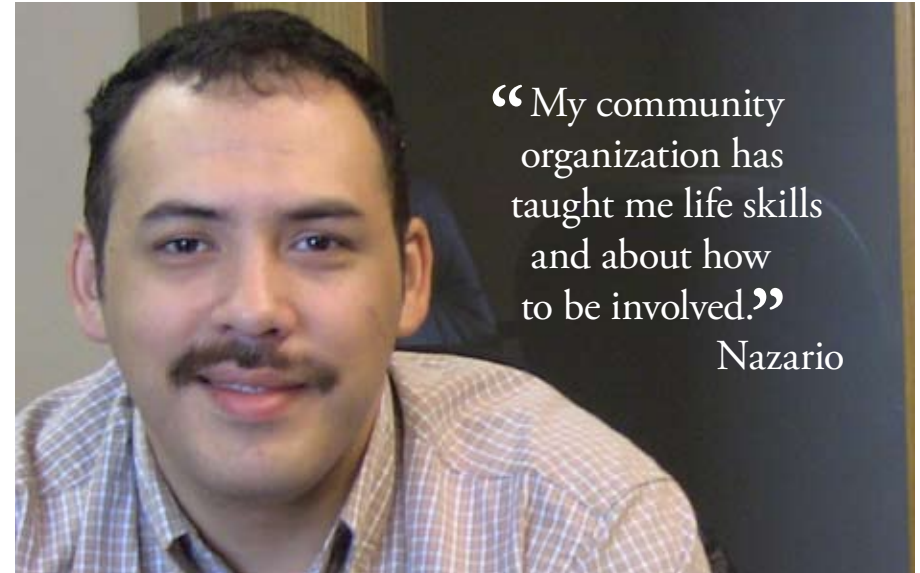
I believe it is important for everyone to be able to thrive in their environment and be a part of the community. I have spoken to numerous individuals about how they can change their lives to be more self-determined. My family has been supportive of my choices of where to live. At first, I lived with a roommate, but now I have a home of my own that I helped design to be accessible and I don't have to make decisions related to anyone else if I don't want to do it. It would be nice to have someone to date, but right now, that is not what I see happening, although I have dated in the past.

Kelly

I enjoy being involved in my community from teaching Sunday School at my church to being involved in a Parks and Recreation organization. I think it's important that the community is accessible for all people with disabilities so I asked City Hall for a sidewalk to be built so that I could get to work more safely. Before that, I was on the street, rather than the sidewalk, so advocating for a sidewalk was important. I'm proud to say the city accepted and now I can get around more easily. I ride a scooter most places and can travel around our community and go to stores and shop.

Nazario

I participate in a community organization that teaches me independent living skills and offers social skills training as well. Through this organization, I get to participate in various programs such as volunteerism and sports. I have also learned how to cook and will often cook the meals for my family. I live at home with my parents, but would like to live in an apartment some day.



“I am in full force and nothing stands in my way of getting things accomplished and being the voice of people throughout Kansas.”

Kathy

Photograph by Daina Gutrine



Lara

Through strong family and community supports I am able to do activities I enjoy. I have always been interested in school, while at the same time holding a variety of after-school jobs and activities. My jobs have given me a chance to acquire new skills and work with many different people. I rely on community supports in my everyday life. I am learning to take the bus to the grocery store or the library. With the bus, I can visit my grandparent on my own.

Mitchell

I have my own town home. I know a lot of people have roommates, but I enjoy my independence. Most people would say that transportation is the number one concern, but I am able to ride the bus for most things. In the evenings I go out with friends. We will usually go to the movies or out to eat. Once a month I also go to social group meetings. It is important to have a support system and I am lucky to have my family, colleagues, and people in my community who support me.

Kathy

I feel as if I am a role model for everyone. I have been a proud homeowner for over 10 years now and am very independent and self-driven. I went from being a consumer to a tax payer when buying my own home. Although I can't drive, I have found ways around by using public transportation and cab companies or even just asking friends for a ride. I have many people in my community who support me and help me get around in the community. My main support, Michelle, helps me do things like go to the grocery store and cook. She gives me advice, listens to me, and is a great friend.

Self-Determination and Real Jobs

Research shows that people who are more self-determined have higher rates of employment and earn more money, as well as having better benefits, like vacation, sick leave, and health care. Hearing from people with disabilities about their jobs is one way to visualize self-determination in action in the world of work.



“I work at a retirement community sorting and delivering mail to the residents. I try to make each resident feel special by talking to them and connecting with them.”
Jessica

Kathy

I love my job! I am working as a legislative liaison for The Self-Advocate Coalition of Kansas. My job includes advocating for other people in Kansas and being able to testify in the state of Kansas. Along my lines of work, I have been fortunate enough to meet state and national legislators and know many governors of Kansas. Through my work, I am able to speak up for the people who are unable to speak up for themselves, and to advocate for self-determined lives for all.

Jessica

Since I am still in school, I am really getting ready for the future by taking classes in the morning and working in the afternoon. I work at a retirement community sorting and delivering mail to the residents. I try to make each resident feel special by talking to them about their lives and their families. I really enjoy making a difference in their day.

Askia

I have worked on a program developing assistive technology for individuals with developmental disabilities. (Askia uses a voice generated device to assist in communication.) Right now I am looking for a job, and it is not easy to find one. One committee I am an advocate for is Employment First, which helped me when I was searching for a job after college.

“I created and developed programs for assistive technology, which helps people like me communicate with the world.”

Askia



“I’d like to get a 4-year degree and get a job working with people.”
Brandon

Brandon

I participate in volunteering at an organization which helps people lead independent lives. I am going to community college so that I can work in computer support for administrative activities. If I had a paying job, I would like to work with people and also with computers. I am a people person. I think self-determination will help me to be more independent in the future and to be clear-minded about what I want to become.

Jenny

I’ve always loved to draw so I started donating my designs to raise money for a disability organization. After a lot of support and encouragement, my business soon spread to t-shirts, coffee mugs, key chains, greeting cards, etc., and my new business was taking off! My mother is my partner in this on-line art business. I was a little nervous at first, but I’m really proud of it now. It took us a long time to realize what all went into having a business, but with funding and support from others, it is fun to do.

Kelly

I work for the Self-Advocate Coalition and I go to meetings so that other self-advocates’ voices can be heard, whether it’s helping them hire or train staff, make their own choices, or become more independent. There are people who are low functioning, but they still need help. Even though a person has a learning disability they still need support. They have a right to have help. I think education of people here in town is important, because sometimes people think we have a disability and we can’t do anything – which is wrong.

Self-Determination and Social Inclusion



Photograph by Diana Gutierrez

Self-determination means making things happen in your own life, instead of others doing things for you. But perhaps the most important supports a person can have to live a self-determined life are friends and family members! As the song says, everybody gets by with a little help from their friends. Whether doing something with friends or with oneself, knowing what you like to do and getting out and doing it are important parts of a better life.

Lara

I enjoy being independent, but I believe that having friends is very important. My friends are important in my life. One of my favorite things to do is go shopping with my aunt and my friend, Kay. They help me pick out clothes and decide what looks best. Kay and I also like to go swimming in the summertime when it's hot outside. Also in the summertime, we go to a camp where we play games, learn how to go grocery shopping, and make choices.

Scott

I enjoy music a lot, especially going to concerts with my friends. I'm very much a relationship person. I enjoy people and relationships. Sometimes my friends and I will plan big activities and other times we will just get together, hang out and talk. I play a huge role in deciding what I want to do each day, whether it is going to work or going somewhere with my friends. I am very much in control of my life and my decisions.

Brandon

I am very interested in social media, especially Facebook. I use Facebook to stay in touch with my friends. I have about 90 friends on Facebook. I also use my webcam to talk to my friends. Other things I enjoy doing are bowling and dancing.

“It's important to educate people here in town because sometimes people think since we have a disability, we can't do anything—which is wrong.”

Kelly

“The most important aspect in my life is a good support system. Between my family, friends, and co-workers I am doing more now than I ever thought possible.”

Brad

Photograph by Diane Guinra



Kelly

Anybody can be self-determined if you have help and natural supports like I do. I have a lot of friends at church who help me get to appointments and things. I am also close to my sister and hope to one day move out to Colorado to be nearer to her. I look forward to moving so that I can meet more people.

Jessica

I love being involved in the community! I am an active Girl Scout. I am also involved in youth group. My friends and I enjoy going to the movies and going bowling. I also like to do the family grocery shopping. My personal care assistant helps me make the shopping list and pick out the best items.

Jenny

I love meeting new people and am not afraid to speak up for what I believe is right. I also enjoy being with my family, whether we go out to dinner, go shopping or just hang out. It feels good to know that so many people care about you. I think it is important in learning how to become an adult to learn to respect oneself, respect others, and earn respect back. It's important to show that there is nothing wrong with having a disability – you don't have to be ashamed, you can be happy about it.

Brad

When I get more time on my hands, I want to do some free-lance work. I like to travel and can travel independently when it is a direct flight. I love going to sporting events and I have attended many baseball games recently. I also have many friends in my community. We usually switch off hosting events such as holiday parties and fantasy football drafts at our houses. This gives me a chance to get out, socialize and see my friends. I can also cook! In fact, there is not much that I cannot do.

Self-Determination and Healthy Living

“I think it’s great to have balance in life. It might take a lot of work, but it’s worth it.”

Mia



Wellness and positive health outcomes for people with disabilities are important to living a better quality life. Self-determined people make choices about their behaviors and actions to care for their health and lead healthy lifestyles.

Mia

I believe having a healthy lifestyle is very important, even though at times it can also be very difficult. I teach a class called “Healthy Lifestyles for People with Down Syndrome-What Do We Know?” Through this program I teach people how to make the right decisions and healthy choices in their life. To be healthy, you must be self-determined. I try to be a good example to those around me of how to live a healthy lifestyle. It is easier to do when you have a team to help you out. My parents were a great example as I was growing up and taught me how to eat healthy. Everyone messes up sometimes but it’s important to get back on track and surround yourself with people who will support you. Another thing I like to do to make sure I am on track is planning out my meals. It helps me make healthy decisions and know what I am going to eat.

Kathy

I try to cook at least two or three times a week to save money. Cooking at home also helps me eat healthier. My support person, Michelle, helps me go grocery shopping and choose healthy meal options. Occasionally I do go out to eat though, because I like to be around people. I think it is very important to have a healthy lifestyle.



“You are
in charge of
your future.”
Mitchell

Remember, you can go to the website for the National Gateway project www.aucd.org/ngsd and see a multimedia collection with video segments of each person here.

Mitchell

To me, it's important to be healthy as well as to speak up for yourself and your health. My health is my responsibility so when I go to the doctor I should be the one to speak to my doctor about my health issues and concerns. I usually write down questions I want to ask before I go. I also try to encourage others to advocate for their health. I speak to people about nutrition and staying fit, telling them why it is important to watch what you eat and to exercise. Exercise is important. People might want to go to the gym and do pushups and sit ups. I do my exercise on the treadmill, but I also do sports for exercise like kayaking and swimming. Although I do advocate for my own health, I also have people, like family and friends, who help me and keep me on track.

Nazario

I like to exercise. I usually jump rope and do pushups. Every Tuesday, I go to a basketball program where they teach me the rules of basketball. This program has also taught me many useful cooking skills. I really enjoy cooking meals for my family. I can cook spaghetti, pizza, and hamburgers but my specialty is soup.

Self-Determination and Self-Advocacy

People who are self-determined advocate for themselves and others. For people with disabilities, being a self-advocate is very important to ensure equal access and to battle discrimination.



“I believe in the importance of educating people on the issues of people with disabilities and I am actively involved in proposing new programs and meeting with policy makers to discuss key issues.”

Askia

Brad

I feel as if I am a great example of a person who shows great self-determination. I have spoken to numerous individuals about how they can change their lives to be more self-determined. To me, self-determination means not only to be independent but to be able to make your own decisions and live your life to the fullest by choosing. The most important aspect in my life is a good support system. Between my family, friends, and co-workers, I am doing more now than I ever thought possible. I am thankful that growing up my parents encouraged me to do things on my own. I believe that is why I am so independent today. I feel I have been self-determined my whole life!

Askia

I made the decision to be self-determined and have been making my own choices, setting goals, and solving problems since my first IEP in the seventh grade. I find creative solutions to every challenge I encounter. From helping craft a custom degree at my college to building my own house, I have not only shaped my life and decisions but have had a significant effect on the lives of many others. I am active in my community, serving on several different committees as a self-advocate. I try to set an example for all who want to be self-determined and believe it just comes down to having the right mind-set.

Mitchell

I try to influence people to speak up for themselves—to share their personal stories. People need to be able to make their own choices and decisions, to be able to advocate for themselves. We learn from the choices we make. To me, self-determination means being able to set high expectations for yourself and fulfilling your dreams. I enjoy being self-determined and helping other people become more self-determined.



Photograph by Diana Gutrie



“I try to encourage other people to stand up for themselves and their rights too.”

Scott

Brandon

Self-determination helps me be a more independent individual. If you just put your mind to it, you will have more success in being self-determined and making your own choices. Although it's hard to be independent, I feel I'm pretty good at determining what my life is and making my own choices.

Kelly

I believe in the importance of helping other self-advocates speak up and receive the support they need and deserve. People with disabilities should still get the support they need and have a voice to choose what is right for them. I don't want people to assume I need help before I ask. Sometimes I need more time or just a little bit of help, not a lot of help. Making choices helps me become more independent in determining my life.

Scott

I'm pretty much in the driver seat of my own life. I want to be the one who decides the direction of my life. While I need support with certain things, it doesn't mean I'm not capable of making good decisions. I think it's important to make your own choices and stand up for your rights. Sometimes as a person with a developmental disability, people want to make all the decisions for you, if you're not careful. I try to be really active, upfront, and honest. I speak my mind. I have a very independent spirit, so I don't really let people make decisions for me.

Jessica

Jessica's mother, Jennifer, says that even though young persons with disabilities need their parents more than the average person, she has begun to step back so her daughter can advocate for herself. Jessica and Jennifer have had to figure out how to balance decision-making between them over time. In sixth grade, Jessica started to be a part of interviewing personal care attendants, asking questions, and eventually became the primary person making decisions about who to hire to take care of her basic needs. "This summer," Jessica mentions, "I chose to take my personal care attendant rather than my mother on a trip to New Mexico to attend a conference, and everything turned out just fine." Jennifer admires her daughter's emerging self-determination and continues to provide support, as needed.

Closing Thoughts

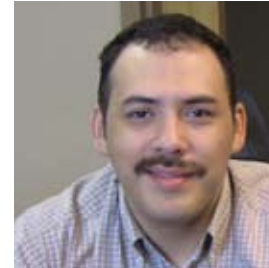
Fundamentally, promoting self-determination is about promoting dignity and respect, valuing people, and raising expectations of and for people with disabilities. Becoming more self-determined is an important part of the transition from being an adolescent to becoming an adult, and to deny anyone the opportunity to learn the skills, have the experiences, and have the supports that enable them to become more self-determined is, fundamentally, to deny them the opportunity to live richer lives as adults. Research shows that self-determination is related to a host of more positive quality of life outcomes for people with disabilities, including better employment and independent living outcomes.

When asked about how being self-determined makes her feel, Kathy says, “It makes me feel good. I am able to make most of my decisions, or know who to ask for help.” Scott says, “I make all my own decisions. It really comes down to me being the one who decides, rather than others.” Lara is content making her own choices, “I make important decisions when needed to get what I want out of life.” For Askia, finding creative alternatives in any situation is something that he prefers to do himself, with the advice or help of his support group of family members, friends, and his case manager. Askia’s advice to someone considering making any change in their life or trying to get different services is, “Don’t ever be afraid to ask.”





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