advising

through self-determination

~ an information guide for advisors ~

featuring:

disability information
effective advising tips
ways to promote self-determination
helpful resources

a project of the

National Gateway to Self-Determination

with input from self-advocates, advisors, & national leaders

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Self-determination refers to a characteristic of a person that leads them to make choices and decisions based on their own preferences and interests, to monitor and regulate their own actions, and to be goal-oriented and self-directing. A person acting in a self-determined way has a voice in the decisions that affect them and is causing things to happen in his or her own life.

Terminology

Throughout this guide, we use the term "advisor." Some self-advocacy organizations may use a different term for their "advisor," it might be facilitator, leader, or even something else. For ease and consistency, we will use the term advisor throughout this guide.

Additionally, we use the term "self-advocate" throughout the guide. Some people with disabilities prefer simply "advocate" or "person with a disability." For ease and consistency, as with the term advisor, we will use the term self-advocate throughout this guide.

who helped...

First and foremost, we would like to thank all the self-advocates and advisors across the country who provided invaluable input in creating this information guide.

The following activities took place in the development of this guide:

1. A survey was sent out to advisors and self-advocates across the country to get their input into what has worked in advising through self-determination, as well as gathering existing resources on advising.

2. A national symposium was conducted at the 2011 AUCD Conference with the Council on Consumer Advocacy (COCA). In this, we gathered information from consumers, advisors, parents, and professional staff at UCEDDs who work with self-advocacy groups. There were over 50 in attendance who worked with us in defining the roles and responsibilities of advisors, as well as roles that UCEDDs could assist with, particularly in promoting self-determination.

3. Prominant self-advocates, advisors, and professionals wrote contributions and reviewed the guide.

4. Materials for this guide were also reviewed by the SABE Self-Determination Committee and SABE Board of Directors.

5. This guide brings together not only resources developed by the National Gateway to Self-Determination, but also many other effective resources. The materials used throughout this guide, and others listed in the Resource Section, are presented as a starting point. It is our hope that you will use them as resources and explore the many options available.

6. This work is a collaboration of many authors and contributors, as listed on the inside front cover. On the inside back cover we also thank the individuals who took the time to carefully and thoughtfully review this guide.

It is our hope that advisors will find that practices and activities promoting self-determination are indeed effective in empowering self-advocates and self-advocacy organizations. We hope this information guide serves as an effective starting point for advisors to develop or enhance their own framework and value system for working with self-advocates and self-advocacy groups.

our goal...

to create an information guide for advisors of self-advocacy organizations which promotes advising through self-determination.

The Administration on Intellectual and Developmental Disabilities (AIDD) held nine Self-Advocacy Summits in 2011 and 2012 involving all of the States and Territories that provided the opportunity for self advocates and their allies to share their perspectives on the state of the self-advocacy movement across the country. At several summits, the role of advisors and allies was discussed and debated at length.

At the heart of the self-advocacy movement is a need for empowerment of people with disabilities to truly lead and to exercise informed decision-making with the help of advisors and allies, who play an important role in ensuring that the voices of people with disabilities are central and primary.

As a result of these discussions, AIDD asked the National Gateway to Self-Determination to create a practical guide for advisors using the concept of self-determination as the framework. The key message we want to impart is that at the heart of the self-advocacy movement is a need for empowerment of people with disabilities to truly lead and to exercise informed decision-making with the help of advisors and allies, who play an important role in ensuring that the voices of people with disabilities are central and primary. At the same time, we need to appreciate everyone's input and, together, work to achieve a more inclusive society for people with disabilities.

This guide focuses on the basic elements of advising a self-advocacy group by promoting self-determination. We will provide you with some general information about disability, advocacy, and self-determination. We also look at the traits of effective advisors and the variety of roles that an advisor can play, as well as how an advisor can better understand and navigate the disability system.

Next we look at ways to develop and understand activities that promote self-determination based on the Developmental Disabilities Act (DD Act) definition (see page 14). By breaking down the sections through the DD Act definition, we are able to begin to build a framework (or an approach) for effective advising through activities that promote self-determination. Concrete examples are provided for sections of the DD Act and suggestions on other effective materials are given on how best to achieve the overall goal of increasing self-determination for people with disabilities.

Additionally, the resource section not only details the University of Illinois at Chicago study about advising but also provides an extensive listing of general resources, training materials and curricula, and materials developed by self-advocacy groups.

The most important element of all is that self-advocates, advisors, and professionals in the field are all working together to have a positive impact on the lives of people with disabilities. By partnering together we can use everyone's gifts and talents to make our communities, states, and nation stronger.

June 2012

Dear Friends of the Self-Advocacy Movement,

Nearly forty years ago, a group of people with intellectual and developmental disabilities came together in Oregon to organize around the best ways to advocate for themselves, calling the group "People First." The hope was to ensure that people with intellectual and developmental disabilities could develop a strong voice in a world where often well -intentioned professionals and family members dominated.

We have come a long way over the past four decades towards achieving that vision. We have tens of thousands of self-advocates working at the local, state, and national level, doing tremendous things – influencing our systems with powerful and meaningful efforts that might have been unthinkable a generation ago. Self-advocacy by people with intellectual and developmental disabilities has greatly contributed to the broader civil rights movement of the disability community in many ways.

At the same time, we know that some of this success is due to the supportive contributions of many professionals, family members, support staff, and other allies. One very critical role has been people serving as advisors to self-advocacy organizations. Yet there has been little consistent support for these advisors to develop, refine and share best practices, and to ensure that self-determination for people with disabilities is at the heart of the work of all advisors.

With this in mind, the National Gateway to Self-Determination, a National Training Initiative funded by the Administration on Intellectual and Developmental Disabilities, developed this guide. It contains information for advisors on effective practices, promoting self-determination, and other useful resources for advisors, both advisors new to the field and those with extensive experience.

Effective advising for self-advocacy organizations provides support in such a manner that people with intellectual and developmental disabilities with diverse needs, including significant communication and behavioral challenges, can exercise self-determination at many levels to pursue both individual and organizational goals. Finding ways to empower both individual people and the collective group, while staying in the background in a support role, is a difficult art demonstrated by the very best advisors.

I would like to thank the National Gateway to Self-Determination for working collaboratively with people with disabilities, family members and advisors in the creation of this important guide. I hope you find it useful!

~Sharon Lewis, Commissioner
Administration on Intellectual and Developmental Disabilities
Administration for Community Living
U.S. Department of Health and Human Services

Advising Through Self-Determination explores the roles that advisors play in the self-advocacy movement. It is timely, as the power of self-advocacy is now receiving the recognition it deserves as the key to self-determination for individuals with developmental disabilities. As advisors, we are crucial in empowering self-advocates to find their voices to speak out on personal and societal human rights issues affecting their lives.

Advisors are often a puzzle to those who observe us. In my role as an advisor over the past 25 years, I have been privileged to observe and learn from many effective advisors and self-advocates from across our nation. From these experiences and my own, advisors are like a chameleon, skilled at changing roles based on the needs of self-advocates and their organizations. Our many roles may include a community organizer, teacher, facilitator, advocate, consultant, event planner, resource specialist, policy analyst, partner, observer, coach, cheerleader, ally, advocate, friend, and above all, a listener.

We must use our skills, art, passion, and compassion to empower and strengthen the voices of self-advocates to determine their destiny.

This manual begins the process of identifying a framework to understand these roles and the body of knowledge that is needed to become an effective advisor. The development of advisors from the local group level to the national organization must parallel the growth and development of self-advocates to strengthen the self-advocacy movement. The exploration of these roles and body of knowledge needed for advisors will lead to the recruitment of a cadre of new advisors who are effective in their roles.

The roles we play are powerful ones in supporting the movement; but we must always remember that we must use our skills, art, passion, and compassion to empower and strengthen the voices of self-advocates to determine their destiny. It should be remembered that there is no single right way to be an advisor; it is about trust, respect, relationships, having fun, and often about blending into the background - like a chameleon.

~ Vicki Hicks Turnage
National Advisor, Self-Advocates Becoming Empowered
Advisor, People First of Alabama

Self-advocates support advisors as much as advisors support them. The purpose of this manual is to help advisors know how to support self-advocates and work together as a team.

It is important for advisors to understand how to support people. Advisors should also understand both the self-advocacy movement and self-determination. This will help advisors to help self-advocates grow and become strong leaders.

Sometimes the most difficult thing is when an advisor thinks one way is best, and the group wants something different. After having a good conversation, and listening and discussing both sides of the issue, the bottom line is that the advisor needs to compromise and go with what the group wants. The advisor helps us to make informed decisions. Maybe the group's decision will turn out to be a good one, maybe not. But in either case, it will be a learning experience for future decisions. Our best advisors give good input and then let us decide. It's ok for us to make mistakes, it's the way everyone learns!

This manual can be used as a tool to strengthen the knowledge and leadership skills of both the advisor and the person with a disability. This manual is meant to be used for learning about tools and resources, but it is important to remember that the real learning about how to effectively advise through self-determination takes time - working side by side with self-advocates as partners.

Whether you are a new advisor or if you have been an advisor before, I hope you enjoy the amazing journey of supporting people to live the lives they dream of. This manual is an opportunity to think of new, exciting ways to be a part of people's lives and the self-advocacy movement!

When we work together it makes it a better world for us all!

~ Tia Nelis
Self-Advocate

basic disability awareness

In her keynote speech at the 2010 Self-Advocates Becoming Empowered (SABE) National Conference, Commissioner Lewis talked about self-advocacy, social capital, and self-determination, saying, "You guys are the champions at the heart of our work.... It's about relationships and it's about letting go and taking risks! It's actually really simple, but it's not easy." She went on to discuss the importance of working in partnership with self-advocates, sometimes supporting, and sometimes getting out of the way. This is one message of this guide... sometimes an advisor needs to support and sometimes an advisor needs to get out of the way.

The second message is that self-advocates and advisors work in partnership, with **SHARED responsibility and MUTUAL respect**. It is important to recognize everyone's contribution. Bottom line, when people with developmental disabilities are more self-determined, their participation in community life is increased, and this results in a **stronger community and better quality of life for everyone.**

In order to effectively advise a group, a core set of knowledge is helpful. In this "basic disability awareness" section, you will find information that will help you as an advisor develop a basic framework about disabilities.

Individual Rights

Laws in the United States dictate that people with disabilities have specific rights: access to equal education, employment, housing, and health care. The Rehabilitation Act of 1992 states that disability is a natural part of the human experience and in no way diminishes the right of individuals to: live independently; enjoy self-determination; make choices; contribute to society; pursue meaningful careers; and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society; and (later in the section)... **the goals of the nation properly include the goal of providing individuals with disabilities the tools necessary to achieve** the above-listed outcomes.

Develop Your Own Framework

In developing your own framework, **it is vital that you know and can articulate your own values and beliefs!** Some basic ideas to help you develop your own framework include:

Definition

- ✔ Disability is a relative idea, viewed differently from culture to culture and even person to person.
- ✔ Disability is not an individual issue, it affects the whole community.

Encouraging People

- ✔ Supporting people with disabilities to be self-determined is beneficial to the individual and the community.
- ✔ People with disabilities should be able to make choices and decisions based on their own preferences and interests.
- ✔ People with disabilities should be given the opportunity to monitor and regulate their own actions.
- ✔ People with disabilities should be able to set goals and direct the attainment of those goals.

Tips

- ✔ Always focus on the person, not the label.
- ✔ Never use diagnosis to generalize, stereotype, devalue, or discriminate.
- ✔ Unless it is relevant to a conversation, you don't need to refer to or mention the disability.
- ✔ Focus on a person's *strengths* (what they *can* do) and not on what they *can't* do.

Research Indicates...

that youth and adults with disabilities are less self-determined than their friends and colleagues without disabilities. This is due mainly to having fewer opportunities to make choices in their daily lives. Advisors need to address this issue by:

- ✔ Having high expectations.
- ✔ Teaching skills promoting self-determination (i.e. choice-making, problem-solving, leadership, and self-advocacy).
- ✔ Providing the opportunity to practice these skills.

Activity Idea!

We all have an important contribution to make. We all have unique abilities, experiences, and talents. An effective advisor not only knows his or her own strengths but also knows the same about the individuals in the group. Create an activity that will help you learn about the individuals in your group, and will help your group learn about you. This is the first and most effective way to foster mutual respect. An activity using "Lifebooks" (see page 31) would be the perfect way to start this journey together.

"People First Language means that people clearly see people with disabilities as people to respect." ~ *Nancy Ward*

People First Language is a respectful way of speech. People First Language puts the person BEFORE the disability. It is important to think of and put the person as an individual first. The disability is just one of many characteristics, qualities, and aspects of the individual. People First Language uses words all people understand.

Self-Advocates Becoming Empowered (SABE) created "People First Language, The Basics" to help spread the word about what type of language is appropriate and respectful. This great resource talks about how different states are changing their legislation to include People First Language. It took people with disabilities and advocates to step up to the plate and get changes made. **What a great illustration of self-determined action through leadership and self-advocacy!**

What does People First Language mean to you?

- ✔ People First Language means that my name is Brad Linnenkamp.
  ~ *Brad Linnenkamp*
- ✔ It means respect... being referred to as everyone wants to be referred to, not as a characteristic of that person.
  ~ *Vicki Hicks Turnage*

Here are some examples of People First, or respectful language:

Hurtful Language	**Respectful Language**
He is retarded.	He is a person with an intellectual (or developmental) disability.
She is handicapped.	She is a person with a disability.
She is a Downs kid.	She is a child with Down Syndrome.
He's wheelchair bound.	He uses a wheelchair.

Using People First Language sets a respectful example to society and is a great way to teach others!

Effective advising for self-advocacy organizations provides support in such a manner that people with intellectual and developmental disabilities with diverse needs, including significant communication and behavioral challenges, can exercise self-determination at many levels to pursue both individual and organizational goals.

~Sharon Lewis, Commissioner, AIDD

Each person has a name.
Please call me by my name.
My name is not a label or a diagnosis.
My name is Bernie.

~ a self-advocate from New Jersey

People First Language is a matter of equality and respect for people with disabilities.

~ Betty Williams

More Resources on Respectful Language

The National Technical Assistance Center for Voting and Cognitive Access has produced a "Guide for Creating Cognitively Accessible Language." This publication has a nice section with step-by-step directions on making an accessible document. Other useful ideas include:

- ✔ Language can be the most welcoming or the most excluding form of communication. When we make language accessible to people with cognitive disabilities, we make it accessible to everyone.
- ✔ Make your point quickly. The fewer words, the better.
- ✔ Use short words and sentences.
- ✔ Big words and acronyms should be followed by a definition in brackets.

These, and other effective materials on Plain Language resources, can be found on the following website:

www.govoter.org

self-advocacy

Self-advocacy and self-determination are critical to empowering individuals with developmental disabilities.

Self-advocates are people with disabilities who work to provide themselves and others with better opportunities and improved services that support choice and control in their everyday lives. Self-advocacy groups provide a way for self-advocates to come together, share their ideas, support each other, and advocate for change. By learning skills that promote self-determination, self-advocates are enabled to take more responsibility and control over their lives.

Self-advocates work in groups at local, state, and national levels, and utilize advisors to support their groups. An advisor is a person with or without a disability who is not a voting member of the self-advocacy group, but who is available to support the group in various ways. Typical advisor responsibilities include assisting with the facilitation of group meetings, providing information on community resources, and supporting self-advocates to assume leadership roles and to speak for themselves. **Advisors need to carefully balance the level of influence with the opportunity for self-advocates to make informed decisions.**

Self-advocacy skills enable people to express their preferences and have a voice in the decisions that directly affect their lives. Strong self-advocates are causal agents in their own lives.... **they cause things to happen to make their lives better.** Simply put, self-advocacy is the ability to stand up for oneself and advocate on one's behalf. Effective self-advocates might testify before a legislative committee on the needs of people with developmental disabilities, speak before community groups, or advocate to family members for individual desires and the supports needed to achieve them.

Self-advocacy skills refer to a set of actions through which people with developmental disabilities speak out or demonstrate in a way that promotes their wishes (or that of a group) to assure **access to and full participation in the community.**

As noted in the introduction, self-advocates, advisors, and professionals in the field all work together to positively impact the lives of people with disabilities. Thanks to everyone's efforts, self-advocates are doing everything - they go to school, they have families, they have careers, they travel. They are a part of our communities, making the communities better for everyone. Throughout this guide, you will read many success stories about self-advocates. The work is not easy, but the rewards are invaluable.

A Brief History of Self-Advocacy

Self-advocacy is a driving force of the civil rights movement for people with developmental disabilities. In order to fully understand the self-advocacy movement and its significance, a brief history is helpful.

For many decades, up until the 1960s, doctors and professionals in the US and Europe encouraged parents of children with developmental disabilities to place their children in residential hospitals and state institutions because it was thought that these children would require significant care and would not be able to live within mainstream society.

Self-advocacy organizations began within states as early as the mid-1970s. Much of their evolution focused on alternatives to institutions and segregated services. People First organizations began as a grass-roots movement.

Inspired and encouraged by the US civil rights movements of the 1960s and 1970s, people with developmental disabilities began to organize into various groups. The first groups in the US came together around issues of deinstitutionalization, advocating that people with disabilities be allowed to move out of large-scale state institutions and live in the community. Around the country, small groups of self-advocates formed independently of each other. In 1990, the first national gathering of self-advocates was held in Estes Park, Colorado. This gathering was the basis for the organization that is now called Self-Advocates Becoming Empowered (SABE).

The self-advocacy movement in the US has grown substantially over the last 40 years. What began as a few small gatherings of self-advocates has grown into a nationwide movement, with local and state self-advocacy groups in all 50 states. Self-advocates have worked tirelessly to change the public perception of people with disabilities.

While self-advocates have influenced significant change, there is still more work to be done as the self-advocacy movement continues. Within the movement itself, self-advocates are working on addressing problems related to the organizational growth of self-advocacy and recruiting new and younger self-advocates. In terms of advocacy work, self-advocates continue to confront negative community perceptions and are working to educate community members on issues such as respectful language and self-determination while working towards achieving real power and control for self-advocates. This work is important to the continuing development of self-advocacy groups.

The Self-Advocacy Movement: The Unacknowledged Civil Rights Movement

This great resource has chapters on the history of the movement, society's relationship to people with disabilities, and more. Make sure you check out Chapters 5 and 6 which delve into advising and other important issues.

self-determination

Being self-determined involves choosing and setting goals, being involved in making life decisions, self-advocating, and working to reach goals.

Self-determination refers to a characteristic of a person that leads them to make choices and decisions based on their own preferences and interests, to monitor and regulate their own actions, and to be goal-oriented and self-directing. A person acting in a self-determined way has a voice in the decisions that affect them and is causing things to happen in his or her own life.

A frequent misinterpretation of self-determination is that it simply means "doing it yourself." For people who may have significant disabilities, this can be problematic. The ability to perform specific behaviors is secondary in importance to being the causal agent. So while a person may not be able to solve a difficult life problem without support, with appropriate support that person is enabled to act as a causal agent in the decision-making process and therefore is more self-determined. The more supports (e.g. friendships and community connections) that are available to people with DD, the more likely it is that they will have the necessary resources to cause things to happen in their lives.

One way to be self-determined is through self-advocacy activities. Advocating for oneself is an excellent demonstration of self-determined action.

Problem-solving skills are important to self-determination. The Illinois Planning Council on Developmental Disabilities described problem-solving behavior as the ability to:

a. recognize and choose between available options,
b. develop a plan of action based on available resources,
c. determine who or what you need to carry out the plan, and
d. elicit support when needed!

DD Act

DD Act Self-Determined Actions

an individual with developmental disabilities, with assistance:

- has the ability and opportunity to make choices and decisions;
- has the ability and opportunity to exercise control over services, supports, and other assistance;
- has the authority to control resources and obtain needed services;
- has the opportunity to participate in and contribute to their communities;
- has the support, including financial, to advocate, develop leadership skills, become trained as a self-advocate, and participate in coalitions and policy-making.

The Social-Ecological Model

The National Gateway to Self-Determination views efforts to promote self-determination in the context of the social-ecological model/ framework. This framework allows you to look at the entire picture when trying to develop activities that promote self-determination, calling for strategies for support to take into account both the capacities of the person and the reality of the environment in which the person lives and works. The social-ecological model looks at not only the person, but also the environmental context. So when creating activities that increase and promote self-determination, we would want to address not only the individuals in the group, but also the environment in which they are living. Elements and situations which need to be examined can include: interpersonal, family, organization, community, policy, and services and supports.

To best promote self-determination, opportunities need to be provided in all of the environmental contexts - at home, at work, at school, and in the community. For example: you can support meaningful participation on a board; you can find or create activities that develop self-advocacy skills; and you can promote building a wider social network (see the section on social capital).

The following **outcomes** can result from **implementing activities that promote self-determination**:

- ✔ Access to community resources and supports.
- ✔ Improved ability to manage one's daily life.
- ✔ Greater community participation and acceptance.
- ✔ Emotional/material/physical well-being.
- ✔ Breadth and variety of daily activities.

Person Environment Fit

Supports to promote self-determination should focus on:

- ✔ enhancing personal capacity,
- ✔ improving opportunity, and
- ✔ modifying the environment.

Other Self-Determination Basics

Expectations, stereotypes, and biases impact everything we do. Put aside your own expectations and work toward goals that are driven by self-advocates. Historically our expectations have been too low for individuals with disabilities. **This may be as big a barrier to living rich full lives as anything else!**

Common misperceptions about self-determination include:

- ✕ Self-determination is control.
- ✕ Self-determination is independent performance.
- ✕ Self-determination is just making a choice.

Interested in learning about self-determination in greater depth? ***What Is Self-Determination and Why Is It Important to People with Developmental Disabilities?*** is an in-depth lecture about self-determination. The lecture and accompanying PowerPoint can be found at http://aucd.org/NGSD/template/page.cfm?id=684. The lecture is divided into five separate segments for ease of viewing. **Check it out!**

social capital

Social capital is the formal and informal support networks that provide you with access to resources.

For anyone to be an effective self-advocate they need social capital. Social capital is the set of relationships and social ties to individuals and organizations that expand your choice-making opportunities, increase your options, and lead to an improved quality of life. For individuals with disabilities and for organizations, increased social capital can further full inclusion in the community, improve access to social support networks, and increase quality of life.

> community participation increases your social capital

Social capital exists both at the individual level and at the community/group level. Three strategies can be used to help self-advocates develop social capital:

1. **Family, friends, and/or parent participation and advocacy are vital!** Family members and friends can help identify key people and resources to increase access to social capital.

2. **Develop and sustain as many peripheral ties as possible!** Develop relationships in the larger community, outside family and close relationships. Get involved in service learning or volunteer programs to develop community inclusion and social capital.

3. **Join organizations!** Not only will you develop individual relationships, but you will benefit from the actions of the group. People with disabilities also need connections that will provide access to support services. People with disabilities and their family members need to learn how to actively seek services from agencies.

Expanding people's social capital by connecting them with social structures in the community enhances their opportunity to make choices that influence quality of life.

People possessing significant social capital generally have the resources, leveraging capacity, and natural community supports needed to achieve greater inclusion and better quality of life as well as the ability to advocate for others.

How can a group increase its social capital? Connect with another group that advocates for something different! For example, when a group made up of people with disabilities connects with an organization that shares the same values but is comprised of advocates for the aging population, the social capital of both organizations is increased.

Lessons Learned

Mia shares some lessons on social capital! To make it work, Mia had to figure out what supports she needed to make things happen in her life. The first social capital lesson for Mia was close to home.... "Lesson One: My parents do have some good ideas, sometimes." She talks about the importance of listening to our families and working together. Parents and siblings are "home base" when it comes to social capital. When you enlarge your circle of support, your social capital grows. For Mia, this started with a mentor who encouraged her strengths and helped Mia to find a job. Finding a job led to having the confidence to go to college and live on her own. Her mentor - her "social capital agent" - used her own social capital to help Mia find the support she needed.

An accessible version of Mia's story can be found at: http://www.youtu.be/UfJbfQVQNRU

Core Values

A core value at the heart of social capital is TRUST. You trust those within your own network, and you trust the people your friends trust. Other values associated with social capital include having friends and allies who are on your side, developing connections to others who can help you, and in turn, helping others. Social capital is connected to self-determination, giving you the power to make decisions, have choices, and add control and direction to your life. It helps you to be a causal agent.... **to cause things to happen in your life!**

Create Opportunities to Intentionally Increase Social Capital

Advisors need to provide opportunities for both the individuals in the group and the group as a whole to increase their social capital.

It is important to connect with other people and groups that have similar interests, not just similar support needs. The community integration has to be **meaningful and valued.** As with everything else, networking and community involvement has to be deliberate and practiced.

Brainstorm with your group about interests and other groups in the community with whom you might plan an activity. What other groups do the self-advocates in your group already belong to? What are their interests? Think "outside the box" - church, library, the zoo, sports, book clubs, community center, the arts, etc.

For More Info on Resources used for Pages 8-17

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People First Language, The Basics, http://www.sabeusa.org/user_storage/File/sabeusa/People%2520First%2520Language%2520Manual.pdf.

Plain Language Resources can be found at: www.govoter.org.

Research to Practice in Self-Determination Series, Issue I: Self-Determination and Self-Advocacy. Editors: Calkins, Wehmeyer. National Gateway to Self-Determination, www.aucd.org/ngsd.

Research to Practice in Self-Determination Series, Issue 2: Self-Determination and Employment. Editors: Calkins, Wehmeyer. National Gateway to Self-Determination, www.aucd.org/ngsd.

Self-Advocacy and the Advisor Role. Collins. (2011). Institute on Disability and Human Development, The University of Illinois at Chicago.

Self-Advocacy Movement: The Unacknowledged Civil Rights Movement. Hayden. (2004). National Institute on Disability and Rehabilitation Research.

What Is Self-Determination and Why Is It Important to People with Developmental Disabilities?, Wehmeyer. National Gateway to Self-Determination, http://aucd.org/NGSD/template/page.cfm?id=684.

follow-up

Items from “Setting the Foundation” that I want to follow-up on:

Basic Disability Awareness:

People First Language:

Self-Advocacy:

Self-Determination:

Social Capital:

advising 101

We asked a lot of people to describe an effective advisor. We received a lot of answers!

At the AUCD 2011 National Conference, we held a **symposium** on this very subject. Attendees included self-advocates, advisors, and professionals in the field. We also sent **questionnaires** to, and have had in-depth interviews with self-advocates and advisors.

The next few pages describe what we learned. **These responses are based on years of experiences and reflections!** They are what self-advocates and advisors have felt for years.

Symposium Responses: Personality Characteristics

When asked about personal characteristics of effective advisors, self-advocates, advisors, and professionals in the field described the following characteristics:

Compassionate
Is able to put self in family's shoes. Thinks in terms of "What would I do if this was my relative?"
Is caring and empathetic - works to have a true understanding of the individual's perspective.
Can focus on others.
Is a good listener - hears every member.
Is interested and open minded.
Is non-manipulative and non-judgmental.
Is self-aware and has self-control.

Resourceful
Is assertive, without being confrontational.
Has own self-determination.
Knows audience.
Is organized and is a problem-solver.
Is curious - continue developing knowledge of self-advocacy, advisors, community resources, etc.

Sense of Mission
Is able to empower rather than control.
Is able to step back.
Can "walk the walk" not just "talk the talk."
Does not need to be front runner.
Knows when to push and when to step back.
Is involved in community (but in a low-key way).
Does not have an agenda nor ego.
Supports individual's goals and respects choices.
Thinks of self as pioneer.

Responsible
Is adaptable, calm, consistent, and reliable.

At the AUCD 2011 Symposium, responses from self-advocates, advisors, and professionals in the field included:

Advocate for Self-Advocates

Turn questions around to self-advocate.
  Encourage individual to find own answers.
Is optimistic and encouraging.
Give opportunities in safe environment first and then practice in "real world."
Have high expectations.
Help build skills to find own voice.
Help develop self confidence.
Help process information, but don't alter it.
Support the individual (and show that support).
  Is able to figure out what support is needed.
Ask if help is needed - another opportunity for choice.
Have knowledge of resources.
Have a big vision, listen to caring supporters (parents, etc.).

Build Relationships

Trust and communication are key.
Create positive supports.
Understand each individual's needs.
  (learn personal/family history)
Let people make mistakes – there is dignity in taking a risk.
Build independence among individuals in group and group as a whole.

Can Teach the Following

Advocacy and advocacy skills.
Decision-making and choice-making.
  "Choice" needs to be a REAL choice.
  All choices carry consequences.
  Open discussion, everyone's opinion matters.
  Give positive feedback/recognition for "thoughtful" decisions.
  Create opportunities to practice these skills.
Advising skills (to further self-determination).
How to access information.
How to be in relationships of mutuality/respect.
Presenting skills (talking in front of a group).

Facilitating Role

Get appropriate resources to the group.
Is well informed to effectively share message/info.
Help the group come to a consensus.
Serve as mediator (when needed).
  When mediating, teach the group the value of mediating and about knowing when to step back.

Strategic Planning

Development of Goals, Direction, and General Agenda.
  Help the group choose direction.
  Offer choices and opportunities.
  Support their goals and respect their choices.
  Ask what they think and want.
  Talk through all the pluses and minuses of options.
    All choices carry consequences.
  Help group come to a consensus (this takes a well-trained and aware advisor!).
  Help with decision, but understand that their choice (individual's or group's) is final.
Support in developing position statements (ex. White Papers).
Help formulate and disseminate their opinions.
Help group call on others for perspectives and expertise.

Provide Support

Support self-advocates in the way they need it (need to be able to figure out where support is needed).

Meeting Management/Organizational Skills

Help with logistics.
Use multiple means - pictures, words, etc.
Facilitate meeting effectively (teach these skills to group).
Arrangement of meeting space - people should sit side-by-side, not in front or behind.
Ask if help is needed – gives an opportunity for choice.

Help Improve/Increase Resources

Knowledge of resources.
Support self-advocates to attend multiple/diverse educational and training opportunities (leadership development classes, etc.).
Develop mentorships.
Provide networking opportunities.
Understanding social media.
Joining "non-disability" community groups.

Other

You have to be ready to respect what self-advocates are going to do ("when you turn them loose") – once you've given them the tools, respect the decisions that they make to be ready to get behind that and honor that.
Parents shouldn't advise groups where son/daughter is a member. Same for direct support staff.

As noted in the Introductory Section, in preparation for this guide, a survey was sent across the country to advisors and self-advocates to get their input into what has worked in advising through self-determination, as well as gathering existing resources on advising. These two pages present a summary of the responses received from Self-Advocates and Advisors. Again, these responses are based on years of experience and reflection.

Questionnaire Responses from Advisors

When advisors were asked about the characteristics of an effective advisor, two main themes emerged.

1. That the advisor is **compassionate -** that he or she listens and assists without giving personal opinions, is respectful at all times, is a good listener, is VERY positive, has a can-do attitude, is flexibile and open, and has patience.

2. That the advisor is a **teacher -** that he or she has the ability to teach and analyze advocacy practices and knows different types of communication.

The responses below illustrate the variety of roles an effective advisor can have!

Advocate for/with Self-Advocates

Assisting with planning testimony at hearings, including assisting people with practicing their delivery and response to questions.
Providing information on advocacy opportunities, possibilities to serve on decision-making and/or advisory boards/committees.
Assisting people in advocating for accommodations at work, meetings, & other community settings.

Teach

Assist with letter writing.
Providing leadership training and feedback to members to build confidence and enhance their leadership, public speaking, and advocacy skills.
Assisting with problem-solving, by asking guiding questions so solutions are determined by members.
Teach about an organization (like non-profit).

Strategic Planning

Ability to assist with planning (short and long-term), and implementation.
Writing grants with self-advocates.
Cultivating donors with self-advocates.
Reporting to funding sources.
Help keep group focused on priorities and mission.
Analyzing policy issues.
Able to research issues quickly so group can act quickly.

Provide Support

Personal assistance (when asked and needed).
Personal supports (emotional and physical assistance if needed and requested).

Meeting Management/Organizational Skills

Arranging for/providing transportation and meals.
Technology.
Assisting with budgeting/finances.
Setting up for meetings; assisting in arranging for space if needed; making coffee and arranging for food if needed.
Assist with meeting and event planning, doing mailings, organizing phone trees, sending e-mail blasts, etc.
Lets the group lead, has the group do most of the leg work for their activities.
Ability to communicate information clearly.
Good writing skills.
Experience with finances, fundraising, and grant-writing.
Experience organizing meetings and events.
Organized.

Help Improve/Increase Resources

Well-connected to issues and opportunities.
Knows the community.
Experience as an advocate themselves.
Help make community connections.

Self-advocates were asked the following question: What do you, **as a self-advocate,** think makes a helpful advisor? A helpful advisor is someone who:

Compassionate
I can trust, is honest, truthful, and dependable.
Cares, is kind, and understanding.
Cares about self-advocates as people.
Wants to help.
Is there for good times and bad times.
Listens.
Respects people.
Listens and gives good advice.
Will be there for me.
Understands me.
I can talk to.
Is supportive.
Has a sense of humor and remains patient.

Teacher
Shows proper communication (intervention skills).
Is "not trying to control our meetings."
Answers any questions that we ask and is there to help and provide good support.
Helps me make choices and decisions on my own.

Sense of Mission
Is a good role model.
Believes in self-determination, independence, and helping us go for our goals.
Believes in the movement.
Wants to help others.
Has lots of knowledge about people with disabilities.
Does not want to take over.
Is not controlling, will stand with me.
Will offer advice and even criticism without trying to control those they are helping.
Agrees with me on taking risks and letting me learn from my mistakes.

Meeting Management/Organizational Skills
Helps organize our meetings.
Is there at meetings.
Helps with transportation.
Assists us in planning events (like 4th of July parade).

Help Improve/Increase Resources
Gives resources and information.
Is very explanatory.

Self-advocates, family members, and professionals met at the AUCD 2011 National Conference for an effective and supportive meeting.

Review of Literature

The University of Illinois at Chicago Institute on Disability and Development conducted an in-depth review of current literature. They identified 5 major themes of interest:

1. Advisor Functions

The various functions of an advisor should evolve over time as the group's needs change. The following four areas were prominent in the literature:

* Leadership development.
* Group facilitation, including conflict resolution, leading discussion, and counseling.
* Planning, organizing, and managing logistics, including transportation and long-term planning.
* Identifying potential resources including grant-writing and connecting with community resources.

2. Empower vs. Control

While there is a major dynamic between the concept of empowering vs. controlling, the most effective advisors are the ones who focus on empowering the individuals in the group. The core values of advisors are key in developing this dynamic, focusing on the social model instead of the medical model - that is, advisors must focus on competence and strengths instead of emphasizing deficit.

3. Training Needs

It is clear not only from the literature, but also from interviews and conversations, that there is a distinct lack of formal training. The literature suggests that training is needed in the following areas:

* History of the self-advocacy movement (in the US and internationally).
* Philosophy and mission of the self-advocacy movement.
* Duties and expectations of advisors.

4. Advisor Turnover

Groups report high levels of advisor turnover, which can disrupt the strength and cohesion of self-advocacy groups and distract them from their advocacy work while they seek out and train new advisors.

5. Support needs of youth vs. adults

Youth may have different support needs than adults who have been involved in self-advocacy for a number of years. Some needs more specific to youth include:

* Leadership development.
* Communication skills.
* Transition.

It is also important to acknowledge that there is a "second wave of self-advocacy" - that younger self-advocates may have a different agenda than older self-advocates.

Best Practice

Supporting an individual through activities that promote self-determination **is** best practice! This guide focuses on providing information and examples to help every advisor start to more effectively incorporate strategies that increase self-determination into meeting agendas and activities of the group they advise.

Learning the skills related to self-determination is vital for increasing an individual's independence. Some of the basic skills which this guide focuses on are: choice, self-advocacy, and leadership.

Research has shown that when an individual has the ability and opportunity to be a causal agent in their own life they will have more positive future outcomes --- which can include education, employment, independent living, and community inclusion.

Direct and explicit teaching methods are especially effective in teaching self-determination skills:

- ✔ Modeling (act out a scenario).
- ✔ Provide feedback: use various prompting techniques and provide multiple opportunities to receive feedback on the new skills.
- ✔ Practice: build opportunities to practice into your daily routine.

Help the self-advocate have a daily plan and recognize opportunities to practice these new skills in a natural environment.

We all need to support each other!

Bringing it all together…

As the above characteristics and roles of an advisor show, the range of advising varies significantly. An advisor can be in a one-on-one advising role, a facilitator for a group of self-advocates, or even support projects and policies that affect people with disabilities throughout the USA and the world. Because of this wide range of roles and responsibilities, it's no wonder people with disabilities, advisors, and other supporters of the disability rights movement find it difficult to understand what we really mean when we talk about advising. Advisors of self-advocates are passionate about the work they do because it keeps them connected with the "real lives" of people living with disabilities. Advisors can also be people with disabilities themselves that need different kinds of support to fulfill their roles. The main thing to keep in mind is that **we all need to support each other in the way that mutually works for individuals with and without disabilities in a respectful and compassionate manner.**

~ Laura Walker Jackson, SABE National Advisor

understanding the network

One of the hardest things for any advisor, new or "seasoned," is to understand the system through which advocacy groups need to navigate. The following two pages provide a brief history of the DD Act and descriptions of the organizations that can serve as resources to advisors.

What is an Act?

An act is a law that starts out as a bill passed by Congress. Once the President signs the bill, it becomes law. Federal agencies are given responsibility for administering the law and creating regulations that interpret how the law will be followed.

A brief history of The DD Act (up to the year 2000)

- 1955: Mental Retardation services priority in the Children's Bureau.
- 1962: President Kennedy appoints Panel on Mental Retardation.
- 1963: Congress first passed the DD Act and University Affiliated Facilities (UAFs) are established (present-day UCEDDs).
- 1970: This reauthorization established funding for Developmental Disabilities Councils (DD Councils).
- 1975: Congress authorized funding for Protection & Advocacy systems (P&As).

Congressional Reauthorization of the DD Act in 2000

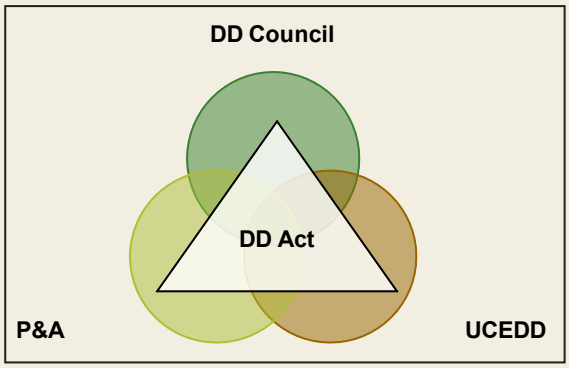
- Changes emphasized: life in the community, lifelong services & individualized supports, and the right to live free of abuse, neglect, financial and sexual exploitation, and violations of legal and human rights.
- Other changes in 2000 included: promoted increased collaboration with State DD Councils and P&As, requirement to develop outcomes data, UCEDDs recognized as an international resource, and identified 'Areas of Emphasis.'
- Mission of the DD Act of 2000: "To assure that individuals with developmental disabilities and their families participate in the design of, and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life…" (Subtitle B – Section 121 – PL 106-402).

DD Act Programs all share 3 major themes

1. Advocacy: active support for a program, initiative, or change.
2. Capacity Building: strengthening local, state, regional, and national communities.
3. Systemic Change: modifying entire programs, policies, services, and/or funding streams.

State DD Network

UCEDD + DD Council + P&A = State DD Network



State Councils on Developmental Disabilities

The DD Councils are charged with identifying the most pressing needs of people with developmental disabilities in their state or territory. There is one in every state and territory. The DD Council must include a majority of individuals with developmental disabilities and family members. The DD Councils use a variety of strategies such as training, educating policy makers and communities, coalition development, barrier elimination, and demonstration of new approaches to service in order to make systems change and build capacity.

State Protection and Advocacy System (P&A)

State P&As provide information and referral services, legal, administrative, and other remedies to resolve problems for individuals and groups of clients with developmental disabilities. The DD Act authorizes P&As to investigate incidents of abuse and neglect and have access to all client records when given permission by the client or the client's representative. The P&As work through mediation, alternative dispute resolution, and litigation to resolve complaints. There is one in every state and territory plus a Native American consortium.

You might encourage a member of your group to contact your state P&A if he or she is having some legal issues, or if you feel someone is having their rights ignored.

University Centers for Excellence in Developmental Disabilities (UCEDDs)

Originated in 1963, UCEDDs have worked towards a shared vision of full community inclusion, for people with and without disabilities. Key components of this vision include independence, productivity, community integration, and self-determination. There is at least one UCEDD in every state and territory. They serve as resources for disability related information for the community and university. UCEDDs work with persons with disabilities, their family members, state and local government agencies, and community providers. UCEDDs conduct research that improves practices of service and supports and are training sites for future professionals with similar values and core beliefs that can and do advise self-advocacy groups.

Members of the DD Network can provide you with excellent resources and can be the first place to call with questions! Take a few minutes and locate the contact information of the following organizations in your state.

My state DD Council phone number is: _____

My state P&A phone number is: _____

My state UCEDD is at: _____ Phone: _____
(name of university)

My reflection… there is no roadmap!

Early in my career I decided the beliefs and values that I would work and live by: I would focus my work on children and adults with DD and their families who have been denied services or excluded from a program or group. Secondly, I do not care if a person cannot read or write, walk, or talk --- what I do care about is if a person is willing to work hard and learn new things. Lastly, I believe everyone can lead a self-determined life with or without supports. I strongly believe that clear values and beliefs are the foundation to being an effective advisor.

Most importantly, an advisor has to have their core values and beliefs clearly defined and they need to have a passion for the role!

Children and adults with DD, their families, and having an older brother with Down syndrome have taught me many things which have influenced my attitude, beliefs, and intense respect for the real experts, people with DD and their families. For people with DD to lead lives **they determine as meaningful**, it can take an array of people, relationships, and individualized supports all working together. Support is not doing for; it is listening to, making sure everyone is included, respecting every voice, and making sure every voice has a chance to be heard. An advisor strives for every member of the group to be included, not excluded. My top 20 suggestions (not in any ranking order) are:

1. Listening very carefully and empathically to the stories from people's lives - they will change yours.
2. Knowing that everyone has gifts and talents - some just need to be pointed out.
3. Honesty when mistakes are made, take ownership and as a group determine "what next."
4. Never leave a meeting or event without every member of the group being heard or having been invited to share.
5. Challenge yourself and others!
6. Look for opportunities to learn, to live, and to give away knowledge and skills with and by other self-advocates.
7. Support does go both ways, this is sometimes hard but critical to your success as an advisor.
8. Non-judgmental and no assumptions.
9. Support is not a 9 to 5 event; it is an ever changing process.
10. Non-readers can be awesome leaders!
11. Information must be shared in words that everyone can understand and handouts that everyone can use.
12. Learning never stops, people will continue to grow in their knowledge and skills, their dreams and desires, and that includes you.
13. Patience and more patience, and more patience.
14. Check your ego at the door. This is not about how great of an advisor you are, it is about how each member of the group can lead more inclusive, self-determined lives of their choosing.
15. Recognition that all members of the group must respect each other's beliefs, attitudes, and need for flexibility.
16. Transportation will be your number one barrier.
17. Mistakes are great teachers.
18. Decision-making is not your job, making sure everyone understands the decision to be made is.
19. Fun, we do our best when we are all having fun.
20. Just do it! Don't question yourself; you have plenty of support from each member of the group, use them.

Simply put, an advisor has to have their core values and beliefs clearly defined and they need to have a passion for the role!

~ Essie Pederson

reflections from a new advisor

The role of an advisor of a self-advocacy group comes with many challenges, yet gives rewards that you never dreamed possible. I am the advisor for a People First group. Each member has their own story, life experiences, and struggles. This group has changed my life for the better and I am lucky to have them in my life.

use supports! The most important thing that I have learned is to use supports in your own life. If you need guidance, ask other advisors or self-advocates that have been involved in the movement for a long time. Find your 'go-to' people, both fellow advisors and self-advocates. Everyone has skills, interests, and experiences that have created an impact on their life.

be an ally! I think of my role of 'advisor' as being more of a consultant or ally. A consultant helps a person or group make choices by discussing what would be the best end result and the path to get there. I draw on my experience and help the group talk through the plan.

consult - don't decide! Being an advisor means to give advice, not control. The key is how you give the advice and that you explain the reasoning behind it. Remember, you are supposed to be promoting decision making. Give your advice and your reasons, and then let the group make the decision.

get involved! Getting involved with your local community is very important. This involvement does not just include the self-advocates, it includes you! Put yourself out there in the community. Tell people that you are an advisor for a self-advocacy group. Let them know what that means. This is especially important in community employment. You can be the best advocate out there to encourage local business owners to hire persons with disabilities.

be organized! Find a way to stay organized that works best for your group. Organization is the key. Setting up a separate email account for the group is a great way to keep all correspondences in one place. Also, sign up for as many listservs as possible. Listservs send out amazing information that can help you understand the system.

systems change! I can't stress enough how important it is to keep track of public policy and how it affects persons with disabilities. There are many resources out there to help understand systems change.

I am thankful every day for the life changing experiences this opportunity has given me.

~ Krystle McCarthy, People First of Missouri Advisor

creating a framework for making choices & decisions

Choice- or decision-making skills are important indicators of self-determined action. The following process describes an effective, easy to use plan of action for making choices and decisions:

Recognize: Recognize your options.
Discuss: Talk about each option for the positive (benefits) and negative (challenges).
Choose: Make a choice based on this process.

Problem-solving can have a similar process and is necessary when you are engaged in a task or situation where the solution to a problem is not easily understood. Just as in teaching any self-determination skills, teaching problem-solving skills can be accomplished by using direct and explicit teaching methods:

Model/Role Play: Act out a scenario.
Prompt/Give Feedback: Use prompting during role-play and give useful feedback.
Practice: Provide multiple opportunities to practice and receive feedback on the new skills.

Keep In Mind

In this Guide, we read over and over about the importance of providing opportunities for self-advocates to practice new skills. When developing activities and giving those opportunities to practice, always keep in mind the importance of the social-ecological model. Make sure you look at the entire picture when trying to develop activities that promote self-determination, taking into account both the **capacities of the person** and the **opportunities in the environment** in which the person lives and works (see page 15 for more on the Social-Ecological Model).

Supports to promote self-determination should focus on:

- ✔ enhancing personal capacity,
- ✔ improving opportunity, and
- ✔ modifying the environment.

A Lifebook is a collection of words, photos, graphics, artwork, and memorabilia that creates a life record. It can serve many purposes in the life of a person with a disability. It can be used to help service coordinators, providers, and friends get to know an individual. It can be used to help plan for the future. It can be used in advocating. It can be used in making choices and decisions.

A Lifebook can also be great fun to make! The focus is on the person and building a picture of their story... their special relationships, their likes and dislikes, modes of communication, and dreams. Creating a Lifebook is a great way to involve family and friends in thinking about the person with a disability.

The results are clear! A Lifebook allows individuals to be active contributors to, or authors of, the services they receive. **It allows them to be causal agents!**

The Missouri Self-Determination Association collaborates with People First Chapters to facilitate the use of Lifebooks as individuals transition from state-run institutions to community settings. This activity helps them build their self-determination and social capital, not to mention the fellowship opportunities it creates during transition.

A parent of a child with autism was tired of explaining what support her son needed. They created a Lifebook and when her son took it to school, she was happy to find that her son and his peers were looking at his Lifebook and his peers were asking her son questions --- having an open dialogue about why he acts the way he does. The Lifebook became a tool for her son to interact with his peers - which is much more positive than the teacher taking the children aside to explain why he is different.

Lifebooks can be a way for family members, professionals, and people with disabilities to network and brainstorm together to build a strong circle of support around an individual. Lifebooks are an excellent tool to help individuals **build their social capital,** enhance their self-determination, and become more effective self-advocates about the choices and decisions in their own lives.

Some self-advocacy groups have developed a fun variation on a LIfebook and have created a Lifebox. A Lifebox can be a much more hands-on, concrete variation of a Lifebook. Think of the meaningful and fun items you might put in a Lifebox when showing your story!

For more details: Here I Am! A Lifebook Kit For Use With Children With Developmental Disabilities. Schroen, Halleen.

Lifebooks in Action!

Members of People First of Missouri were trained on what a Lifebook is and how to make their own. Upon watching the PowerPoint “ScrapAbilities: Living the Self-Determined Life,” members chose their own scrapbook and printed out pictures of people, places, and things important in their life. The group was also provided with stamps, magazines, and stickers to make pages that showcased their life, hopes, dreams, and anything else they wanted to share. Lifebooks are a way for people to express themselves on a personal level and show new people how much they enjoy living in the community. Members created pages about their favorite hobbies, sports teams, and interests. This was also a chance for members to connect with each other on a more personal level. Many chapters have adopted the idea of Lifebooks and have planned on making it a part of chapter activities.

As an advisor, I learned a lot about group members through this activity. It showcases individuality on a deeper level. Self-advocates are able to outline what they want out of their life and how they want to be supported. Members were also able to help each other think through what they wanted to include in their book. The members that participated in this activity really enjoyed it and many continued working on them into the night. Advisors should also create their own Lifebook so that the self-advocates that they are supporting can get to know them better.

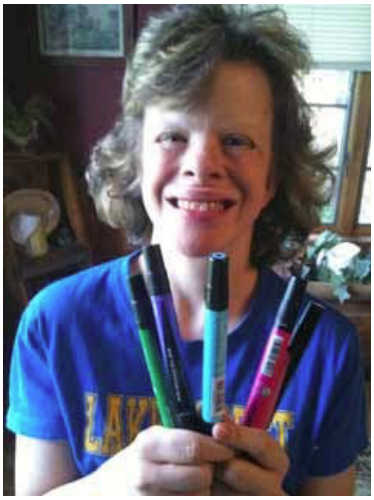
Lifebooks can be an ongoing activity, with pages being added all the time! Examples of pages include: What I Love About Me!, How I Can Advocate for Myself, People I Am Thankful For, Activities I Love to Do, Things I Bet You Didn’t Know About Me, What I Dream About, What I Like and Dislike, The Basics About Me, and How I Communicate. The list can go on and on! Lifebooks are a chance for a self-advocate to create an “autobiography” of their life and tell the world what is really important to them!

"Tell people your dreams.... if you want a job, a good first step is to volunteer to show people that you can get yourself to the job, do the tasks, and that you are responsible." ~ Cindy

Lessons Learned

Cindy had an unhappy childhood. She felt as if no one listened to her and she didn't care about anything. She met Chris. Chris is about the same age and enjoyed sports like Cindy does. Chris helped Cindy to become better at sports. Cindy learned to trust Chris and understood that Chris wanted her to be the best person she could be. Cindy started to believe in herself. Through Chris' support, Cindy joined Special Olympics. She has been with her team now for over 20 years and has a built-in family and support network. Her social capital grew with her relationship with Chris and then it grew to a larger level with her friends at Special Olympics. Cindy now works as an Advocate Specialist with People First of Wisconsin. She comes to work with a purpose: to help all people... those with intellectual disabilities and those without.

Cindy is more self-determined because she worked to increase her social capital.



Lessons Learned

Jenny participated in Girls at Work: Self-Directed Customized Employment Planning, which provides an accessible and motivating format for completing an eight step goal-oriented problem-solving process focusing on post-secondary education or employment.

Jenny is now a small business owner and sells her art on cards, t-shirts, magnets, cups, canvas, and more. Jenny has a website (www.jennyludesigns.com) and is often found at professional conferences.

Jenny is a role model for other young women as a guest speaker and teacher at Girls at Work events.

Research shows that individuals with developmental disabilities showed improved self-determination and life choices when they were in a less restrictive environment.

Jenny demonstrated self-determined actions by starting her own business. Here (above) is an example of her art.

More Resources About Choice & Decision-Making

It's My Future! Planning for What I Want in My Life is a self-directed planning process. The following excerpt from this user-friendly resource describes how "It's My Future!" can help people with DD reach their goals:

> "Do you sometimes feel like your planning meeting is useless because nothing ever changes? Have you ever felt that all anybody talks about is your health or things you're not doing right? Do you have dreams and ideas of what you want in life, but your dreams just never come up? At the end of your meeting do you feel like you never got to talk about what you want? If you answered "yes!" to any of these questions, then this book is for you! Starting today …this book will help you get ready for your next planning meeting. You will have a chance to learn some things…things that will help you be more in charge, more in control at your next planning meeting so that you will be able to get more of the things you want in your life. You will learn how to make more of your own decisions about things that are important to you. And set some goals to reach the things you want."

It's My Future! can be found at: http://www.aucd.org/docs/Its%20My%20Future.pdf.

Person-Centered Planning is a commonly used method to assist individuals in planning for their future. Common characteristics of this approach include: look at the individual as a person not as a disability, use understandable language not professional terms, center planning around the individual's unique strengths and interests, and most importantly, give the individual and those closest to him a substantial voice in the process.

Person-Centered Planning can help an individual with disabilities set goals, make choices, and advocate for themself. It is also an approach that can be effictively used in organizations and can result in: increased social networks, increased community involvement, increased daily activities, improved contact with friends, and improved choice-making.

The Future is Now! This is a model of a future planning curriculum that includes siblings. Katie Arnold talks about the importance of family future planning, which creates a dialogue within families to plan for the future. It is through this planning process that her family came to understand the importance of self-determination for her sister. For Katie, self-determination means that her sister has the support and tools to make meaningful choices and create the life she wants to live.

creating a framework for managing services & supports

Storytelling

Telling your personal story is one way to exercise control and obtain authority over services, supports, and resources.

Personal stories are powerful. When told effectively, our personal stories hold people's attention, trigger feelings, and are memorable. As a result, learning how to tell your personal story to a variety of audiences is **one way to begin to exercise control and obtain authority over services, supports, and resources.** We all have a lifetime of stories, so it is helpful to think about them as chapters or snapshots. We can also have different versions of a story depending on the audience and what we are trying to accomplish. For example, if a person is telling a story to a family member, he may highlight different parts of the story than when he is telling the same story to his doctor or his boss.

The National Gateway to Self-Determination (NGSD) developed a training to help people learn how to tell their stories called **SUCCESS** in Telling Your Story. SUCCESS focuses on the six elements of a well-told story: Simplicity, Unexpectedness, Concreteness, Credibility, Emotions, and Stories. The goals of this training are to talk about why it is important to tell our stories, who we tell our stories to, and what makes a good story. We also spend time telling and listening to personal stories.

Pam, from Longview, Texas, participated in the SUCCESS in Telling Your Story training and went on to tell a story from her life about the steps she took to get guardianship over herself and how being her own guardian has changed her life. You can watch the video version of her story at the NGSD YouTube channel: http://youtu.be/RLwQtanzV0A.

Below is Pam's story in her own words.

"About five years ago my dad had passed away. My dad was my Guardian. And every time I had to go somewhere I had to call my guardian. If I wanted to go and spend money, I had to go and call my guardian. When he passed, I decided to go and get guardianship. I went and I saw a lawyer about it and went to court and the judge asked me if I knew my medications and I knew the medications. He asked me if I knew anything about money. He held up a dollar bill and I told him what it was. He held a five dollar bill up. You know he showed me several bills and he said, "Who told you that you need a guardian? You don't need a guardian. You need full guardianship." And he gave me guardianship over myself.

(When people have guardianship over themselves) they can make decisions if they want to go places. They can make decisions about buying stuff. They can make a difference in somebody's life. I lived in a group home for 11 and a half years or 12 and I decided I didn't want to live in a group home any longer. So I moved in with my aunt and my aunt does foster care with me. And she is a nurse and so if I get sick I got a nurse to take care of me. And it's been great living in her home and going when I want to. (Now) I can buy my own clothes. I can go as I want. I can date when I want to. . . . Anybody that would love to be their own guardian I would recommend it."

By learning how to tell her story, Pam became more self-determined and became her own guardian!

Design a storytelling session for your group!

SUCCESS in Telling Your Story has been a tremendously successful program. Visit the National Gateway to Self-Determination website (www.aucd.org/ngsd) to download the SUCCESS in Telling Your Story Training Manual developed by George Gotto at the UMKC Institute for Human Development. Contact George for more information at: gottog@umkc.edu.

Below is an outline to get the stories going in your self-advocacy group!

Steps to Helping People tell their Story

1. Talk about why we tell our stories.
    a. They help us to make friends.
    b. They express our self-determination:
        i. Allow us to describe what we want to happen in our lives.
        ii. A platform to explain our preferences and choices.
        iii. Help us describe our decisions.
    c. They can empower the storyteller and the audience.
    d. They can make a difference to individuals, systems, and organizations.
    e. They help others learn about us and our everyday lives.

2. Talk about who we tell our stories to, our audience.
    a. Family and friends.
    b. Community members and organizations.
    c. Policy and systems (decision makers, elected officials).

3. Talk about the elements of a well-told story.
    a. Keep it simple.
    b. Unexpectedness, surprise people if you can.
    c. Be clear and use concrete examples.
    d. Establish your credibility, tell the audience something about yourself.
    e. Use emotions, making people feel something during your story helps them to remember it.
    f. Tell a story, don't just give facts or history, give details that make your story come alive.

4. Listen to others telling their story.

5. Practice telling your story.

6. Visit the National Gateway to Self-Determination website to watch videos of self-advocates telling their stories (www.aucd.org/ngsd).

creating a framework for community participation

The 2010 SABE National Conference focused on self-determination. One key-note event celebrated the life of Eunice Kennedy Shriver. Community participation and living lives of full inclusion was a key focus of her legacy. Over 800 self-advocates, supporters, and professionals joined hands in a moment of remembrance.

Project STIR Classes Result in Community Participation and MORE!

People with developmental disabilities often lack the opportunities to learn to advocate, develop leadership skills, and participate in their communities, not to mention the opportunity to make everyday choices or express their preferences. As a result, they often have limited leadership and choice-making skills. In recognition of this problem, the Adair County SB40 Developmental Disability Board and the Kirksville Regional Office for the Missouri Division on Developmental Disabilities sponsored a training program called **Project STIR** (Steps Toward Independence and Responsibility, developed at the UNC Carolina Institute for Developmental Disabilities). The purpose of this program is to empower people with developmental disabilities, their families, friends, and other supporters, by providing the practical "how to" tools necessary for anyone to make choices and decisions about how they live their lives.

A total of 26 people with developmental disabilities completed the Project STIR curriculum in Adair County during 2011. Within a year of graduating from the program, these self-advocates compiled an impressive list of achievements through their own efforts in self-advocacy and self-determination. Though their successes cannot be attributed solely to having completed Project STIR, these self-advocates have certainly utilized all they learned about communication, problem-solving, rights and responsibilities to accomplish a long list of accomplishments in a short time (see list on page 37—some individuals are included in more than one category).

For a complete description of Project STIR please visit the following website.http://www.mo-sda.org/project-stir.

Successful Outcomes from Project STIR Classes

Great Demonstrations of Self-Determined Action!

5 have begun jobs **in the community.**

1 has **begun his own business.**

2 volunteer regularly in the community.

1 presented on competitive employment with his boss at the 3rd Annual Disability Day Conference at Truman State University in October 2011.

11 attended the 2011 Real Voices, Real Choices conference and participated in a presentation on Project STIR (for most, it was the first conference they ever attended).

3 presented information about Project STIR and self-determination for persons with developmental disabilities on a morning talk show on a local radio station.

2 have been elected officers for their People First group.

1 was appointed to **serve on the Region II Advisory Council.**

1 volunteered and assisted in teaching the second Project STIR class.

3 have begun **actively seeking to reduce level of guardianship.**

7 are actively serving on a **self-advocates advisory committee** to work with TSU students to develop a follow-up curriculum for Project STIR grads, to provide more practice and real life application of the skills taught in Project STIR.

2 are actively serving with other community representatives on a Participatory Action Research advisory group in connection with UMKC Institute for Human Development to explore attitudes toward self-determination found in provider agency staff of Adair County.

1 successfully **advocated for major changes in her life**. She convinced her guardian to allow her to choose a new provider agency and to reduce the hours of support staff in her home from 8 hours per day to less than 8 hours per month. She has lived successfully with the reduced level of support since July 1, 2011.

1 has obtained her learner's permit to drive.

1 applied and was selected by Habitat for Humanity to receive a fully accessible Habitat Home to be built this year for her and her husband.

3 have begun dating relationships.

~ Deb Wohlers, Director, Adair County SB40 DD Board

Community Participation through Employment

The Self-Determined Learning Model of Instruction was first developed for educators to enhance self-determination by empowering students. A later version, the Self-Determined Career Develpment Model, focuses on career and employment goals. This could be the basis of a great activity for self-advocacy groups!

Self-Determined Career Development Model Activity!

Individuals who already have employment can use this activity to re-visit their current life plan. They can also help those individuals who don't yet have employment. The following briefly describes the phases of the model and some examples of how it might be used:

Phase 1: "What are my career and job goals?"

A. Group members identify a few different jobs that might interest them - that are in line with their strengths and needs related to a job.

B. Talk together about these options and help each member to put them in order of preference. Talk about what the individual would need to change in order to get the job they want.

C. After identifying a job of choice, each individual then will develop job related goals:
   i. write down the goal, making it specific and measurable,
   ii. identify specific objectives that can be tracked,
   iii. set a starting date,
   iv. take ownership of the goal, express the goal in a positive manner, and make sure the goal is attainable.

An example: *After thinking about things that interest her, Lucy decided to look for a job helping in an office. After writing down the goal she then decided to set a start date and to tell people that this is what she is working toward.*

Phase 2 continued on next page!

Phase 2: "What is my plan?"

A. Develop a plan to see if you are working toward your goal. Discuss barriers and make a specific plan of how to remove these.

The same example continued: *Lucy develops her plan to achieve her goal. She identifies the following barriers:*

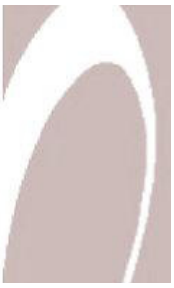
Barrier: *She realized that she needed some more practical skills. Two other people in her self-advocacy group were also interested in similar employment, so the group decided to spend two meetings learning office skills. Together the group and the advisor made a list of office skills and they chose two specific skills to teach the group: sorting mail and making copies. They were lucky enough to hold their meetings in a setting where they could use the copy machine and the staff mailboxes.*

Barrier: *Once she has skills, how does she find a job? Lucy makes a plan to talk to her family and her support team to see if they have some ideas. Lucy realizes that her neighbor's church might need a part-time person to work in the office. Lucy now has specific office skills and asks her neighbor who she should call. Lucy was able to follow through and get the job.*

Phase 3: "What have I achieved?"

Participants evaluate progress toward their goal and make changes to their plan as needed.

Example continued: *Now that Lucy has the job she is happy to be more involved in the community. She has a whole new group of friends that support her. She has increased her social capital. Her employment plan is to learn new skills to be even more help in the office.*



As a "strategic "goal about 10 years ago, our members decided that they needed to be at the tables where decisions were being made about them. Members now serve on 20+ boards and committees. At our monthly meetings, they report on their activities and solicit issues from self-advocates. ~ an advisor

For More Info...

Ten Steps to Independence: Promoting Self-Determination in the Home. Wehmeyer, David, Palmer. (2010). National Gateway to Self-Determination, www.aucd.org/ngsd.

National Gateway to Self-Determination Project Highlights. National Gateway to Self-Determination, www.aucd.org/ngsd.

Research to Practice in Self-Determination Series, Issue 2: Self-Determination and Employment. Editors: Calkins, Wehmeyer. National Gateway to Self-Determination, www.aucd.org/ngsd.

Self-Determined Career Development Model. Wehmeyer, Lattimore, & Palmer. 2003. http://www.aucd.org/NGSD/template/product_view.cfm?id=16.

creating a framework for self-advocacy & leadership

Last, but certainly not least, on the DD Act's list of self-determined activities we find:

> has the support, including financial, to advocate, develop leadership skills, become trained as a self-advocate, and participate in coalitions and policy-making.

Self-advocacy is **the heart and soul of the work of self-advocacy organizations** --- to advocate, to lead, and to participate! The other DD Act self-determined activities can easily fall into this last item. If a person is more self-determined because they have a job, then they have successfully advocated for themself. If a person is involved in a community organization, then they are partipating and advocating.

Self-advocating skills may easily be the best demonstration of self-determined action. As we noted earlier, self-determination refers to actions that enable a person to be a causal agent in his or her life; **to make or cause things to happen.** That is exactly what we are doing through self-advocacy activities! Having a voice in the decisions that affect your life through self-advocacy is exactly acting in a self-determined way. **A strong self-advocate causes things to happen to make his or her life better!**

Just as with choice-making and community participation, **self-advocacy and leadership skills can be learned and taught.** Self-advocacy skills do not necessarily come naturally to people. It is important to TEACH individuals how to be strong self-advocates. There are four self-advocacy skills that enhance a person's self-determination: assertiveness, rights and responsibilities, communication, and leadership. The table at the top of the next page describes these in more detail.

> Finding ways to empower both individual people and the collective group, while staying in the background in a support role, is a difficult art demonstrated by the very best advisors.
>
> *~Sharon Lewis, Commissioner, AIDD*

Self-Advocacy Skills that Lead to Self-Determination

Self-Advocacy Skill	Description
Assertiveness	The ability to communicate an opinion and defend personal rights in a way that enhances mutual respect and minimizes potential conflict.
Rights & Reponsibilities	Expressing one's rights is the core element of assertive behavior. People should know their rights and the accompanying responsibilities.
Communication	Includes conversation skills, listening skills, and body language skills. Developing these skills enhances the ability to be an effective self-advocate.
Leadership	Leaders guide or direct others on a course of action, influence the opinions and behaviors of others, and behave as an example.

"Beyond Tokenism: Partnering with People with Diverse Abilities On Consumer Advisory Boards" was created for use with Consumer Advisory Boards, yet a lot of the material can be helpful for advisors of self-advocacy groups as well.

As you advise and partner with self-advocates, remember these points:

- ✔ Don't make assumptions about what someone can and cannot do.
- ✔ Don't keep someone "in the box." Let them explore all their ideas - don't squelch something because you think they can't accomplish it.
- ✔ Don't see someone as their disability - look at the whole person.
- ✔ When partnering with someone who has a personal care assistant, make sure you talk to the individual and not their assistant.
- ✔ Self-advocates have credibility.
- ✔ We all have diverse abilities and valuable expertise gained through our life experiences.
- ✔ Learn how each member likes to learn, communicate, and participate so that you can effectively involve them.
- ✔ Always ASK! Don't ASSUME! Ask if someone wants your help. Ask if someone wants to participate. Ask and give choices. This goes for the group as well - work together on group priorities, preferences, goals, etc. **Don't assume that you know what the group wants.**
- ✔ Advisors and self-advocates need to check-in with each other on a regular basis!

Use a Variety of Materials

There are many publications available that have a **different target audience or goal**, and yet have great ideas that can help an advisor and self-advocacy group work together. These two pages present just a few more resources that can be effective. The resource section at the back has even more great ideas.

"Guidelines for Building Partnerships with Self-Advocacy Organizations"

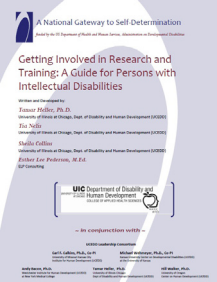
"Guidelines for Building Partnerships with Self-Advocacy Organizations" is just one example of a useful resource with a different target audience. While the purpose of these guidelines is "to help professional organizations, such as as Protection and Advocacy agencies, to form genuine partnerships with state and local self-advocacy organizations," there are many great tips about working with self-advocacy organizations:

- ✔ Communication and trust must be developed together.
- ✔ At first, self-advocacy leaders may be reluctant to question things that are said.
- ✔ Use straightforward language and materials.
- ✔ Ask everyone if they understand what something means. Don't put one person on the spot.
- ✔ Involve self-advocates at all levels of plannning. Don't assign someone a task, instead review all the options and invite individuals to take the role that they want.

For more great ideas, this resource, developed by the National Technical Assistance Center for Voting and Cognitive Access can be found at: http://sabeusa.org/user_storage/govoter/ResourceClearinghouse/PDF/GuideforPartneringwithSelf-AdvocacyOrgs8-5-05.pdf.

As advisors, we are crucial in empowering self-advocates to find their voices to speak out on personal and societal human rights issues affecting their lives.

Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities


A National Gateway to Self-Determination

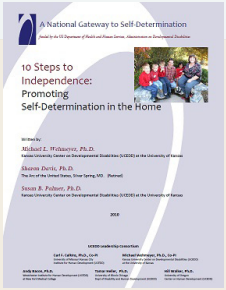
Getting Involved in Research and Training: A Guide for Persons with Intellectual Disabilities

This is a newly created resource by the team at the University of Illinois at Chicago Department of Disability and Human Development. As a result of the rapid growth of the self-advocacy movement, professionals and individuals with disabilities are working together more and more. This guide gives great ideas about how self-advocates can get more involved in research and training activities, including:

- ✔ Things you do to to help with a research project: give information, be a subject, help design, and more.
- ✔ Examples of ways self-advocates have been involved: participatory action research, interviews, trainings.
- ✔ What you need to know before working on a research project: getting support, feeling comfortable.

This product is available at http://aucd.org/NGSD/template/link.cfm.

10 Steps to Independence: Promoting Self-Determination in the Home


A National Gateway to Self-Determination

10 Steps to Independence: Promoting Self-Determination in the Home

This is a great, quick resource that can give an advisor some excellent, straight-forward approaches, including:

- ✔ Exploration: Find opportunities for self-advocates to have the independence to explore options.
- ✔ Emphasize Abilities: Encourage everyone's unique abilities.
- ✔ Goal Process: Recognize the process of reaching goals, not just the outcomes.
- ✔ Choice: Don't leave choice-making opportunities to chance. Take every opportunity to allow the self-advocate to make choices.

This product is available at http://aucd.org/NGSD/template/link.cfm.

Boards for All

Boards for All, a collaborative project of the California State Council on Developmental Disabilities and the Eastern Los Angeles Regional Center, is a webcast training series about the functions of effective councils, board of directors, and committees. This traing has won an Award of Distinction from the Center for Plain Language, honoring the best in clear communication and plain language, celebrating documents and web sites from government, non-profits, and private companies that succeed in communicating clearly.

To access this training series click on the following link http://www.scddadvocacy.org/SCDD_Board_Training/index.shtml.

effective advisors in action!

The following two pages provide some great examples of how effective advisors helped self-advocates live in a more self-determined manner.

How did your advisor help you learn about setting goals?

- They helped us understand that getting what we want requires planning and setting goals in order to make it happen.
- Our chapter sets goals and the advisor is there to help.
- Sets goals as whole organization, not individually.
- We try to meet our goals every day. We also talk about certain goals we are meeting about on a daily basis.

How did your advisor help you learn about being independent?

- They always help us advocate for more independence.
- They helped us have the confidence in ourselves to make decisions and accept the results of our decisions. They encouraged us to think about what we want and what we think about things.
- By fighting for our rights.
- My personal goal has been helped very much by my staff and with resources she has shown me.
- They helped me understand my sister has a choice about not going to a nursing home.

How did your advisor help you learn about self-advocacy?

- They helped us learn how to speak up for ourselves about issues we believe in. We gained confidence in ourselves in order to do so. Getting confidence is hard and sometimes takes a long time to achieve.
- We learned to speak up for our rights and feel more included.
- We received training and attended workshops.
- We constantly discussed concepts in meetings and had opportunities to practice.
- We helped people find their own houses.
- We learned how to stand up for ourselves and speak for ourselves.
- Speaking out for myself is very important and my advisor helped me to see myself as a person and feel proud and self-confident.
- By teaching us about dependency we learned how to advocate for ourselves to overcome dependency.
- They really assist us to educate each other. They support peer to peer connections.

An effective advisor supports officers in planning and organizing. The advisor's role varies depending upon the support needs of the membership, but is always supportive, involving officers and members in processes and remaining constantly vigilant for opportunities to transfer responsibility.

How did your advisor help you learn about making choices and decisions?

- ✔ Supported me in going to the Capitol to talk about the community living choice.
- ✔ They helped us recognize and identify our options and helped us examine the good points and bad points about each option so we could make choices. And then they supported that decision.
- ✔ They give you good information first about what you are deciding on.
- ✔ I trust my advisor enough to ask questions about problems I am having. He helps me understand different issues so I can make good choices.
- ✔ I think it is important to be able to make our own choices but I also think along with making our own choices we have to learn the consequences for them.
- ✔ An effective advisor imparts information he/she may have to offer in understandable ways so that the group can make as well-informed decision as possible.
- ✔ He/she helps people identify places/people to whom they can go to get information so that they're making an informed choice.

How did your advisor help you learn about leading?

- ✔ Our group has a Board with Co-Presidents, Co-Vice-Presidents, etc., so that twice the number of people get leadership experience and can represent the group.
- ✔ Show them what is available in their communities, use internet or local DD networks that are willing to help. Have the president run the meetings, the secretary read and take minutes, and the treasurer share the report. Advisors should sit amongst self-advocates.

An effective advisor interacts with self-advocates as he/she would with other professional colleagues. An effective advisor doesn't condescend, coddle, or control. An effective advisor asks questions rather than squelch ideas. "If we have the car wash in the rain, do you think we'll have many customers?"-as opposed to- " We should cancel the car wash; we won't have many customers on a rainy day."

effective self-advocacy groups in action!

Self-advocates participate in a restrictive housing demonstration in Alabama. They are acting in a self-determined way to let their voices be heard regarding their housing preferences.

Alabama:
Alabama is one of the oldest self-advocacy organizations in the nation and began in 1987. People First of Alabama led the charge in CLOSING INSTITUTIONS in Alabama since 1996. The last one closed in December 2011. Through the leadership of People First of Alabama, the state legislature passed a Respectful Language Bill and advocated for the removal of the “R" word from the state department providing services to individuals with developmental disabilities.

Rhode Island:
Rhode Island Advocates in Action hosts statewide conferences every year and in 2000 the statewide organization co-hosted the National Self-Advocacy conference with SABE. More than 1,200 people attended. The statewide organization coordinates a year-long Leadership Series training for individuals who have a developmental disability, families and support staff. Class members learn leadership skills, including public speaking and facilitation skills. The "This is Us" disability awareness experience is shared with schools, colleges, businesses, support agencies and others throughout the state.

Vermont
Vermont’s Statewide organization, Green Mountain Self Advocates, took the lead in getting Vermont’s Respectful Language Bill passed as a member of Vermont Coalition for Disability Rights. Leaders continue to do peer-facilitated trainings using our curriculums on 1. Sexuality Education for People with Developmental Disabilities; 2. Recognizing and Responding to Abuse; 3. Getting Your Message Across: Making Communication Cognitively Accessible; and 4. Working with Think College Vermont - a great example of full inclusion.

effective self-advocates in action!

Hearing stories from other self-advocates about how they learned to advocate and lead more self-determined lives makes this real!

NATIONAL GATEWAY TO SELF-DETERMINATION

MARCH 2011

Research to Practice in Self-Determination

Issue I: Self-Determination and Self-Advocacy

LEARN ABOUT:

The Link Between Self-Determination and Self-Advocacy

Sliding Perspectives on Self-Advocacy

The Steps to Building Social Capital

Moving Beyond Tokenism

Research to Practice in Self-Determination Series

Introduction

The first issue in the National Gateway Research to Practice in Self-Determination Series is devoted to self-advocacy. This issue (Research to Practice in Self-Determination Series, Issue I: Self-Determination and Self-Advocacy) can be found on the Gateway's website at: www.aucd.org/ngsd.

Throughout this issue, there are great stories of how individuals learned to become stronger, more effective self-advocates. Nancy Ward, Chester Finn, Tia Nelis, and Bryon Murray are self-advocates from the NTI SABE Self-Determination Committee. Here are some glimpses into their stories from the article "Self-Advocates Leading Self-Determined Lives."

Tia: I was worried about discrimination when I first got into self-advocacy. I saw people in the professional role and thought they knew best. When I was younger, I didn't disgree with them even if they were wrong.... My first time "protesting" was when I was in a meeting, and I was told to stand up and talk about something. The teacher kept interrupting me and I finally told her to be quiet! We had to teach her how to let us do things on our own. Self-advocacy helped me learn how to communicate my opinions and needs in a positive way. I went from being a local self-advocate to the national level. If I can do it, anyone can.

Nancy: Because our state was one of the first to develop a self-advocacy organization, I didn't have role models. It took me five years to gain the confidence **through practicing speaking up for myself** and not being afraid to ask for support. I learned how to speak out for myself and I have done so all over the country and the world for decades now. I never dreamed that my life would be what it is... and be a part of the self-advocacy movement. My experience has allowed me to go to seven different countries and advocate for people with disabilities all over the world.

Bryon: I was encouraged to participate in committees at the state level because someone pushed me to do it. It took me years to realize I was capable of not only advocating for myself but also being able to advocate for everyone with a developmental disability across the nation.

Chester: I went from a group of four to being the President of our state organization to serving three terms as President of SABE. Part of that was due to working as a self-advocate and working for the state governor and commissioner. I learned through work to advocate for myself. It just became a part of my life. I was able to testify at an appropriations committee. That was the night the DD Act was passed. I just talked about people's lives and that people didn't want to go to institutions. The committee had information from professionals, but they needed to hear from somebody talking about their real life.

These stories show that each of these self-advocates needed some support and encouragement to get where they are today. They note that their best supports came from other self-advocates who are great mentors.

Check out the entire issue for more articles and stories of self-advocacy in action!

Mentoring! A terrific and effective way to incorporate the sentiment of these stories might be for advisors to set up mentors within the group. Teaming up experienced self-advocates with newer self-advocates would be a great way to tap into this potential.

social capital web

organizing YOUR social capital network

The National Gateway to Self-Determination has created a new tool to help individuals and groups intentionally organize and expand their social capital. Social capital consists of the formal and informal support networks that provide you with access to resources. It is the set of relationships and social ties to individuals and organizations that expand your choice-making opportunities, increase your options, and lead to an improved quality of life.

The Social Capital Web is a simple activity that gives a visual picture of the connections in someone's life, which can then be translated into the connections and capital that a group has as well.

We all have greater social capital than we think. Before we begin to intentionally increase our social capital, it's helpful to get a picture of the social capital that we already have!

This exercise will help you get a clearer picture of the people in your life that provide you with the support you need. You will also get a picture of the people in their lives, who in turn are probably willing to help you when needed.

1. Inventory! Make a list of people in your life and group by area identified below. List only a name or two in as many areas as you can—by choosing a few from a variety of areas, we can identify a larger, more diverse, and effective social capital network, instead of ending up with a number of people all with the same network.

A. Family, Friends, and Neighbors
B. Church, Groups, and Memberships (book clubs, health clubs, music groups, etc.)
C. Work
D. Support (support groups)

Don't forget people you interact with on a less-often basis! The person who cuts your hair, your auto mechanic, your piano teacher, the choir director at church…..

2. Interview! Get together with each person on your list and "interview them." Learn their story.... who are the people in their life? What are they interested in? How might they be able to help you or your self-advocacy group? Don't look for something specific - don't go into the interview thinking "I need to find someone who can help me with our financial records." Instead, just listen and **begin to see a picture of the web of connections that you are developing!**

3. Develop! Develop your own Social Capital Web. After you've interviewed the people listed on your inventory, now begin to draw a visual picture of your social capital web! **(See Jane's example on the next page.)**

4. Expand! Finally, get together with your self-advocacy group and compare your webs. You might begin to see some common connections, and you might begin to see how you can use your social capital for projects, activities, and advocacy!

A full copy of this tool, along with pages to help "fill in the blanks," can be found at: www.aucd.org/ngsd.

jane's social capital web

Family, Friends, Neighbors

Family
Claire (daughter) is a high school student and volunteers at the local children's hospital. She can always find a group of teens to volunteer at events.
Bruce (husband) works at a library. They often have events promoting English as a second language.

Friends
Rhonda: Works in a local small business. Owner is very supportive of community organizations.
Spouse's Job: Fred works in a health care administration organization. He is always willing to help out!
Other connections: Their neighbor is on the city council and is always interested in safety issues.

Neighbors
Linda: Both she and her husband Bob are nurses. They would be interested in presenting a class on being healthy.

Church, Clubs, Groups

Church
Choir Director, Bill, directs a local community choir that often gives concerts to raise funds for charitable organizations. They might sing for an event supporting our group!
Spouse's Job: Laura, an artist, loves to paint. She might paint a picture that we can use on our poster or raffle off at an event.

Book Club
Pam
Job: High School Counselor
Interests: Gardening—would love to help develop a community garden.

Hair Dresser
Lana: her husband works in construction.

Work
Joe is a teacher.
Interests: Dogs. Would love to look into service animals.

Jodi
Interests: Loves to cook. Would be more than willing to cater an event.

Business Organizations
Main Street Business Women's Club: focus is on educating young women about career options.

Support
Dr. Lisa
Interests: Has college age kids. Might be interested in working with youth with disabilities.

School Counselor
Ann
Is Claire's school counselor and is active in high school sports.

Now apply your social capital to solve a problem or design an activity!

Our self-advocacy group wants to create a community project to build a gazebo and plant a garden in a local park. What kind of social capital do we have that will help develop this project?

Pam from Book Club loves to garden and mentioned developing a community garden.

Rhonda's neighbor is on the city council and might be able to help with building permits and approval process.

Lana's husband works in construction. We can contact him to see if he can help with design and construction. Maybe his company would be willing to donate supplies or give a good price.

Claire's friends from high school are always willing to volunteer with community groups. They can help with the actual planting of the garden.

Laura is an artist and will help paint the signs for the garden and gazebo.

university of illinois at chicago research study

A team from the University of Illinois at Chicago Institute on Disability and Human Development decided to do a study in order to learn more about the important issues concerning advisors to self-advocacy groups. It's also interesting to learn how a research study is designed!

Approach: The input of experienced self-advocates and advisors is important in understanding the role of advisors in self-advocacy because they provide rich, first-hand information and perspectives based on their experiences. We hoped to gain a better understanding of the interactions between self-advocates and advisors from the perspectives of those involved.

Participants: To recruit participants for this study, we asked members of the executive leadership boards of Self-Advocates Becoming Empowered (SABE) and the National Youth Leadership Network (NYLN) to nominate potential participants who met our eligibility criteria for each group. We have recruited 12 participants for this study: four youth self-advocates (between the ages of 18 and 28), four adult self-advocates (with at least 10 years experience in self-advocacy), and four "effective" advisors (with at least 5 years experience advising self-advocacy groups).

Research Questions: We aimed to answer the following questions.

- How do self-advocates and advisors define the role of an advisor?
- What formal and informal training do advisors receive?
- What are the barriers advisors and self-advocates encounter while navigating a relationship of providing and receiving support?
- How can self-advocates and advisors be better supported?

Methods: Qualitative interviews were conducted with participants over the phone and face-to-face. The interviews lasted between 30 minutes to 1 hour and were audio recorded, transcribed into hard copy, and coded. Participants were asked to choose a name that we would use for them throughout the study to protect their identity and confidentiality. This research project was approved by the University of Illinois at Chicago Office for the Protection of Research Subjects (approval #2011-0760).

Research Team: The research team consisted of two researchers: a graduate student in a disability studies program and a self-advocate with experience participating in research activities. The self-advocate researcher was a founding member of the self-advocacy movement and has significant experience working with advisors and self-advocacy groups.

What we have learned so far: While our research study is still in progress, here are some initial findings of ways advisors may provide better support to self-advocacy groups.

1. **Set Clear Expectations and Check-In Often:** Many of the people we interviewed emphasized the importance of establishing clear expectations of advisors and group members early on and checking in with each other on a continuing basis.

   "So I think that the advisors should go in clearly stating it, 'If I'm not doing what you need me to do, please let me know and I'll step back. And I'll do something else if this is not what you want me to do.'"

   "I think it's important to sit down with that person every 6 months to say 'Is this working?' What's not working? What can we fix? What can we do differently? You know, just like in a marriage, just like in a friendship, just like with co-workers, we just forget to take the time to sit down and say... How can we make this better? How can we be stronger as a team?"

2. Group Belongs to Self-Advocates: The advisor plays a major supporting role in much of what the group does, but the group belongs to self-advocates. This means that group members decide the group's mission, agenda, advocacy activities, and positions on issues. The role of the advisor is to support the group in developing and fulfilling their mission and goals without inserting their own opinion or agenda.

"My job has always been enhanced the more I get out of the way, the people take the lead. And I take the view that their organization, I'm here to support."

"I think it's a philosophical thing that people have to have, more than a specific skill or anything. It's that understanding that this is not my group, this is the self-advocates' group…[Self-advocates] have to be the leaders and they have to be the people who are speaking. And if you are not directly affected, you need to be in the back-ground, in an organizing role, you do not need to be up front."

As one self-advocate put it, *"Let the chapters run the meetings."*

3. Defer to Self-Advocates: When in meetings, advisors should defer to self-advocates as much as possible to answer questions and participate in the discussion.

"Sitting on state and national boards, being asked to give state and national testimony and it's a very powerful place. And sometimes support staff get sucked into that power vacuum. And they forget that it's not them who was invited to the table, but rather the self-advocate. And that when they're in that professional role, they need to defer to that self-advocate. And when people ask about a policy issue, the support staff, when they're in that professional role, need to defer to the self-advocate."

4. Technology: Participants suggested that in the future, the self-advocacy movement will rely more heavily on technology for many advocacy activities.

"For the youth in our different groups, they all want me to text them. They don't want a long conversation, they want a quick text, an answer to their question, and bye, see you later. Whereas some of the other folks, they want to keep you on the phone for a really long time and they're not aware that they've been on for an hour and you need to do something else. But the youth are very aware. They want quick answers and want to be quickly satisfied with what's going on. A lot of the youth use Facebook and a lot of the other older folks either they're afraid or their families are afraid for them to even try it. And we can't even talk them into letting them to having an account. And that's why we're trying to get more people on Yakkit.org, but a lot of our other folks, they don't have computers, they don't know how to use them, they don't know what a great resource it is, and they're terrified of them. Whereas the youth, "where can I find it on the web?" "What are you talking about?" "Send me an email about it," or "Send me a text," or "Send me a Facebook message," you know, and its all about that."

5. Enjoy It! Our participants told us that the best advisors enjoy what they do and have fun doing it. Advisors can help boost morale and camaraderie within the group.

"I mean, its amazing, like you could be doing really boring work. We were working on bylaws. Boring! But, you know, if you just make it fun, and you crack some jokes or things, then people can enjoy even something as boring as bylaws. So, maybe that's just having that attitude of absolutely, it's important work, but it can always be fun. And recognizing that having fun doesn't make the meaning any less."

"But you know, part of that role is having fun with people. I mean, part of being an advisor is being part of the group. I mean, you have a different role, maybe, then being a self-advocate, but you're part of the group, and having fun and enjoying and being part of the camaraderie is important, you know, I mean, you're not some stiff person that's been asked to help something and you're some expert or something."

general resources

(For ease of use, resources are listed with title first, followed by authors, and web details on how to locate them.)

Accessing Social Capital: Implications for Persons with Disabilities. Gotto, Calkins, Jackson, Walker, Beckmann. (2010). National Gateway to Self-Determination, www.aucd.org/ngsd.

Beyond Tokenism: Partnering with People with Diverse Abilities On Consumer Advisory Boards. Stevens, Ibañez. (2004) Center for Development and Disability, University of New Mexico (CDD). http://www.aucd.org/docs/ucedd/cac_walker060107/a6_beyond_tokenism.pdf.

Consumer Advisory Committee Orientation Curriculum. Walker, L. (2007). Silver Spring, MD: Association of University Centers on Disabilities.

Envisioning the Future: Allies in Self-Advocacy Report. Caldwell, Arnold, Rizzolo. (2011). Institute on Disability and Human Development, The University of Illinois at Chicago.

Exceptionality, Special Issue: Promoting Self-Determination. Routledge. Volume 19, No. 1, Jan 2011.

Getting Involved in Research and Training Projects: A Guide for Persons with Disabilities. Caldwell, Arnold, Rizzolo. (2011). Institute on Disability and Human Development, The University of Illinois at Chicago. National Gateway to Self-Determination, www.aucd.org/docs/GettingInvolvedinResearch.pdf.

Guide for Creating Cognitively Accessible Language. The National Technical Assistance Center for Voting and Cognitive Access. www.govoter.org.

National Gateway to Self-Determination Project Highlights. National Gateway to Self-Determination, www.aucd.org/ngsd.

People First Language, the Basics. Self-Advocates Becoming Empowered. www.sabeusa.org.

Person-Centered Planning: Finding Directions for Change Using Personal Futures Planning. Mount, Beth. 2000. Amenia, NY: Capacity Works.

Promoting Self-Determination for Adults: A Practice Guide. Vatland, Strickland-Cohen, Lowman, Doren, Horner, Walker. National Gateway to Self-Determination, www.aucd.org/ngsd.

The role of the advisor is to support self-advocates in being a successful group. I am there to help give information about things the group wants to do, to help direct them, and support them in the activities they chose to do, to help them try and most times succeed!

Research to Practice in Self-Determination Series, Issue I: Self-Determination and Self-Advocacy. Editors: Calkins, Wehmeyer. National Gateway to Self-Determination, www.aucd.org/ngsd.

Research to Practice in Self-Determination Series, Issue 2: Self-Determination and Employment. Editors: Calkins, Wehmeyer. National Gateway to Self-Determination, www.aucd.org/ngsd.

Self-Advocacy and the Advisor Role. Collins. (2011). Institute on Disability and Human Development, The University of Illinois at Chicago.

Self-Advocacy Movement: The Unacknowledged Civil Rights Movement. Hayden. (2004). National Institute on Disability and Rehabilitation Research.

Social Capital Web: Organizing Your Social Capital Network. Calkins, Beckmann. (2012). National Gateway to Self-Determination, www.aucd.org/ngsd.

Ten Steps to Independence: Promoting Self-Determination in the Home. Wehmeyer, David, Palmer. (2010). National Gateway to Self-Determination, www.aucd.org/ngsd.

What Is Self-Determination and Why Is It Important? National Gateway to Self-Determination, www.aucd.org/ngsd.

What Is Self-Determination and Why Is It Important to People with Developmental Disabilities? Wehmeyer. National Gateway to Self-Determination, www.aucd.org/ngsd.

www.sabeusa.org

Check out this web site for a great way to connect with other self-advocacy groups and advisors!

training materials & curricula

(For ease of use, resources are listed with title first, followed by authors, and web details on how to locate them.)

Boards for All. California State Council on Developmental Disabilities.
http://www.scddadvocacy.org/SCDD_Board_Training/index.shtml

Future is Now: A future planning training curriculum for families and their adult relatives with developmental disabilities. Factor, Debrine, Caldwell, Arnold, Kramer, Nelis, Heller. (2010).
Chicago: Rehabilitation Research and Training Center (RRTC) on Aging with Developmental Disabilities: Lifespan Health and Function.

It's My Future! Planning for What I Want in My Life, A Self-Directed Planning Process. Bolding, Wehmeyer, Lawrence. http://www.aucd.org/docs/Its%20My%20Future.pdf.

Lifebooks, "Here I Am! A Lifebook Kit For Use With Children With Developmental Disabilities." Schroen, Halleen.

Partners in Living. The Minnesota Governor's Council on Developmental Disabilities.
http://www.partnersinpolicymaking.com/living/

Partners in Policy Making.
http://www.partnersinpolicymaking.com/

Project STIR (Steps Toward Independence and Responsibility). Zuver. The Carolina Institute for Developmental Disabilities. http://www.cidd.unc.edu/education/default.aspx?id=30

Self-Determination, Tools for Direct Support Staff, Respect, Choice, Decisions, Family. Thorin. Iris Media Inc, www.lookiris.com

Self-Determined Career Development Model. Wehmeyer, Lattimore, & Palmer. 2003.
http://www.aucd.org/NGSD/template/product_view.cfm?id=16

SUCCESS in Telling Your Story. Gotto, G. 2012.
National Gateway to Self-Determination, www.aucd.org/ngsd.

training materials developed by self-advocacy groups

All About Groups. SANYS (Self-Advocacy Association of New York State).
http://www.sanys.org/AllAboutGroups22007web.pdf

Boardsmanship: Inclusive and Accessible. People First of California.
http://www.peoplefirstca.org/PDF/boardsmanship%20English-FINAL.pdf

Communication. Florida Grassroots Self-Advocacy. http://floridaselfadvocacy.com

Guide to Becoming a Qualified People First Helper/Advisor: People First of California.
http://www.peoplefirstca.org/tool_box.html

Guidelines for Building Partnerships with Self-Advocacy Organizations. National Technical Assistance Center for Voting and Cognitive Access. http://sabeusa.org/user_storage/govoter/ResourceClearinghouse/PDF/GuideforPartneringwithSelf-AdvocacyOrgs8-5-05.pdf

I'm a Person First, My Disability Comes Last: The Arc of New Jersey.
http://www.arcnj.org/programs/self_advocacy.html

Introduction to Self-Advocacy. Florida Grassroots Self-Advocacy. http://floridaselfadvocacy.com/

Peer-to-Peer Get Together Guide. People First of California
http://www.peoplefirstca.org/PDF/PFCA%20Peer%20to%20Peer%20Handbook%202011.pdf

People First Community Services Inclusion. People First of California.
http://www.peoplefirstca.org/PDF/CSO_English_web.pdf

People First Youth Handbook: People First of California.
http://www.peoplefirstca.org/PDF/Youth%20Book%20Final%20061511.pdf

Relationships: The People in Our Lives. Florida Grassroots Self-Advocacy. Bacon, J.
http://floridaselfadvocacy.com

Role and Responsibility of the Group Advisor. Florida Grassroots Self-Advocacy.
http://floridaselfadvocacy.com/

Role of an Advisor. The RIOT! Report.

Role of the Advisor, Facilitating Self-Advocacy. Self Advocacy Coalition of Kansas. 2006.

We Have Choices: Wheel Power. SANYS (Self-Advocacy Association of New York State).
http://www.sanys.org/WeHaveChoices4.pdf

2011-2012 Self-Advocacy Advisor and Officer Handbook. The Arc of New Jersey.
http://www.arcnj.org/programs/self_advocacy.html

notes

thank you!

We conclude this guide the way we started, with gratitude to all the self-advocates and advisors across the country who provided invaluable input in creating this information guide.

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teach

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lead

listen

advocate

decision-making

high expectations

be the voice in your life