

NATIONAL GATEWAY

TO SELF-DETERMINATION



MARCH 2011

Research to Practice in
Self-Determination

Issue 1:
Self-Determination and
Self-Advocacy

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 A National Gateway
to Self-Determination

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Research to Practice in Self-Determination Series

Introduction

People who are self-determined know what they want and how to get it. They choose and set goals, then work to reach them. They advocate on their own behalf, and are involved in solving problems and making decisions about their lives.

The purpose of this series, Research to Practice in Self-Determination, is to describe key issues in the field of developmental disabilities that can be enhanced by considering efforts to promote self-determination. Each issue is prepared with a social-ecological framework in mind. This framework calls for strategies for intervention and support to take into account both the capacities of the person and the demands of the environment. Interventions to promote self-determination should focus both on enhancing personal capacity, improving opportunity, and modifying the environment. A series of seven issues will be produced, each focusing on a specific topic: self-advocacy, health, employment, community services, aging, family support, and siblings. The format for these issues will include definitions, a brief review of the literature, promising practices, applied examples, and targeted recommendations for scaling-up efforts. This series is

intended for use by people with developmental disabilities, family members, professionals, state and federal agencies, and academic programs. By collaborating with and enabling each of these entities, the goal of full inclusion for people with developmental disabilities can be realized.



Chester Finn, past president of SABE, presents a plaque to Carl Calkins during the 2010 SABE conference. The conference included themes about self-determination, self-advocacy, and social capital.



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Self-Determination and Self-Advocacy

Carl F. Calkins, Laura Walker Jackson, Cynthia Beckmann

Promoting self-advocacy is important to the development of the self-determination of people with developmental disabilities. Self-advocacy skills enable people to express their preferences and keep someone else from making decisions about and for them. Strong self-advocates are causal agents in their own lives; they cause things to happen to make their lives better.

What is Self-Advocacy?

For the purpose of this brief, self-advocacy is defined as a set of behaviors that enable people with developmental disabilities to speak out or demonstrate their preferences in a way that promotes their needs and desires or those of a collective group to assure their access to and full participation in the community. Simply put, it is the ability to stand up for oneself and advocate on one's own behalf. Effective self-advocates might testify before a legislative committee on the needs of people with developmental disabilities, speak before community groups, serve on advisory boards, or advocate to family members, staff, or employers for individual desires and the supports needed to achieve them.

Self-advocacy has been identified as a movement within the United States and other countries as well and is referenced throughout the Developmental Disabilities Act (Pt III). It is called for in the mission of University Centers for Excellence, Planning Councils, and Protection and Advocacy Councils with the primary outcome being leadership training and support of people with developmental disabilities.

The national self-advocacy organization Self-Advocates Becoming Empowered (SABE) defines self-advocacy in the following way:

"[It] is about independent groups of people with disabilities working together for justice by helping each other take charge of our lives and fight discrimination. It teaches us how to make decisions and choices that affect our lives so we can be more independent. It also teaches us responsibilities. The way we learn about advocating for ourselves is by supporting each other and helping each other

gain confidence in ourselves so we can speak out for what we believe in."

As a national organization SABE is concerned with ensuring that people with disabilities are "treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends; and to learn from their mistakes" (<http://www.sabeusa.org/?catid=165>).

Statewide self-advocacy organizations exist in almost all states and territories. These groups initially focused on legal and human rights, but recently have moved toward advocating for the broader concept of inclusion. Much as other social movements and groups, their targeted priorities include access to the same services, supports, and opportunities as other citizens in the community.

What is Self-Determination?

Self-determination derives from both philosophical roots (i.e. determinism) and psychological or behavioral outcomes (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003), each of which is broadly situated within theories of human agency. For the purpose of this brief, we take a human agentic perspective on self-determination, which views people as active contributors to, or "authors" of, their behavior. As such, self-determination is a construct that en-

Self-advocacy is about independent groups of people with disabilities working together for justice...

compasses choosing and setting goals, being involved in making life decisions, self-advocating, and working to reach goals. Importantly enhanced self-determination contributes to attainment of more positive outcomes, such as employment, education, community living, and an enhanced quality of life (Wehmeyer et al., 2003).

The National Gateway to Self-Determination project strongly suggests that self-determination be used in the context of a social ecological model. This model allows consideration for activities that promote self-determination to include strategies that address the individual in an environmental context. Thus, efforts directed at promoting self-determination can target change in environmental opportunities such as interpersonal, family, organization, community, and policy context, as well as services and supports for the person. The social ecological context is particularly useful as one considers building social capital in the context of self-advocacy - formal and informal

Table 1: 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 and Responsibilities	Expressing one's rights is the core element of assertive behavior. Therefore, 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 show the way by going in advance.



support networks that help an individual have greater resources in the community.

A focus on promoting self-determination can also be found in the DD Act, which defines Self-Determined Actions as actions

“in which 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.”

Activities that promote self-determination are often found in school-based

Self-determination refers to actions that enable a person to be a causal agent in his or her life.

curricula for people with disabilities. Additionally, there is an increasing recognition of the importance of self-determination in programs for adults funded by the Centers on Medicaid and Medicare Services relating to standards for adult community living programs.

Self-Advocacy and Self-Determination in Practice

Self-determination, as discussed previously, refers to actions that enable a person to be a causal agent in his or her life; to make or cause things to happen. One means of doing this involves engaging in self-advocacy activities. If a person has a voice in the decisions that affect life through self-advocacy, he or she is likely to become more self-determined. Advocating for oneself is an excellent demonstration of self-determined action.

Self-advocacy skills do not necessarily come naturally to people. It is important to teach individuals how to be strong self-advocates. According to Wehmeyer (2007, pp. 60-72) there are four self-advocacy

skills that enhance a person’s self-determination. These are outlined in Table 1. There are also a number of programs that focus on promoting self-advocacy and enhancing self-determination. One of the best examples of this is Project STIR (Steps Toward Independence and Responsibility), a training program for self-advocates designed to provide people with the tools to advocate for themselves, mobilize others in advocacy and gain leadership experience. Self-advocacy and self-determination are also the focal point of training programs and curricula like “My Voice, My Choice,” and Partners in Policy Making.

Need for Scaling-Up

There is an important link between self-advocacy and self-determination. Efforts that consider both in tandem, especially those that address the environmental context in addition to skills of the individual, will create powerful results. The question that remains is what strategic efforts can be made to ensure more comprehensive application. The National Gateway to Self-Determination has built a repository of conceptual papers, tools, and other resources to assist in this process. These are summarized in Table 2, and their descriptions can be found on the National Gateway to Self-Determination Web site (www.aucd.org/ngsd).

Given the multitude of resources that currently exist, what is called for is an ongoing training program at the local, state, and national level. The following steps could be followed to promote self-determination within the self-advocacy movement.

1. Build a leadership initiative supporting self-determination and self-advocacy at the state level. This could be accomplished by integrating Partners in Policy Making, People First, State agencies, UCEDDs, Protection and Advocacy Councils, and DD Planning Councils in a statewide leadership initiative focused on training advocates in leadership.
2. Build social capital for people and organizations using the self-determination social ecological model. This can be accomplished by a statewide training initiative on building social capital. The National Gateway to Self-Determination is currently developing a tool, the Social Capital Implementation Practices (SCIP),

which will help self-advocates build social capital within specific environmental contexts. It will help individuals and organizations access resources that can improve their quality of life.

3. Target the development of new curricula or enhance existing curricula using the social ecological self-determination model on state priority need areas (e.g. transition, health, or aging).

It should be noted that the Administration on Developmental Disabilities is holding a series of Self-Advocacy Summits across the country (see “Self-Advocacy Summits” on page 16). These summits will focus on the state of practice of advocacy with all the key partners. This is an excellent opportunity to consider scaling-up efforts in self-determination and self-advocacy.

In summary, self-determination and self-advocacy are critical in empowering people with developmental disabilities. It is time for all key partners, individuals with developmental disabilities and agencies alike, to join in a concerted effort to scale-up efforts to promote self-determination and self-advocacy. By providing the requisite supports we can achieve the outcome and expectation that individuals with developmental disabilities can and will be contributing citizens in a welcoming community.

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Table 2: National Gateway to Self-Determination Resources

<i>PRODUCTS</i>		<i>AUDIENCE</i>				<i>OUTCOMES</i>		
		UCEDDs	Self-Advocates	Families	State Agencies/ Service Providers	Advocacy	Capacity Building	Systemic Change
Partnerships								
1.	NTI Leadership Consortium	X	X	X	X	X	X	X
2.	National S-D Alliance	X	X	X	X	X	X	X
3.	Self-Determination Task Forces	X	X	X	X	X	X	X
Online Resources								
5.	National Gateway to S-D Resource Guide	X			X		X	X
6.	S-D in Self-Advocates' Lives: Stories		X	X		X		
7.	Web-Based Presentation: "What is Self-Determination"	X		X	X		X	
Written Products								
8.	Exceptionality Special Issue	X			X		X	
9.	National Gateway on S-D Research to Practice Briefs	X	X	X	X		X	
10.	White Paper Series	X			X		X	
11.	Self-Determination Brochures	X	X	X	X	X	X	
12.	Scaling-Up S-D Textbook	X			X		X	X
Tools								
13.	Practice Guidelines				X		X	X
14.	Train the Trainer Manual: Scaling-Up to Promote Self-Determination	X					X	
15.	SABE Opportunities for SD from the National Core Indicators Survey		X				X	
16.	Social Capital Implementation Practices (SCIP)	X	X	X	X		X	
Conferences								
17.	Self-Determination Initiative at SABE 2010 National Conference		X			X	X	
18.	Sibling Leadership Network Conference			X		X	X	

Self-Advocates Leading Self-Determined Lives

Nancy Ward, Chester Finn, Tia Nelis, Bryon Murray

In January 2011, four national leaders in the self-advocacy movement met to talk about self-determination and self-advocacy in their lives, how they envision the movement currently in the United States, and where they believe it should go in the future. This conversation was inspired by the recent Self Advocates Becoming Empowered (SABE) 2010 National Self-Advocacy Conference in Kansas City. Nearly 800 self-advocates participated in this event and a new group of leaders was voted onto the national SABE Board. This gave these 'old-timers' reason to pause and reflect on how they and SABE arrived at this point.

People need to find their voice and tell people what they want and need. *You* are the one that knows you best.

The Impossible is Possible

Each of us is used to speaking in front of hundreds of people, has met United States Presidents and other major political figures, traveled all over the world, and have been to most of the 50 states. Our lives were nothing like this when we began as self-advocates on our journeys of self-determination. The following are our reflections on how we got started.

Tia Nelis: "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 disagree with them even if they were wrong. I didn't know if I wanted to be a part of it because a teacher in high school introduced me to the self-advocacy movement. I thought, 'Oh great

another person in authority will hold a meeting to tell us what to do.' I would pretend I couldn't talk so I could get out of going to the meetings. The teacher really thought I couldn't talk. This was my first time protesting. At my first meeting I was told to stand up and talk about when you applied for a job and they turned me down because they knew I was in special education. 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. When people get told things and are not able to speak their opinion it will build up anyway and explode in a negative way. Self-advocacy helped me learn how to communicate my opinions and needs in a positive way. I had an advisor that helped me learn who is now a really good friend. She and I are able to talk openly with each other. People need to find their voice and tell people what they want and need. You are the one that knows you best. When

you first learn to find your voice it is not always going to come out in a good way. I went from being a local self-advocate to national level. If I can do it, anyone can."

Nancy Ward: "Because [our state] was one of the first states 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 be 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. I became the first president of SABE. My goal was to have the organization have a way that everybody can share ideas."



At the SABE conference (left to right), Chester Finn, Tia Nelis, Katie Arnold, Bryon Murray, and Nancy Ward.



Bryon Murray: “I was introduced by my doctor to a support person who has three children with severe disabilities and one passed away. She was really involved with the disability rights movement. 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.”

Self-advocacy helped me learn how to communicate my opinions and needs in a positive way.

Chester Finn: “My first meeting was on a boat and I didn’t know if I wanted to go. 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 working to advocate for myself. It just became a part of my life. The first SABE event I went to was the meeting in Canada and a few months later I was already in my state organization. We went to a national conference in Virginia. We drove a van there and a friend said come to this regional meeting and I was nominated to run for representative. After that I took part in helping with stuff and was hooked. At my first meeting I met Tia and Nancy and they put me to work. I was asked by the President to serve on committees. Tia wanted me to be a liaison for Project Leadership. I asked, ‘Oooh, what’s a liaison?’ I worked on the DD act to push for funding for self-advocacy activities. I was then asked to testify at the appropriations committee with AUCD and was the last person to speak. Legislators were writing things down. That night the DD Act was passed. I just talked about people’s lives and that people didn’t want to go to institutions. They had all the other information from

professionals but they needed to hear from somebody talking about their real life.

Learning from Others

Our stories show that each of us needed some support and encouragement to get where we are. Our best supports came from other self-advocates who are great mentors for people with disabilities that haven’t been a part of the movement or had role models or supports that help them to know they can be the driving force in their own life. Sometimes this can be just someone who you look up to and see they are able to make their own decisions. Other times it is formal mentor or teacher that changes the way you view yourself and live your life. It is important for people with experience in being a self-advocate to help the people who are still learning. Also, people who are new self-advocates should look for mentors who have been there. It is a great way to build social capital and to practice self-determination in your life.

Recommendations for Enhancing Self-Determination

Based on our experiences we have the following recommendations for people with disabilities, their family members, and professionals in the field.

- There needs to be a range of leadership and self-determination training available from Self-Determination 101 to Advanced training for established self-advocate leaders.
- People with disabilities need to know what seems impossible is possible.
- Mentors that have your best interest in mind are most helpful to learn to lead the life you want to be in control of.
- Make sure mentors or friends and other supports are someone who believes in you and doesn’t give up on you.
- Self-advocacy skills are part of what gives you the confidence to speak up for yourself.
- It shouldn’t just be about disability. Discrimination happens to a lot of people and everyone needs to be the person in control of their life.
- Remember everyone is a person and disability can happen to anyone, even you.

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It is important for people with experience in being self-advocates to help people who are still learning about self-advocacy.



Self-Determination and Supports

Mia Peterson, with Jana Peterson

My name is Mia Peterson. And I am a self-advocate! Today, I will share what self-determination means to me, and the supports that got me there. I will share about my team.

It all started out over ten years ago, on February 21, 1997. I moved from Iowa where I lived with my parents to Cincinnati, Ohio. It was tough to move far away from my family to a new state. Let me tell you how I got there and how it happened.

Sometimes it takes a lot of lessons to get there. I say to people, “This is what I was determined to do for myself.” I need to be self-determined for myself, for what my plan is. For example, I got a new job in Cincinnati, and I wanted to move there so I could learn new things and be more independent. I wanted to find my voice. I had to know in my heart that this is what I wanted to do. I had a dream to be independent, and I knew that I could do it. It was a big lesson in self-determination because I had to do a lot of things on my own. It is a lot of work for me. I watched my parents drive away when I moved to Cincinnati, and that was hard. To make it work, I had to figure out what supports I needed, to make things happen in my life. The kind of supports I needed were ones that would teach me more independence and safety in my neighborhood, living on a budget, learning to cook and shop for food, making friends in the community, joining my YMCA, going to church, learning about my neighborhood.

I also had other dreams. I always dreamed of going to college. It was one of my biggest dreams. I proved that I

could do it, and I did it. I took classes at Xavier University in Ohio. I also dreamed of having a boyfriend and having someone to go on big trips with and to travel with. My boyfriend and I now go on cruises and trips together. Having my own apartment is a big dream, too. Those dreams are things that I now have, and that is self-determined to me.

It took a lot of lessons on my part. I will tell you about some lessons I learned.

Lesson One: My parents do have SOME good ideas, sometimes.

It is really important to listen to our family. A lot of times they are right. We support each other with ideas. At times I like to do things my own way, but most of the time I listen to their advice, too. It took a lot of team work. When out of state, it was much harder. The biggest concern was my safety. It still is now. It took a lot of team work for all of us.

Working together with my family and other supports to be self-determined is not always easy. Sometimes I want to accomplish things on my own. Sometimes I feel like people tell me how I should do things all the time. One thing that has helped me is learning about the Seven Habits of Highly Effective People. I have been a trainer of these habits so I really know them. My favorite habit is “Synergize.” I call this TEAMwork, or Together Everyone Achieves More. Another of my favorite habits is “Seek first to understand, and then to be understood.” This is about listening to the point of view of the other person. I also really like “Have the attitude of win-win.” Sometimes there is a way that both people can win. I need to tell people about what supports I need to reach my dreams, and sometimes we all need to listen. Something I have learned is that doing things for myself means letting others in. It is great to have family and the supports being given to me.

Lesson Two: Doing things that are scary can teach you a lot about things you will like.

Understanding how to take transportation by myself was a big part of being independent so I could go places. It helps me get to places when I want, like going to the YMCA or the store. It was hard to determine my way around. I needed to learn to take a cab without someone with me. That was scary at first. There was a cab driver I got to know, and he was a good help for me. He helped me get to the airport!

I also learned how to use a bus. I learned a lot. At times it’s ok to ask for help. I usually walk to the store, but if it’s raining and I get stuck, I can call someone. Sometimes I can take the bus, or someone can come get me. Knowing when to ask for help when I needed it the most was a big part of learning how to get to places on my own.

Lesson Three: It is ok to let people who support you know what you are feeling and not to be afraid to speak from your heart.

My mentor, Essie, worked with me on this. There are many supports that are out there. It is hard to say what you feel. It is important how we say it, without hurting anyone’s feelings. I learned a lot to find my own independence. When I was in high school I didn’t know what self-advocacy was. One of the hardest things for me was speaking up to adults. I was just afraid to speak up. All I could do was write out what I was really thinking and feeling. I started working on my writing talents. Sometimes it helps to write things out and choose the right words that I really want to say. To become a self-advocate and learn to speak out, I worked very hard. Public speaking really helped me out. I started being in school plays and contest speech. I took a high school speech class and journalism. I also took a college class in presentational speaking and one in inter

All the lessons I have learned make me stronger in my self-determination.



personal relationships. I had to work to be less shy and be more assertive.

When I was 19 years old my dad and I went to a national conference on Down syndrome in Anaheim, California. We heard about a lady, Essie Pederson, who was working with people who had Down syndrome to write for a newsletter. I had written some stories, and I really wanted them published, but I was too shy to talk to her. My dad introduced us and told her that his daughter was a writer and wanted her stories published in a newsletter. Right away she began talking to me and not my dad. She looked over my papers and smiled and loved them right away. She helped me to get my stories published in a newsletter and from then on my writing career began. Since then I have learned that I like it better when people in my life include me in conversations about my life choices. It can also help when I speak up. Self-determination means I am included in life choices and I can work hard to make things happen for myself.

Lesson Four: It is good to have a mentor/friend.

Let's talk about a role of a mentor. My mentor's name is Essie. She found my skills and gave me a great job. She hired me to work on a newsletter. She needed to see what I could do, so she had me do some writing for her. I typed some letters for her Board of Directors. When she saw those skills, she gave me the chance to try writing a regular column, called "Mia Peterson Speaks Out." Every issue of the column had a theme. She would give me advice and help me know people to interview. Before I knew it I started writing articles, and I got better and better. That was a good support. She would sit next to me, write some things down, and I would start with that. It really helped me. When she saw how great I was doing, she would give me the chance to try things that were harder. She also was my partner for Partners in Policy Making. Partners in Policy Making helped me learn about leadership and how to become partners with people to get things accomplished. Before I knew it, Essie and I wrote a grant together for an organization for People First. We started People First of Ohio. Then I got a new job, but I still had a chance to do things with Essie, even when I didn't work with her anymore.



Mia Peterson prior to testifying before Congress about the importance of the Americans with Disabilities Act (ADA) on the 10th anniversary of the ADA.

Before I lived on my own, Essie helped me find a job where I could be a nanny helper to a little girl with Down syndrome, and I lived with the family. She is 13 or 14 now, and that makes me feel old! Essie also got me to chase my dream of going to college. She helped me live in the same building where she lived for a while when I was trying to find my first apartment. She helped me in being independent, and to find the right kind of supports. And I did it!

To make it work, I had to figure out what supports I needed, to make things happen in my life.

Lesson Five: Without the support of people who love me, I could not follow my dreams.

We all have dreams. My leaving Iowa was hard on all of us in the family. Without family, those supports could not happen. You have to want it. My family supports me with my ideas, but we tend to discuss things. Sometimes it's a good idea to hear their ideas and concerns, and we work together as a team. There's a saying, "Nothing about me without me" when it's a person they're talking about.

My dad helps me find more work. We had a situation that we were talking about small ways to try to get more work. In a meeting, I talk about myself, but sometimes it's harder to get the point across when it's about myself. My dad puts more language to it. He has a way with certain words. He uses words that might make it helpful for them to understand what I am saying. It's not that I don't do it myself, but it's a great way to support me. I do think it's helpful when he fills in the dots of what I am saying.

Sometimes it's not just mom and dad, but my sisters that give me support. They can help me figure out situations when



mom and dad are not there for support if I need it. Sometimes it is good to get my sisters' opinions, not just mom and dad. Sometimes it is nice to get more perspectives. I like support when we are talking as sisters, and not a parent role. Sometimes it's nice just to talk to them if I'm having a hard day. They might give me ideas of fun things I can do or just talk about tough situations. They will think up fun things to do as a family, and I can join them. It feels good to be included to go out on the town and have fun. To me that's a support. We all as a family love to be active. It's good to get advice about exercise. My family also supports my safety. They also like to support my activities by giving me rides, joining me with fun activities, and also inviting me to do things. Being invited

to be able to show how I got it worked out for myself. But it's great to have a team to work with when I need it the most.

Sometimes supports can start to take over, and I don't like that. Sometimes it's hard to know what to do. Sometimes I try to talk to them in private. It's great to have the support of family to listen. They can jot down notes and help me communicate at the next point. That's a good way of support for me.

Conclusion: All the lessons I have learned make me stronger in my self-determination.

I need to work hard to keep up all the things I have learned and make things happen in my life. The big thing I want

supports, most of all we really need to work together to make things happen. To go to Ohio, I needed Essie to give me the job in Ohio. To reach my dreams in Ohio, she worked with me, not without me. I also needed the support of my family. It made my time in Ohio a really good one.

Here is what I currently do now. I have several jobs. For one, I am self-employed. What I do is presentin--I tell my own story. My business is Aiming High. I go nationwide, statewide, and locally. I also work at a grocery store called Dahl's. I bag groceries and do drive up. I work at a YMCA. My job is in the Fitness Center. I keep things cleaned and make sure people have clean towels, and sometimes we do their laundry and put it back in their locker. My last job is at the Iowa Workforce Planning and Assistance. I assist on many different projects.

Remember self-determination is a great thing! You can do it!

Mia Peterson – Aiming High, Des Moines, IA. Mia owns a Self-Advocacy business called Aiming High. She writes and gives speeches about her life story, including the importance of supports in her life. She is also past president of People First of Ohio. To learn more about Aiming High, follow the Aiming High page on Facebook.

I had to know in my heart that this is what I wanted. I had a dream to be independent; I knew I could do it.

to do fun things is good support right there. It's nice to have support and love.

My boyfriend lives out of town, but I call him and email him quite a bit. It is good support right there to support one another. Sometimes we just talk and email back and forth, and getting his ideas is a good support. We like to take cruises. We talk about planning the trip together, and we work together on ideas. He has a travel agent that he talks to, which helps us plan trips. He tells me what he needs from me to support him back. We will make a plan, and then we will talk on the phone. He will report back to me and I will report back to him. We support each other by talking it out. It's not just those trips. We do that with other things too. He also supports me in making good, healthy choices.

I always carry my cell phone with me. It is good to have support in what it is that I do, and my family to back me up when I'm having trouble, especially if I'm by myself and I'm stuck. Then I call someone. First I try to do it myself as an independent adult. Sometimes it's not easy to ask family for help when I cannot do it myself. I like

everyone to remember is TEAMwork, because Together Everyone Achieves More – T.E.A.M. Even though this is about



Mia Peterson says that support from family, friends, and mentors help her practice self-determination. Here, she is pictured with her sister, Jana Peterson.



Using Lifebooks for Self-Advocacy

Kyla Eversman

What is a Lifebook?

A Lifebook is a collection of words, photos, graphics, artwork, and memorabilia that creates a life record. Lifebooks were first introduced as a tool for social workers and adoptive parents to tell the story of child's life before adoption.

A Lifebook 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 and for self-advocacy. It creates a picture of the individual; it records important events, organizes emergency and medical information, and encourages communication among the circle of support including your family members, friends, and professionals.

In England, Lifebooks have been used to deal with the issues faced by individuals with learning disabilities who have aging parents or caregivers. The Lifetime of Caring Project (<http://www.lifetimecaring.org.uk/>) reports, "The process of planning is like constructing a bridge between now and the future, a useful tool in this process can be the development of Lifebooks of the son or daughter with a disability."

Lifebooks fulfill many roles.

- Lifebooks can be great fun to do for the person with a disability. The focus of attention is on them and building a picture of their story and them as a person; their special relationships, likes and dislikes, modes of communication, and aspirations for the future.
- Putting together a Lifebook is a great way of involving family and friends in thinking about the person with a disability. By thinking about their past and present it is possible to engage people in thinking about the future and how it might be different.
- Lifebooks ensure that vital information about the person with disabilities is not lost and can provide the staff who are supporting them, both now and in the future, with valuable insights into the person themselves.

- Lifebooks can be used during therapy to help individuals come to terms with their disabilities.

The Missouri Self-Determination Association (MoSDA) is a group of self-advocates, parents, and professionals who are interested in scaling-up efforts to promote self-determination throughout the state in all programs that serve people with disabilities. One way MoSDA is doing this is through Lifebook facilitation training. Training is provided to service professionals and the individuals they serve in an effort to enhance the self-determination and to redefine the services which are provided. This allows individuals to be active contributors to or authors of the services they receive. MoSDA will also collaborate with People First Chapters to facilitate the use of Lifebooks as individuals transition from state-run institutions to community settings. This activity helps them to build their self-determination and social capital, not to mention the fellowship opportunities it creates during transition.

Creating a Lifebook can also serve as the foundation for person-centered planning. In creating a Lifebook, individuals become more involved in the planning of their services. This is done all year long versus during a meeting that might occur once or twice a year. Below are some examples of how people with developmental disabilities and their families have used Lifebooks.

A parent of a child with autism was tired of explaining what her son needed to be supported. She began using a Lifebook to record this information and share with professionals. When she brought her son's Lifebook to his school she was happy to find that her son and his peers were looking at the Lifebook and his peers were asking her son questions and having an open dialog regarding why he did the things he does. The Lifebook became a tool for her son to interact with his peers versus the teacher taking the children aside to explain why her son was different.

In another case, an individual had a reputation for having severe behaviors—so much so that only one male staff person

could work with him at a day program. Goals within his behavioral support plan were to increase his "circle of supports," develop routines, and catch him being happy. A Lifebook was used as a tool to do all three. Pictures were used to show the routines that he needed to do each day. Staff members were requested to take pictures of him being happy no less than once per week. Initially, staff members complained that he was never happy and his behaviors prevented them from interacting with him. The manager persisted and staff members started to focus their efforts on finding times and situations

Lifebooks... allow individuals to be active contributors to or authors of the services they receive.

when he was happy and discovered that they were able to take pictures of him smiling. They added these pictures to his Lifebook, which they reviewed with him every morning. Soon other staff members became interested in seeing if they could figure out ways to make him happy and attempted to try new things and more pictures of him being happy were added. His parents were asked for pictures of him when he was young and soon staff and his peers were commenting on how cute he was when he was a child, adding to the positive feedback he was receiving from staff. Over the course of a few months his reputation changed and he had many more people in his life. The same person took his Lifebook to his planning meeting and he was finally able to explain what he

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Linux: Assistive Technology that's Economical

Spencer Hunley

If money were no object, any person with a disability would most likely be using the latest and most advanced technology in their daily lives, giving them the ability to live the life they choose on their terms. But, assistive technology as a whole has not exactly caught up to us (people with disabilities). Often, the best technology costs money and the newer the innovation, the higher the price. If the technology doesn't exist to address the demand, the situation becomes substantially dire. The possibilities of our current technological development, as well as obstacles to utilizing it, are much more apparent when viewed from the side of people with disabilities.

Enter Linux

This article will introduce the assistive technology side of Linux operating systems, open-source software applications. I will discuss how people with disabilities can utilize them on their own. A variety of assistive technology software is available through Linux, including: interaction applications, text-to-speech, screen readers, screen magnifiers, gesture recognition, head tracking, and many others. We are on the brink of technological revolution—from an open-source smart phone operating system (i.e., Android), to Linux assistive technology applications and programs, we have a monumental opportunity to improve the quality of life for all persons with disabilities.

So what IS Linux?

Linux is a family of computer operating systems that use the same base platform for all kinds of programs and applications. Linux can be used on personal computers and smart phones (i.e., Android). Linux-based software is free and open-source, which means that anyone can view and modify it to their heart's content at no cost. Linux application distributions (henceforth referred to as distributions) are operating systems that are based on the Linux platform.

There are hundreds, if not thousands, of Linux distributions available for free.

An example of one of the best distributions for people with disabilities, specifically those with visual challenges, is called Vinux. According to their website (<http://vinux.org.uk/>), Vinux is “optimized for visually impaired users. It provides a screen-reader, full-screen magnification and support for Braille displays out of the box.” Vinux, like most Linux distributions, can be run off of a CD that tests your hardware to determine whether it works for your computer. If you need more applications besides a screen reader, magnification and support for Braille, additional applications can be downloaded and installed from software repositories available for free to users of the Vinux distribution. If you are interested in a different distribution, a comprehensive list of distributions can be viewed on the [Linux website](#).

Through Linux, all people with disabilities can afford the assistive technology they need.

If you desire free and open-source accessible/assistive technology applications, there are many available. A few examples of the Linux-based accessible applications include Mousetrap, a program that allows users to utilize a webcam and their head to move the mouse on-screen; Kmouth, a text-to-speech program for those who cannot speak; Orca, a screen-reader and magnifier all in one; a gesture recognition program, various on-screen keyboards, and more.



Spencer Hunley provides technology assistance to a member of the Youth Leadership Council at the UMKC Institute for Human Development.

Why is Linux a Good Alternative to Pricier Proprietary Operating Systems, Applications and Software?

There are many benefits to using Linux-based systems, including availability, free access, large selection of software products, software integrity, and available technical assistance for products.

Linux is freely available for anyone who wishes to use it. As assistive technology prices have risen over the years, the number of people with disabilities who can afford to purchase it has declined. While insurance and government assistance sometimes pays for assistive technology, the end user may not get what they really need or want, and is at the mercy of the product covered by insurance, Medicare, Medicaid and social security. Through Linux, all people with disabilities can afford the assistive technology they need.

Another benefit of Linux is that it is open-source. This frees the end user from unnecessary registrations and terms of service agreement requirements. Since the source code (or computer programming code) is available to everyone, Linux software provides the ability to have your specific device customized for your exact needs at the ‘meat and potatoes’ level – where the software is written. The use of free software repositories is another benefit of using Linux. Most distributions allow you to install software from a manager that is a part of the distribution itself, instead of installing software the old-fashioned way (i.e. buying the program at a store, and then installing it). The selection of free software is wide and vast, and includes many different categories. A major benefit



of this feature is that you can try out software and applications easily and for free without spending money on a purchase. This makes it easier to select software that you know will meet your needs.

Yet another benefit of Linux is that, compared to other proprietary company operating systems, Linux is fast and virtually maintenance-free. Start up and shut down times are very quick, and Linux requires no defragmentation. Like the software itself, updates and upgrades are free as well, ensuring that you always have the latest and greatest versions running. Updates are easy, with no rebooting required. The durability and excellent endurance of Linux add to its reputation of being versatile, working on a multitude of computers, no matter the make or model. Also, Linux is largely immune to most viruses, spyware and malware due to the difference in programming language.

Most distributions are community-backed and maintained by teams with a larger community of developers, testers and users. This makes finding an answer to your question, troubleshooting, or even suggesting a new feature much easier than having to talk to a company's technical support. Often times you can do an online search about your inquiry and quickly find an answer. Accessibility is generally embraced more by Linux developers and maintainers, in contrast to proprietary systems which often force a consumer to locate and purchase additional software somewhere else for their needs.

Businesses, schools, and even governments use various Linux products and systems around the world. For example, Netflix, IBM, Google, Facebook, Twitter, the London Stock Exchange, the Tokyo Stock Exchange, the Chicago Mercantile Exchange, Conoco, Panasonic, Toyota, Travelocity, Virgin America, Omaha Steaks, Amazon.com, Wikipedia, Tommy Hilfiger, NASA, the U.S. Department of Defense and all military branches, the

U.S. Postal Service, the entire country of Spain, the city of Munich in Germany (as well as German Universities), the French Parliament, the city of Garden Grove in California, the city of Largo in Florida, and many, many more all use a form of Linux in their infrastructure.

Although most people are less familiar with Linux and its products than they are with proprietary software, I have observed

Accessibility tools are not a luxury; they assist persons with disabilities to live the life they choose and be more self-determined.

the benefits to people with disabilities who have made the switch to Linux. One example is a young man who had trouble reading due to various disabilities. I know him through a leadership training course entitled YouthLEAD. An Eagle Scout and employed worker, Paul was able to obtain a netbook through YouthLEAD. However, the operating system on the Netbook required a lot of reading, making it extremely hard to use by someone with reading difficulties. I installed a Linux operating system as a primary system on Paul's Netbook, and introduced all of the accessible features he wanted. This included menu symbols for different programs as well as for specific folders. Two years later, Paul still uses the Netbook, and favors the Linux system over the proprietary system.

Recommendations

If you would like to use Linux-based systems and software, I have a few recommendations.

You should learn as much as you can about the technology so that

you are informed. Start by visiting my blog (<http://thelatte.posterous.com/>) or other internet sources.

You will want to try some things out. Before you download Linux, you can run it as a live CD. This will allow you to check out the features before making the switch. Don't feel that you need to purchase new hardware/devices or completely change your software to try

Linux. You can start with your existing computer or netbook and install Linux to run next to the operating system that you already use (e.g., Windows).

From there, you can try various distributions and applications (either from a live cd or by downloading from a software repository) to find what best fits your needs.

Conclusions

The year 2010 brought a lot of assistive technology issues to the forefront. The FCC's ruling on Net Neutrality, the 20th Anniversary of the ADA, Health Care reform, and the rapid technological development of smart phones and other technologies create landmark opportunities to achieve major advancements for accessibility in internet communications, social networks, portable computing, and other technologies. More people with disabilities will continue to be on the internet and use assistive technologies. This is an easy prediction. As people with disabilities become more technology-savvy, more of us will be using technology on a more consistent basis. Linux provides us with a cost-effective way to meet many of our assistive technology needs.

This is important because accessibility tools are not an optional luxury for many people with disabilities. These instruments assist persons with disabilities to live the life they choose and be more self-determined. They level the playing field

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As people with disabilities become more technology-savvy, more of us will be using technology on a more consistent basis.



Sibling Perspective on Self-Advocacy and Self-Determination

Katie Arnold

My sister, Patrice, has shaped my worldview. Growing up in our family as the second of five children and the oldest daughter, I had a close relationship with my sister. Early on, I was not aware that Patrice had an intellectual disability though I noticed people sometimes reacted to her in a surprised or sad way. My school friends would sometimes ask me questions about what was different with my sister and I would do my best to respond. I learned how to advocate at a young age when people would stare at Patrice in public or make comments about her “difference.” The “r” word used in any context still sets me off today because I so

bilitation Research and Training Center on Aging and Developmental Disabilities, Lifespan Health and Function. In my work I have learned the importance of family future planning which creates a dialogue within families to plan for the future. This may sound very simple, yet it is a critical process for breaking down planning into manageable tasks that can often be overwhelming. It has been through my family’s future planning that we have come to understand the importance of self-determination for my sister.

My family’s future planning meetings began five years ago when I went to my mother and talked about starting a

It has been through my family’s future planning that we have come to understand the importance of self-determination for my sister.

tell she was feeling really overwhelmed. Although I had done a little preparation with Patrice before the meeting, I quickly realized that we needed to reframe the meetings so that she was included and was able to share her desires for the future.

Finding out what Patrice wanted for the future proved to be a challenge. Her intellectual disability make it hard for her to process information and articulate her thoughts. Most often her responses to questions were “yes/no” or “I don’t know.” Patrice and I created a scrapbook with pictures of important things in her life—the people, the foods, the activities, and her dreams for the future. She loves cutting out pictures from magazines and putting together collages, so this was the perfect activity that was fun for her and created a tool that she could use to share things about herself with others.

We realized that as a family we had gotten into the habit of answering for Patrice since it took her longer to respond. While our family feels we know Patrice and have her best interest at heart, we realized that we were contributing to her “learned helplessness.” By acknowledging this as a family, we are more aware of when we should step back and allow Patrice to be her own advocate, speak for herself and make decisions for herself. It has not been easy, especially for my parents. We are still working on it, though we are all really making progress, and Patrice is blossoming.

Patrice has been learning about self-advocacy, and she is getting involved in a self-advocacy group. After she met some self-advocacy leaders including Tia



Katie Arnold (left) says that her experiences growing up with her sister Patrice (right), who has developmental disabilities, has fed her passion about her work with people with disabilities.

closely relate it to negativity that people have toward people with disabilities and, more personally, toward my sister.

Patrice has influenced my career path. I now work in the disability field at Illinois’ University Center for Excellence in Developmental Disabilities, and I am also a project manager within the Reha-

dialogue within our family. At our first meeting, we quickly discovered that we all had very different assumptions about what the future might hold for Patrice and our family. Also, the tone was not inclusive of Patrice. Everyone tended to talk about Patrice with her there. It made me really uncomfortable, and I could



Nelis, a founding member of Self Advocates Becoming Empowered (SABE), she wanted to learn more. Patrice and I researched the groups in her area. Patrice is speaking up for herself and making more decisions about what she wants for the future, including her desire to move into her own apartment. The idea of Patrice living in her own apartment was something my family never seriously considered in the past. Yet, when an opportunity arose in her community, she and my parents began looking into it, and it is likely that she will move in to her own place this coming summer. With our parents and two brothers living in the same community, Patrice will have a lot of natural supports to help her be successful in her new home. She is very excited!

To me, self-determination means that my sister has the support and tools to make meaningful choices and create the life she wants to live. It is to my benefit as a sister that Patrice be self-determined because if she has her own life, then I can also have my own life. This will only enhance our sister relationship. I see families where the parents are no longer able to provide support for the person with disabilities and the siblings step in and take on a parental role. This can shift the sibling relationship in ways that do not always work for the person with disabilities or the siblings.

Siblings often play an important role in providing natural supports for their brothers and sisters with disabilities, especially as parents age. Yet, navigating the disability service system and getting support for themselves as siblings can be difficult and overwhelming. Siblings want to be included in supports that are provided to families. Siblings need information, just like parents and people with disabilities. There is an important need for information and support on planning for the future, specifically. “The Future

Siblings often play an important role in providing natural supports, especially as parents age.

To me, self-determination means that my sister has the support and tools to make meaningful choices and create the life she wants to live.

is Now” is a model of a future planning curriculum that includes siblings and has tested outcomes (Factor, et al., 2010; Heller & Caldwell, 2006) that could be a helpful resource for other siblings.

Siblings are often invested in supporting their brothers and sisters with developmental disabilities to become self-determined. Siblings of people with developmental disabilities often have additional caregiving responsibilities



Siblings and self-advocates attend the International Sibling Conference (left to right): Marvin Moss, Katie Arnold, Tia Nelis, Essie Pederson, and Bryon Murray with his sister Kayla.

compared to most people. Many siblings juggle the care of aging parents, their own children, as well as their sibling with developmental disabilities. Siblings are worried about how this will impact their own relationships, careers, and health.

One way siblings and self advocates are working together is the national Sibling Leadership Network (SLN). The SLN, founded in 2007, is an organization created to support siblings of people with disabilities throughout the lifespan. The mission is to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families. The SLN values the input of self advocates and works collaboratively with the national Self Advocates Becoming Empowered (SABE). SABE as an organization is a model for the SLN as the organization develops. The SLN has a network of over 200 leaders of

sibling groups, organizations, and individuals including state chapters and international partners. Currently there are six SLN state chapters (IL, NY, OK, OH, TN, WI), and the groundwork to nurture and develop additional chapters throughout the country is in place. For more details visit www.siblingleadership.org.

As well as on the national level, siblings and self advocates are working together at the local level. In Illinois, the state SLN chapter, Supporting Illinois Brothers and Sisters (SIBS), has developed a relationship with a self advocacy group and they presented about their partnership at the statewide Arc of Illinois conference. Siblings have a lot to learn from each other about ways to support each other and work together. Upon attending the SABE conference this past year, I saw self advocates from across the country speak up for themselves. I heard a self advocate clearly state to “listen first and then support so we can create our own lives”. Self-determination will be a lot easier if we all try to follow this advice.

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Self-Advocacy Summits

ADD is emphasizing their commitment to self-advocacy by holding a series of regional meetings in the Spring of 2011 to strengthen and enhance self-advocacy efforts. The purpose of the summits is four-fold:

- to assess what is currently happening in the states in self-advocacy – the support structures, activities, accomplishments and challenges;
- to plan steps we can take to strengthen and enhance current efforts at the state level;
- to develop recommendations for actions that we can take at the national level; and
- to develop policy recommendations that can lead to a stronger, more effective, and long lasting self-advocacy movement across the country.

“Our hope is that these summits will bring together the leadership of the developmental disabilities field to energize and guide our efforts to support the self-advocacy movement at both a state and national level.” (Sharon Lewis, Commissioner, ADD)

For more details on the summits, visit <http://alliesinselfadvocacy.org/>.

*Using Lifebooks...
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wanted and what made him happy. The focus of the meeting changed from professionals deciding what was best for him to him describing what made him happy.

One final example: a Lifebook was found to have unforeseen benefits for a family whose member with a disability moved from the state institution where she lived for over twenty-five years to a home in the community near one of her siblings. The Lifebook was created to ensure that the new people who supported her would have a greater understanding of her history and how to support her. But, the Lifebook also became a tool for her siblings to discuss and come to terms with the loss they suffered all those years ago when their sister was removed from the family at such a young age. As they looked at her Lifebook and added photos and information, not only were they able to come to terms with the past, they were able to envision and plan for a future with their sister.

Lastly, Lifebooks combined with scrapbooking can be a way for professionals, family members, and people with disabilities to network and brainstorm together to build a strong circle of support around an individual. They are a tool to help people with developmental disabilities to effectively communicate their needs, likes, and dislikes. Lifebooks are an excellent tool that can help individuals build their social capital, enhance their self-determination and become more effective self-advocates.

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*Linux...
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so that everyone has an equal opportunity to achieve their own dreams, something that all Americans deeply cherish. As an autistic professional, I strongly believe that Linux is one way to make assistive technologies completely accessible. A larger body of available and affordable assistive technologies and accessibility devices will mean greater opportunities for self-determination and realization of dreams by people with disabilities.

While today's popular computer operating systems do come standard with some accessibility, they can be very basic with few options to extensively customize the tools for individualized needs. Many people can make better use of technology or gain enhanced access through the extra tools and devices offered by Linux-based operating systems. In this way, individuals in need of assistive technology have alternatives to the often expensive, proprietary software and hardware that are currently available.

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A 2010 SABE conference participant engages in self-advocacy.



Steps to Increased Social Capital in the Lives of Self-Advocates

George Gotto and Hill Walker

A person with a developmental disability cannot be an effective, self-advocate without adequate stores of social capital. Social capital has the potential to play an important role in the lives of individuals with disabilities who are at high risk of being marginalized and experiencing diminished self-determination (Trainor, 2008; Field et al., 1998). Trainor (2008, p. 158) noted that students with disability who are in the midst of post-secondary transition lack social capital, which affects their transition outcomes. She argued further that expanding the social relationships of students with disabilities and connecting them to social structures enhances their opportunities to make choices that influence quality of life.

As a generic concept, social capital refers to a set of relationships and social ties to individuals and organizations that can expand one's choice-making opportunities, increase one's options, and lead to a more enriched quality of life. For our purposes social capital is defined as *"the personal and collective power of people with disabilities and organizations to further their full inclusion within the community, to access social support networks, and to increase their quality of life"* (Walker, et al., in press). Social capital exists at both individual and societal/community levels in the same way as other forms of capital (e.g., economic, political, cultural) that are accessible to multiple layers of society.

A fundamental, core value at the heart of social capital is trust; that is, the trusting of others within one's social network and trusting of those whom your friends trust. Other important values associated with social capital include *having friends and allies who are on your side, developing connections to others who can help you, and being of assistance to others* (Gardner, Ward, & Weintraub, 2010). Individuals with high levels of social capital are expected to work toward the common good of everyone in their community or network.

The sociologist Pierre Bourdieu (1980, 1986) was the first to suggest that forms of capital (economic, social, cultural) are fungible—they can be traded for one another (Portes, 2000). Portes explained further, "social capital of any significance can seldom be acquired, for example, without the investment of some material resources and the possessions of some cultural knowledge, enabling the individual to establish relations with others" (2000, p. 3). Lin (1999, p. 40) referred to trading one form of capital for another as an "instrumental action," which is taken to obtain resources not possessed by the individual actor. Three returns result from instrumental action: economic return (i.e., employment, customer base); political return (i.e., hierarchical positions); and social return (i.e., personal reputation

A fundamental, core value at the heart of social capital is trust.

or trust from the community). Because each of these "returns" is so important to quality of life, it is very important for self-advocates to have social capital.

However, as Portes (1998) observed, social networks are not a natural given; they require effort and must be constructed through multiple investment strategies. Through an exhaustive examination of the social capital literature (Gotto et al., 2010), we have identified three strategies



George Jesien of AUCD, and Geoffrey Caldwell make a presentation at the SABE conference.



that can be used to help self-advocates develop social capital in their lives.

1. Family and/or parent participation and advocacy in the lives of people who are just developing their own social capital are vitally important

Parent and/or family participation is inextricably linked to the development of

2. Develop and sustain as many peripheral ties as possible

Peripheral ties in a social network are often the most important when accessing opportunities outside a person's bonded social network. A person's intimate relationships rarely possess much information that the person does not already know (Rogers, 2003). Therefore it is extremely important for individuals with disabilities

association with the group. At the same time, they benefit from the actions of the group in the form of improved laws, education opportunities, and employment opportunities to name just a few. Additionally, people with disabilities need to make connections with those social structures that provide access to support services (e.g., food stamps, employment incentive programs, and medical coverage). This is particularly important for adults with disabilities because many of the agencies and organizations that serve them maintain eligibility criteria, unlike the entitlement criteria established in the IDEA for school-aged children and youth in which the school personnel are required to provide services (Trainor, 2008). Therefore, people with disabilities and their family members need to be taught how to actively seek services from agencies.

Social capital is strongly connected to self-determination in that it gives the person the power to make decisions, make choices and adds control and direction to one's life. People who possess a significant amount of social capital, as a rule, have the resources, leveraging capacity, and natural community supports necessary to achieve greater inclusion and a better quality of life as well as the ability to advocate for others who may not have the ability to do so themselves. Lastly, as we have stated elsewhere, "social capital can lead to a more emotionally satisfying lifestyle, create more diverse choices, and allows for greater autonomy in decision-making—elements that are critical to realizing greater self-determination in one's life" (Walker, et al., 2011, p. 16).

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Social capital is the personal and collective power of people with disabilities and organizations to further their full inclusion within the community, to access social support networks, and to increase their quality of life.

social capital, particularly for youth who are transitioning into adulthood. Bourdieu (1986) pointed out that capital of all kinds was transferred from parent to child. Trainor (2008, p. 156) noted that family participation affects a student's ability to gain social capital through their school. If parents do not participate in school activities it severely limits a student's ability to access the capital available through the school. This means the student with a disability is losing access to valuable post-secondary opportunities that set the life course of the individual. Horvat and colleagues (2003) found that parents typically intervened on behalf of their school-aged children to obtain effective teachers and receive required services. At the same time, teachers act as gatekeepers who mediate social capital resources for children (Lareau & Horvat, 1999). This points to the importance of family members helping their child with a disability identify those important "gatekeepers" and help them develop relationships that will increase their access to social capital.

to develop relationships with individuals in the larger community, outside the family and close friendships. For youth with disabilities, relationships with resource-bearing adults help socialize them into shared norms, encourage the development of meaningful social roles, and prepare them for leadership roles within their local communities and larger society (Jarrett, et al., 2005, p. 42). One way to develop these relationships is to involve people with disabilities in service learning or volunteer programs to help develop community inclusion and by extension social capital.

3. Connect with and/or join important social structures (i.e., advocacy organizations, religious organization, etc.)

Individuals not only gain personal social capital but also accrue the benefits of the groups' larger social capital. For example, the people with disabilities who are members of Self-advocates Becoming Empowered (SABE) develop important individual relationships through their



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Exceptionality, Volume 19, Number 1, 2011

Special Issue: Promoting Self-Determination

This issue of *Exceptionality* was prepared by participants in an Administration on Developmental Disabilities-funded National Training Initiative on Scaling up Efforts to Promote Self-Determination, titled "The National Gateway to Self-Determination."

The articles introduce a social-ecological model of intervention designed to drive efforts to scale up self-determination; a discussion of moderating and mediating variables that will impact efforts to promote self-determination; a review of the literature related to critical issues across the lifespan pertaining to promoting self-determination; and provide a framework for scaling up efforts to promote the self-determination of youth and adults with developmental disabilities. The Issue includes the following articles:

- **Introduction to the Special issue on Scaling Up Efforts to Promote the Self-Determination of People with Developmental Disabilities.** By Carl F. Calkins, Michael L. Wehmeyer, Ansley Bacon, Tamar Heller and Hill M. Walker
- **A Social-Ecological Approach to Promote Self-Determination.** By Hill M. Walker, Carl F. Calkins, Michael L. Wehmeyer, Laura Walker Jackson, Ansley Bacon, Susan B. Palmer, George S. Jesien, Margaret A. Nygren, Tamar Heller, George S. Gotto, Brian H. Abery, and David R. Johnson
- **Personal Self-Determination and Moderating Variables that Impact Efforts to Promote Self-Determination.** By Michael L. Wehmeyer, Brian H. Abery, Dalun Zhang, Karen Ward, Derrick Willis, Waheeda Amin Hossain, Fabricio Balcazar, Allison Ball, Ansley Bacon, Carl F. Calkins, Tamar Heller, Tawara Goode, Robette Dias, George S. Jesien, Tom McVeigh, Margaret A. Nygren, Susan B. Palmer, and Hill M. Walker
- **Self-Determination across the Life Span: Issues and Gaps.** By Tamar Heller, Abigail Schindler, Susan B. Palmer, Michael L. Wehmeyer, Wendy Parent, Ronda Jenson, Brian H. Abery, Wendy Geringer, Ansley Bacon, and David M. O'Hara
- **Lessons Learned in Scaling Up Effective Practices: Implications for Promoting Self-Determination within Developmental Disabilities.** By Ansley Bacon, Hill M. Walker, Allen A. Schwartz, David M. O'Hara, Carl F. Calkins, and Michael L. Wehmeyer

Shy to Self-Confident: Discovering Talents of People with Disabilities

Amy Sharer

My name is Amy Sharer and I work for the Center on Community Accessibility (CCA) at Oregon Health & Science University in Portland, Oregon.

I was originally hired as a student assistant to perform tasks related to data entry, mailing, and producing materials in alternative formats. When I first heard about the job opening, I remember thinking to myself, “Dad talks about data entry. It’s with a computer. But I don’t know much else about it. I wonder if I could learn.” I didn’t have much self-confidence in the professional world, and I had always had the impression that I was “unemployable” due to disabilities and use of a service dog. Even though my dog makes me independent and able to consider employment, I always imagined difficulty getting an employer to understand my need for

my service dog, especially since a person can’t “see” my disability. When the job announcement was made, I remember looking around at all the other young adults in the room, thinking, “Surely, someone’s got to be interested. Isn’t there anyone else who is interested in this job? Raise a hand, solve my doubts; I’d really like the position, but I’m not sure I’m ready for the professional world yet. Besides, some people don’t have anything at all to do this summer.” I enjoyed my work volunteering at the K-12 schools, was getting ready to volunteer at summer school, and had been a well-respected high school track and field manager for six seasons.

Nobody’s hand moved. Just as the recruiter turned her head toward the door, I cautiously raised my hand. If someone else (with more confidence) wasn’t go-

ing to speak up, I guess I could. “I’d be interested in learning more,” I voiced. The recruiter nodded and came over to me. “Write your name and contact information on this piece of paper,” she said. I carefully printed my name, phone number, and email address on the lines she indicated. “Thank you,” she said, asking again for any other person’s interest. Nobody responded. She and I exchanged a few last words, and then she left.

Then I thought to myself,
“But I have to try.”

Two hours later, I called home before I started my long trip. “You have an email,” said my mother, reading it from my computer. The recruiter had sent me information about the position and asked me to get in touch with her as soon as possible. Memorizing the phone number, I called the recruiter back. The recruiter asked if I could come in for an interview. I remember looking down at myself while thinking, “I’m wearing jeans, not slacks. Not interview clothes. A zippered sweatshirt, too. It looks fine for my meeting, but not for a job interview.” Then I thought to myself, “But I have to try. Home is so far away. Besides, maybe they will understand. This will be excellent practice, even if I don’t get the job. I have summer school volunteer plans at the K-12 schools as my backup plan, but I need to take this opportunity for the practice. I need real-world job interview experience. The worst that can happen is that I don’t get the job.”

Before I knew it, I was in a meeting room with two potential supervisors and the recruiter. Taking a deep breath, I remembered my mother’s conversation with me from the previous evening. “Sell yourself!” my mother had told me the night before. “Stop being so modest,” she had detailed in reference to my tendency



Amy Sharer (with her service dog, Tux) works at the Center for Community Accessibility at the Oregon Institute on Human Development, Oregon Health & Science University.



to downplay my capabilities, talents and roles. I have always felt more comfortable taking on the role of a quiet and reliable worker who got the job done without fanfare. However, as my mother pointed out that evening, “Sometime you are going to get a job opportunity, a job interview, and you need to take credit for your talents.” Well, Mom, I have to say – perfect timing. And I tried my best; even though I had to come up with a definition for the concept for “sell[ing] yourself” from my own mind with fifteen seconds warning. Half a week later, I had my first day at my new job.

Working for a UCEDD has taught me how easy it is to employ people with disabilities. In the few days leading up to my first day, my human resources contact asked me if I needed any accommodations to fill out the hiring paperwork and then spent a half day making sure that the forms were either in Microsoft Word or Adobe fillable PDFs before sending them to me to do at home. Making the majority of the forms compatible with Microsoft Word took some time on her part, but it really made an impression on me that my workplace was so willing to accommodate my disability and make the hiring process easier for me. I was able to have the stress-free gift of filling out all the paperwork at home, asking my family tax- and personal information-related questions so I had all forms filled out upon arrival at the human resources office two days later. Once at the human resources office, I was pleasantly surprised to find out that there were no issues with the presence of my service dog and everyone in the human resources office and in my building loves dogs!

As far as obtaining accommodations at my job, the easy process has shown me how simple it should be at all employers and businesses. My department finds it important to produce accessible materials to begin with, so most documents have a 14-point sans serif font I can work with easily. Additionally, when I found the data entry database hard to read when I first arrived at my job, a supervisor fixed the font to have better size and contrast. Cost: Nothing. When a worker in a nearby office spoke up that he was allergic to dogs and the proximity was too much for him, my office was able to be moved further away from his office and closer to my co-workers. Cost: Nothing. When I expressed concern that using the phone was

a struggle for me because of my Autism Spectrum Disorder, my co-workers prepared scripts for me so I wouldn't lose my train of thought when leaving messages for partners and participants. Co-workers also respected my preference to communicate via e-mail or face-to-face instead of phone or voicemail when possible. Cost for these

Cerebral Palsy, Autism Spectrum Disorder, a service dog – those things concerned me more than they did my co-workers.

accommodations: nothing, and in the case of phone scripts and e-mails? Better productivity and records for our projects.

Over the past two and a half years, I have been enabled and encouraged to take on new responsibilities at CCA. I began as a student assistant doing data entry, mailings, and making sure that documents were in accessible alternative formats for people with disabilities. Now, I have had leading roles in several research studies. I've mastered survey processes such as: development of the survey measure, recruitment of participants, survey implementation, participant follow-up, and the incredible amount of administrative organization it takes to make research studies successful. After spending many hours asking questions of my ever patient co-workers and watching their talents with their computers (and projects), I have also become the point-person for everything database-related: collecting the data for entry, entering the data, data verification, and database creation and maintenance.

I'm very proud of myself for how far I've stepped out of my shell and blossomed at CCA, but I'm more proud of my co-workers for believing in me and giving me the opportunities (and encouragement) to step out of my shell! I had good self-determination and self-advocacy skills before coming to work for CCA, and I had an interest in community outreach and education regarding people with disabilities, but working at CCA has taught me so much more. When I first got hired, all I

could think about was the impact “having a disability” had on my job. I was ready for my co-workers to have questions and concerns; prepared to need to change minds and break down attitudinal barriers. I didn't have to do any of that. My co-workers just saw me as Amy and saw my talents, skills, and mind. Cerebral Palsy, Autism Spectrum Disorder, a service dog – those things concerned me more than they did my co-workers. The acceptance and minor impact that my disabilities and medical devices have on my work life has carried over into my educational and personal lives, also, where I promptly look at people and say, “You have concerns or worries about my disability? All I see are my talents and desire to get the task done. Let's do it.”

Thank you to CCA for teaching me life lessons that I likely would have not learned for a long time. Thank you for teaching me that talents, skills, and brains are first and foremost; the need for accommodations, medical devices, and the presence of diagnoses are not barriers. Thank you for showing me how easy it is to accommodate people with disabilities and passing on hints and tips to encourage the breakdown of attitudinal barriers in other places I frequent, such as school and businesses. Thank you for giving me skills, talent and education that I take back to the schools with me to educate my classmates and professors about accommodating and integrating people with disabilities. Most of all, thank you for believing in me, showing and teaching me new tasks, allowing me opportunities to learn, grow, and experiment, and taking the time to share your knowledge and experiences with me to shape me into the person I am today.

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Perspectives on a Consumer Advisory Committee: Roles, Responsibilities, and Reality

Carl F. Calkins, Laura Walker Jackson, and Cathy Enfield

Introduction

This paper aims to define the purpose of a Consumer Advisory Committee (CAC) for a University Center for Excellence in Developmental Disabilities (UCEDD) in the context of the letter and spirit of the law. It also provides personal perspectives from a UCEDD director and a CAC member. The authors conclude with organizational and training responses on developing and maintaining a successful CAC.

Ultimately, the purpose of a CAC is to ensure a consumer voice in UCEDD activities. However, to fully understand the purpose and intent of a CAC it is important to begin with its origins, the Developmental Disabilities Act (DD Act, 2000), which defines and mandates the role of the CAC for UCEDDs. The technical requirements outlined in the Act provide a starting point for engaging in a discussion on their intent. Requirements as defined by the DD Act are outlined below.

Reading into these technical requirements gets at the intent of the law which fundamentally aims to ensure a consumer voice is heard in the operations of a UCEDD. In addition there is an expectation for individuals with developmental disabilities and their family members to participate in the core functions of a UCEDD. Other requirements aim to ensure the consumer voice is a culturally diverse one and encourages collaboration with other DD Act programs and state agencies. Our focus in this paper is to look at the larger issue of consumer participation in the work of a UCEDD as is the intent of the law.

The Act imposes a “one-size fits all” approach to including consumers in the work of a network of individually unique UCEDDs. This can be problematic but the guidelines are general enough to give individual UCEDDs the latitude to create an infrastructure that meets the needs of the program as well as support its members to have a meaningful role. The authors

offer their respective reflections from Missouri’s UCEDD, the UMKC Institute for Human Development, to provide a platform for discussions around developing a successful CAC. The general context of serving on boards and committees with and for professional organizations in the disability field is also taken into account.

The following are perceptions and challenges in working towards a successful CAC from the perspectives of a UCEDD director who has 30 years of experience working with CACs and who helped form the national council of CACs (the Council on Community Advocacy (COCA)) and a self-advocate with local, state, and national experience who currently serves on a CAC.

UCEDD Director’s Perspective

My role is to identify an organizational structure for our CAC that makes sense for the functions of our UCEDD and to provide the appropriate information and training necessary for it to be successful. This responsibility is defined in the letter

- The majority of the members must be individuals with developmental disabilities and family members of such individuals.
- The CAC must include:
 - Individuals with developmental disabilities and related disabilities;
 - Family members of individuals with developmental disabilities;
 - A representative of the State Protection and Advocacy system;
 - A representative of the State Council on Developmental Disabilities;
 - A representative of a self-advocacy organization; and
 - Representatives of organizations that may include parent training and information centers, entities carrying out activities of the Assistive Technology Act, relevant State agencies, and other community groups concerned with the welfare of individuals with developmental disabilities and their families.
- Membership of the CAC must represent the racial and ethnic diversity of the state.
- The CAC must do the following things:
 - Consult with the Director of the Center regarding the development of the 5-year plan;
 - Participate in an annual review of, and comment on, the progress of the university Center in meeting the projected goals contained in the plan;
 - Make recommendations to the university Center Director regarding any proposed revisions of the plan that might be necessary; and
 - Meet as often as necessary to carry out the role of the committee, but at a minimum twice during each grant year.



and spirit of the law. It is important to note that an advisory committee is critical for any Center or Institute in a community setting. The committee can serve to promote programmatic direction, act as a forum for sharing accomplishments, and can also be a protector/advocate of the program from internal and external threats, challenges, or opportunities.

It is important to understand the function of advisory capacities for a UCEDD in a larger context of advisory channels. The nature of advisory functions for the UMKC Institute for Human Development has evolved over the years. Currently, this advisory need is met through an integration of input from our CAC, the Missouri DD Council and the University Chancellor's advisory council.

Addressing some of the realities for CACs can help UCEDDs and advisory committee members create strategies for success. I highlight some of the realities I identified while working with and developing CACs during my tenure:

1. **CAC as a Requirement:** The pro forma role many committees play is a reality that must be considered first. This reality cannot be dismissed by even a highly developed CAC given the nature of the directive in the DD Act.
2. **Lack of Social Capital:** Historically people with disabilities have not had a large share of social capital in society. This is still true today, though I have seen improvements over the years.
3. **Need for Meaningful Participation:** Many UCEDDs and national initiatives within the UCEDD network have strived to define and address meaningful participation for people with disabilities and their family members in the context of serving on boards or committees with professionals.
4. **Training and Support:** I have seen a failure to meet the needs of both the UCEDD and the CAC members due to lack of basic training and organizational support.

A meaningful relationship between a CAC and a UCEDD creates a better world for people with developmental disabilities and their family members in your state.

5. **Understanding the Core Functions:** CAC members need to have a basic understanding of the organizational functions of a UCEDD in order to assume a meaningful, informed advisory capacity.
6. **Infrastructure for Participation:** The UCEDD has the responsibility of creating an infrastructure and environment that allows for engaged and meaningful participation.
7. **Definition of Outcomes:** Allowing for recognition of accomplishments or outcomes reinforces CAC members and the important role they are playing in advising the UCEDD. By defining anticipated outcomes, members and the Center can see tangible effects of their work together. This assists with retention of CAC members as well as enhances the work they do.
8. **The Size Dilemma:** In general, it is important to take into account the size of a committee in relation to what you hope to accomplish with the group. The question of membership is closely tied to the size. A UCEDD must identify what voices and experiences need to be at the table while keeping in mind the membership guidelines established in the DD Act.
9. **Necessity of Funding and Resources:** Directors frequently balance meeting the needs of people with disabilities in the state within the current range of funding and resources available. The reality is that even though an advisory committee has identified a need in the community, the UCEDD may or may not have the necessary means to address the identified need. The advisory committee can play a role in assisting the UCEDD

in identifying or strategizing in creating funding and/or resources that could meet an unmet need.

10. **Relationship with Director:** The DD Act clearly states that the CAC advises the UCEDD Director. Relationship building between the CAC and the director is essential to make this function of the CAC a meaningful reality.
11. **The 5-year Core Grant:** The DD Act not only states that the CAC must advise the UCEDD Director but it must also consult with the Director regarding the development of the 5-year plan and core grant and participate in an annual review of, and comment on, the progress of the UCEDD in meeting the projected goals contained in the plan and make recommendations to the Director regarding any proposed revisions of the plan that might be necessary. This is a primary role of the committee and the reality here is significant preparation through training and support must be provided to the membership of the committee to be prepared to take on such a task.

Over the years as Director of our Center, I can say my experience utilizing, developing, and maintaining a CAC is a positive one. Through much thought and reflection I have identified the preceding needs and realities that I know face many Directors and CAC members. Frequent reassessment of the fit of an advisory committee with the directions in which our program is headed helps to make this prescriptive framework of a CAC meet our advisory needs.

Self-Advocate/ People First Member's Perspective

My name is Cathy Enfield. I live in the community on my own with the supports I need to be part of the community. I believe I should speak up for people who cannot speak for themselves and that

CAC members and UCEDD Directors can work together to identify what tools both parties need in order to foster a successful role for the CAC.

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Beyond Tokenism

Bill Krebs, as told to George Gotto

Hi, my name is Bill Krebs and I am from Philadelphia, Pennsylvania. For the past several years I have been working on a project called “Beyond Tokenism.” I became involved in this movement when the Pennsylvania Developmental Disability Council had a project called “Board Inclusion.” They took a bunch of self-advocates who were serving on boards to try and figure out what was needed for us to be active members when we serve on boards. The first thing we did was change the name because we realized that people with disabilities, no matter what your disabilities, were put on the board just to be a token, not a voice. So, we renamed it “Beyond Tokenism.”

Goals of Beyond Tokenism

As the name says, the main goal of “Beyond Tokenism” is to find ways for self-advocates to contribute to boards and organizations and not just be tokens. We broke this down into small goals. The first is to help self-advocates to fully participate in boards and policy groups. Second, we want to have more self-advocates serving on boards and teaching organizations. Self-advocates should not just take up a spot so organizations can check the self-advocate box in their checklist. Once self-advocates are on boards, we need to speak out and have a voice. This means having the confidence to speak out when you are at a meeting. It also means that boards need to be open to letting self-advocates speak. Next, self-advocates need to learn to be an effective board member. They can only do this with help from the board. There are a lot of things that boards and organizations can do to help self-advocates become effective board members.

Helping Self-Advocates be Effective Board Members

There are several things a board can do help self-advocates be active members of the board. First, organizations should have one or more self-advocates as members of their boards. This shows that they value the self-advocate’s input and believe self-

advocates have important opinions to offer. Second, members of the board who do not have disabilities need to increase their own confidence to work with self-advocates on the board. They can do this by spending some time talking with the self-advocates and getting to know them. This can help board members feel more comfortable talking to self-advocates and listening to their opinions. Third, conversation levels during the board meetings should support self-advocates to serve on the board. It is important that boards use words in the agenda, materials, and the discussions so that self-advocates understand. This is how they support the self-advocate’s participation. Fourth, self-advocates are just like other people, sometimes they are shy or nervous to speak up. So, board members should know to ask self-advocates for their opinion and give them a chance to participate. Fifth, asking self-advocates for their opinion means that board members



Bill Krebs has spent the last 26 years fighting for the rights of people with intellectual disabilities.

should be willing to listen to those opinions. Learning to increase your ability to listen to self-advocates is an important way to help them be more than a token. Sixth, board members should learn to increase their ability to engage self-advocates on

their boards. This means including them in committees and other board activities and listening to their opinions.

All boards for all types of organizations should have a person with a disability on them. Common sense says people with disabilities should be included.

How Can a Self-Advocate be a Good Board Member?

When we first started working on this, my friends used to talk about “steps” to becoming a good board member. But I said, “Hey, steps are boring. Let’s talk about a football field because everyone understands football.” You start at the goal line and move up. First you have to be invited to serve on boards and that is the ten yard line. Then you move up and you have to be accepted on the board, the 20 yard line. Then you have a mentor on the board—the 30 yard line. Then you share your opinion on the board, you are speaking up on the board. Every ten yards represents another goal towards being fully included on the board. And before you know it you are at the goal line.

Sometimes there are barriers to participating on a board. These are like the defense on the football field that keep self-advocates from making it to the goal line. The offense wants you to go, go, go but the defense will try to stop you in your tracks every time. But there are ways to get around these barriers. One barrier that a self-advocate might have is to understand everything that goes on during a meeting. One way around this barrier is finding a mentor who can help you during and before the meeting. Hav-



ing a mentor also helps the self-advocate get to know people on the board and feel more comfortable speaking up. How do you find a mentor? This is easy. Some organizations already have them and will offer them to you. Someone you know like a friend or family member, someone you can trust can also serve as a mentor. Or another board member who can take you under their wing is a good mentor to have. Boards should always ask the self-advocate how they would like to deal with this. Does the self-advocate want the board to give them a mentor? Or, does the self-advocate want to find their own mentor? The important thing is having someone

People with disabilities have effectiveness because they lived it, they breathed it, walked it, they talked it, and saw it and it is part of their life.

who can have a pre-meeting to go over the agenda so self-advocates will understand what will be happening in the meeting.

Another barrier for self-advocates who serve on boards is transportation, especially if you are from a rural area. There are a few ways to deal with this. One is making carfare and bus fare available and reimbursing board members for their transportation costs. Another solution is to find other board members who are willing to give you a ride or using family and friends who are willing to help. It is also helpful for organizations to give an allowance if self-advocates need to stay over for the night. It is important for self-advocates who serve on boards to know that they should ask for the accommodations they need.

Another barrier that self-advocates run into is access. Boards need to make sure that they hold all of their meetings in a place that is accessible, where self-advocates don't have to go up stairs or squeeze into spaces that are

too small for them. When you have a wheelchair this is really important.

Sometimes technology can be a problem. A lot of self-advocates don't have a computer or email. That is why it is important to have someone (like a mentor) who can call the self-advocate and tell them about meetings and events. Or you can mail all the information to them two weeks in advance. On our board, if a self-advocate doesn't have the agenda with all materials two weeks in advance to look at and talk about with their mentor, then they won't discuss those items at the meeting. It is dropped from the agenda. We have cancelled discussions because members didn't have their materials in time.

Organizations That Should Have a Person with a Disability on their Board

All boards for all types of organizations should have a person with a disability on them. Common sense says people with disabilities should be included. We are a part of the community. We participate in the community like all other people and we should be included in any board that is in the community. People with disabilities want to know what's going on out there and be a part of it. All boards for all people should include a person with a disability.

For an example, take an average board. It will include all types of professionals. Well the professional never walked in my step, he never saw through my eyes, never heard my voice and listened to what I had to say. People with disabilities have effectiveness because they lived it, they breathed it, walked it, they talked it, and saw it and it is part of their life. No college degree will ever make them understand what a person with a disability goes through in their daily life. Maybe if they have a family member, a friend, a relative or someone they know, they may have some idea what a person with a disability goes through, but not totally. When a person with a disability is on the board they are very effective. They don't want to be a token that is there just to be there. When boards look at the records from their meeting they will see that there was a priest, there was a cop, a lawyer, the CEO, and parents. They should also see that there was a self-advocate.

Bill Krebs – Philadelphia, PA. Bill Krebs is a self-advocate from Philadelphia. He has spent the last 26 years fighting for the rights of people with intellectual disabilities. If you would like him to conduct a training on Beyond Tokenism with your organization please contact him at: mr.trouble64@yahoo.com.

SELF-ADVOCACY

RESPONSES TO DISABILITY: Increased employment and educational opportunities; greater inclusion of people with disabilities in the community.

There are still tens of thousands of people with disabilities in institutions, and thousands more in nursing homes.

label jars not people

SKELTON WORKERS FOR THE RIGHT TO LIVE WITH DIGNITY

BOARDS

"NOTHING ABOUT ME WITHOUT ME"

Self-advocates in Minnesota organized and pushed for the right to hold a union election at their workplace. Workers not only demonstrated their ability to speak for themselves, but also urged the improvement of economic justice. Many skilled workers at this time were paid less than \$7.00 per hour with no vacation or sick leave. The workers would not even let the workers vote on whether to have union representation, but through legislation, self-advocates did win \$55,000 through legislation, and advocates did win \$55,000 at each pay.

An important goal in self-advocacy is closing institutions. Institutionalization did the damage, worth living for — job, independence, choice, control, feelings, autonomy — and make you give up on life itself. As self-advocates we must close doors, every institution and isolate our institutions, brothers and sisters who are now waiting away.

Self-advocates in Connecticut held a press conference from within the Southbury Training School, an institution they wanted to close. Three TV networks covered the event, and the show "60 Minutes" later did an investigative report on Southbury.

We must be listened to as we express ourselves, and we must be allowed to make our own mistakes. We must help those who have higher support needs and cannot speak for themselves, so their decisions can be understood and respected.

PERSONS WITH DEVELOPMENTAL DISABILITIES ADVOCATE FOR THEMSELVES AND OTHERS WITH DISABILITIES, PROCLAIMING "WE ARE PEOPLE FIRST!"

The Disability Rights Timeline, displayed at the SABE conference, includes the important role of the self-advocacy movement.



Attendees of the 2010 SABE conference join together to honor the legacy of Eunice Kennedy Shriver, who dedicated her life to promotion of unity.

*Perspectives on a CAC...
continued from page 23*

is what I try to do. I want to help other people, especially people with disabilities.

I am on lots of boards and committees as a representative for people with disabilities. Most of them are involved either directly or indirectly with programs the UCEDD supports or works with. I have been fortunate to attend the national Association of University Centers on Disabilities (AUCD) Conference and experience firsthand the work of COCA and AUCD. This helped me understand the different roles that UCEDDs have in different states and some of the issues in maintaining a CAC. My first contact with the UCEDD was through programs that relate directly to supports provided by the UCEDD. I first learned about the UCEDD through my involvement in People First and later with SABE. My experiences with programs and partnerships with the UCEDD have helped me to be more effective when trying to educate my legislators. I also have great relationships with my Missouri State Representative and Senator. I am also a member of the Mayor's Committee on Disabilities in Kansas City, Missouri.

Taking into account all of the experience I have had serving on the UCEDD's CAC and advising or participating in the programs it supports, I would like to share a self-advocate's perspective of what a UCEDD is and what role it plays in Missouri. The UCEDD means people working together to get more information to help people with disabilities. The UCEDD and its programs have helped me meet new people, make new friends, and be more

aware of other people's problems and how they deal with their lives. The UCEDD helps people with disabilities and their families understand the things that affect their lives and how to deal with them. It has given me the opportunity to learn about many things that

affect my life and how to have input into those decisions. I think the most important thing the UCEDD does is to support programs that help people with disabilities to live in the community and to help us understand how to be a good self-advocate.

I enjoy serving on boards and committees to provide a voice of a person with a disability, but there are also problems which make participating difficult for me. Boards and committees tend to forget that some members cannot move quickly through discussions and need help to understand what is being said. These groups invite people with disabilities to participate but they do not make accommodations which enable them to be effective. Also there is a real fear among persons with disabilities that their input will not be considered or they will be ignored or even dismissed from the board if they show signs of not understanding. Boards and committees need to be aware of the differences in their members and conduct meetings in ways that enable everyone to participate effectively.

Despite these problems, I am very happy and fortunate to serve with these groups. I am very appreciative of the role my UCEDD plays in encouraging and supporting these activities and the role that it continues to play in encouraging and supporting me. The Missouri UCEDD has empowered me to be part of the solution to the problems people with disabilities face each day.

Conclusion

A lot of the challenges described in this paper can be met with an organizational response to the structure and operations of a

CAC. Other needs can be met by providing the necessary training to prepare individuals for their roles on a CAC. CAC members and UCEDD Directors can work together to identify what tools both parties need in order to foster a successful role for the CAC. Training materials and other technical assistance is available for UCEDDs to use with their CACs. The authors encourage CAC members and UCEDD Directors and staff to take a step back and think about what a CAC is, both in the letter and spirit of the law, what is a meaningful role it can play for your particular UCEDD, and how to make it beneficial for both parties. This will provide a framework for crafting a training and organizational response towards enhancing your CAC. Though challenging and time-consuming, this relationship building is very important work. A meaningful relationship between a CAC and a UCEDD creates a better world for people with developmental disabilities and their family members in your state.

Reference

Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106-402, Sec. 154, 114 Stat. 1722 (2000).

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Cathy Enfield – SABE and People First of Missouri. Cathy has worked as a self-advocate leader for the past 20 years. She is currently a representative to the SABE board and the Treasurer for People First of Missouri. She has also served as Community Advisory Council member for the UMKC-IHD UCEDD.



Using Participatory Action Research to Promote Self-Advocacy and Self-Determination of People with Disabilities

Consumer Involvement in Shaping Montana State and Local Public Health Policy and Practice

Meg Traci and Tom Seekins

The National Council on Disability—15 presidentially-appointed “...people with disabilities, parents or guardians of people with disabilities, or other people who have substantial knowledge or experience relating to disability policy or program” (www.ncd.gov) working on self-determined macro-level decisions—established the goal of improving the health of people with disability in their 1986 report, *Toward Independence*. In doing so, they ushered in an era in which disability has emerged as a significant new issue in public health. Among the many new efforts, the Centers for Disease Control and Prevention has funded several states to operate capacity-building programs in disability and health. The purpose of these programs is to demonstrate approaches to delivering health promotion to people with disabilities.

Montana’s University Center for Excellence in Disabilities). The mission and long-term goals of the MTDH Program are to reduce secondary conditions, improve the health of people with disabilities, and eliminate health disparities experienced by people with disabilities. A key element to program success is the involvement of people with disabilities in shaping the agenda and advocating for action.

MTDH’s Approach to Disability and Health Advocacy

Advocating in the field of disability raises some complicated questions (e.g., Who is advocating and for what?). Some groups organize around a specific impairment and advocate positions that benefit only people with that impairment. For example, blind people were successful in advocating for social security benefits that are about double what any other group receives. Conversely, some groups organize individuals who experience similar problems regardless of their specific impairment and advocate positions that benefit all people with disabilities. The effort to organize across disability groups to pass the American’s with Disabilities Act is an example of that approach.

MTDH adopted a cross-disability social planning approach to involve consumers in shaping Montana’s Public Health Agenda. We organized three groups of consumer advocates to involve in the essential services of public health—assessment, policy development, assurance, and research. In doing so, we used standard methods derived from Participatory Action Research (PAR) and Community Based Participatory

Research (CBPR) practices. These three groups are 1) the MTDH Advisory Board, 2) MTDH Disability Advisors, and 3) MTDH Accessibility Ambassadors. In doing so, we used standard methods derived from Participatory Action Research (PAR) and Community Based Participatory Research (CBPR) practices.

MTDH is guided by an Advisory Board composed of 12 representatives from across the State; seven (58%) have personal experience with disability. At its inception, the Board focused on policy development and practices for 1) improving the health of two target populations, adults with physical disabilities and adults with intellectual and developmental disabilities (I/DD); and 2) including disability in public health assessment, policy development, assurance and research processes (e.g., Disability Advisors and the Accessibility Ambassadors programs). Over time, the Board built its capacity to develop and implement the first statewide strategic plan for improving the health of Montanans with disabilities.

MTDH’s capacity was expanded by two Board-determined projects. The first, MTDH Disability Advisors, identify issues of importance that are being addressed by the public health bodies on which they serve and report those issues and opportunities to the MTDH Advisory Board. The Advisory Board then can design efforts to address those issues. This may include clarifying issues through state-wide data collection and promoting exemplary practices—activities often accomplished by the second MTDH Advisory Board project-- a statewide corps of MTDH Accessibility Ambassadors.

Achieving impact takes time and persistent engagement.

The Montana Disability and Health program (MTDH), a CDC Disability and Health capacity-building program, was established in 2002 as a partnership between the Montana Department of Public Health and Human Services and the Rural Institute on Disabilities (Mon-

Looking Back: Building a Collaborative Environment for Public Health Planning

MTDH's initial capacity to work with adults with physical and adults with intellectual and developmental disabilities (I/DD) grew over fourteen years of our participatory action research aimed at developing evidenced-based health



Montana Disability and Health program Accessibility Ambassadors Travis Hoffman and Dennis Ommundson conduct an accessibility assessment of a mammography center.

interventions for both target populations. Self-advocates from Montana Centers for Independent Living (CIL) and from the Montana Council on Developmental Disabilities invited University of Montana researchers to join them in working toward the health-related goal set by the NCD. Knowledgeable disability leaders and representatives participated in all stages of research that produced three empirically validated interventions: 1) Living Well with a Disability (LWD), a health promotion program for adults with chronic conditions and mobility impairments; 2) MENU AIDDS, a self-managed nutritional intervention for individuals with I/DD living in supported arrangements; and 3) Have Healthy Teeth, an oral health program developed with and delivered by People First Chapters to its local members.

Through this research, these same disability leaders and representatives acquired expertise in PAR, CBPR and public health. These relationships expanded under MTDH into partnerships that make up a statewide Disability and Health Network. Individuals from the Network were first recruited to serve on the MTDH Advisory Board. Later, individuals from the Network

would be recruited to serve as MTDH Disability Advisors to participate in traditional public health networks (e.g., Montana Cardiovascular Health Taskforce Committee, Diabetes Coalition, Dental Access Coalition, Cancer Control Coalition, etc.) and as MTDH Accessibility Ambassadors to work statewide to promote awareness of the benefits of accessibility through accessibility evaluations and resource dissemination. The Network facilitates communication and increased interactions between the disability community and the public health community. Overtime, this communication fosters partnerships at local levels and around issues outside MTDH's scope. In an ongoing dynamic process, people with disabilities identify issues and public health provides data (e.g., U.S. Census and Behavioral Risk Factor Surveillance Survey reports), resources (e.g., small grants), and programs (e.g., screening programs) that pertain to the issues.

Information shared can be amplified when members of the Disability and Health network belong to other networks through which they can provide education about the issues. For example, when Diabetes Coalition members understand the importance of state print materials being available in alternative formats, they carry this knowledge to their work in hospital-based and private practices. Additionally,

The development of educated allies is something to celebrate.

Network activities afford members gained understanding and capacity to collaborate on MTDH and other initiatives. For example, ongoing Accessibility Ambassador projects increase interactions between the independent living community and the health care community around accessibility evaluations and resources. These afford increased opportunities for IL advocates to educate health care providers about independent living services and self-advocacy groups and for health care providers to educate IL advocates about

A key element to a program's success is the involvement of people with disabilities in shaping the program's agenda and advocating for action.

health care services and programs. Anecdotally, this increased awareness has led to better referral between the two systems.

MTDH Disability Advisors Achieving Self-Determined Public Health Decisions

MTDH Disability Advisors was a project of the Advisory Board that grew out of involved advocates setting the course for the program. It promoted self-determination on two levels. First, a volunteer group of Board members worked together at the second in-person Advisory Board meeting and during a series of subsequent conference calls to answer the question: "How do we get the biggest bang for our buck?" Second, the working group developed a plan to direct \$10,000 to support the recruitment, training, and support of individuals to serve as MTDH Disability Advisors on selected State agency advisory bodies. Advisors are openly recruited with a standard recruitment form from among trained CIL, People First, and other disability-rights self-advocates. Disability Advisors also have direct experience with the public health issue concerning the advisory group and are able to represent those perspectives as well (e.g., the Advisor is managing diabetes or asthma; the Advisor is a direct family member of a cancer survivor). Their participation raises the group members' awareness and increases the responsiveness of the generic programs to the needs of people with disabilities. MTDH program staff documented the process developed by the working group and expanded it for adaptation elsewhere, including a resource list that is maintained



and updated on-line: <http://rtc.ruralinstitute.umt.edu/advocacy/Advisory.htm>.

The MTDH program provides a full-day, in-person orientation and training on 1) programmatic support to Disability Advisors; 2) public health content relevant to disability and health and to the individual committees (e.g., MTDH strategic plan, other public health state plans, specific public health data on subpopulations with disabilities, issues unique to the disability experience affecting access to public health

represent the interests of people with disabilities to the generic service programs.

Broadly, the Disability Advisors program reflects a state level policy to integrate disability issues into the policy development and advisory group activities of public health programs. Still, achieving impacts takes time and persistent engagement. When first introduced to an advisory group, Disability Advisors celebrate seemingly smaller achievements such as being included on the committee email distribution lists, which reflect the acceptance and membership on the committee. This may be followed by the committee planning ahead for specific accommodations for the Advisor (e.g., distributed alternative formats of meeting materials). MTDH staff initially provided training to bureau chiefs and project leads on including Disability Advisors. This involved providing guidelines to committee coordinators and support for making accommodations as needed. The Department has maintained this capacity, assuming responsibility for recruitment of Disability Advisors, conversion of meeting materials to alternative formats, and the cost of travel support and logistics coordination for Disability Advisors. Program commitment to inclusionary practices, reduces the self-advocacy burden of Disability Advisors, allowing them to focus on self-determination in macro-decision making activities of the committee.

The influence of the Disability Advisors grows as their number of interactions with board members increases.

The influence of Disability Advisors strengthens as the number of interactions and amount of dialogue increases. Sometimes a senior member of the advisory group personally knows the Disability Advisor, and during breaks and lunch, the senior member may prompt the Advisor to expand on his or her roles as an Advisor. Also, we have seen public health professionals who participate in multiple advisory groups assume mentoring roles when new Advisors are introduced to new groups. MTDH project directors attending advisory group meetings have also benefitted from these interactions. These occurrences can help build comfort and relationships within the group. For example, simple instruction on the culture of group introductions and how to describe the multiple roles an Advisor has (e.g., CIL staff person, MTDH Disability Advisor, person with diabetes) can improve the quality of an Advisors' introductory statement in ways that connect them to other committee members during the course of the meeting. MTDH also supports Disability Advisors' growth within advisory groups by preparing public health data and resources about persons with disabilities that would be relevant to the Advisory Group. For example, accessibility data provided by Accessibility Ambassadors' evaluations have supported Disability Advisors' ability to advocate for a focus on removing barriers to public health resources uniquely experienced by persons with disabilities. Disability Advisors can distribute this information as written materials or can organize the materials for presentation to the group. Critically, Disability Advisors present this information with personal and professional experiences

There are a lot of things that organizations can do to help self-advocates become effective board members.

resources); and 3) on committee process (e.g., training provided by members of the local chapter of the League of Women Voters). Advisors are compensated up to \$100 for a day-long meeting plus allowable expenses for committee work. The Disability Advisors participate as full members and



Montana Disability Advisor, Darren Larson, and Michael O'Neil, Executive Director of the Montana Home Choice Coalition discuss housing policy and visitability at the Montana Housing Partnership Conference held June 15-17, 2010 in Helena, Montana.

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Surveying Self-Advocates: Using iPads Embodies Self-Determination

Allen A. Schwartz and Daniel K. Davies

Recently, the National Gateway to Self-Determination (NGSD) co-sponsored the Self Advocates Becoming Empowered (SABE) 2010 National Self Advocacy Conference. Approximately 750 self-advocates from 41 states attended this conference, where self-determination was a key focus of the agenda. The first session featured Sharon Lewis, the Commissioner of the Administration on Developmental Disabilities, who discussed self-determination in her keynote address. The second session focused on self-determination and building social capital; and the third focused on “Self-Determination in 2020.” Another event that focused on self-determination was the SABE Self-Determination survey. The aims of this survey were to ask self-advocates about aspects of their lives related to self-determination, and to test the use of an assistive technology that enabled self-advocates to answer in a more self-determined manner.

Choosing a Tool to Survey Self-Advocates

Before we were able to test an assistive technology that empowered self-advocates to respond to questions about self-determination outcomes on their own, we had to choose a survey tool. Over the years, a variety of surveys have been developed to collect information about the activities, experiences, attitudes, and quality of life of people with intellectual and developmental disabilities. One widely-used survey is the National Core Indicators (NCI), jointly developed by the Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disabilities Services (NASDDDS). The NCI is a set of surveys answered by adults with disabilities, families, providers, and government agency personnel. Developed over a decade ago and now used by 30 states, this set of surveys has allowed program directors

and researchers to track the performance of their service systems. In addition to providing information on how well service systems are performing, use of the NCI has also provided information about how people with disabilities are living, working, and being included and supported.

Some of the NCI questions for adults with disabilities ask about choices, community participation, relationships, and independent living—in other words, the questions are outcome indicators that are typically associated with self-determination. We decided to use items from NCI to develop our own tool to briefly assess specific aspects in the lives of adults with disabilities related to self-determination. Our goal is to continue to collect information about these types of activities using assistive technology, so that we can track changes in how people respond over time. This may give us an indication about whether people with disabilities are becoming more self-determined.

Creating a New Way to Survey Self-advocates

The leadership consortium of the NGSD project adopted the following operational definition of self-determined action: “We understand self-determined action to refer to the characteristics of a person that lead him to make choices and decisions based on his own preferences and interests, to monitor and regulate his own actions, and to be goal-oriented and self-directing.” Further, we believe that both the abilities of the person and the opportunities presented by the environment contribute to the degree to which people become more self-determined. Therefore, the first step was to select 30 or so questions that best captured outcomes related to self-determination in line with that definition.

The NCI survey of adults with intellectual and developmental disabilities is

usually conducted through an interview process. Family members and staff people, as well as an interviewer, may be present at the time of the survey. The presence of others can impact the answers people

The survey process enabled self-advocates to participate in a more self-determined manner.

give to personal questions. We wanted to use a method that honored the capabilities of people with disabilities and allowed them to speak for themselves as much as possible. Our hope was that this would make people feel comfortable and enable them to give honest answers about how they feel. To accomplish this we wanted a survey process that would allow self-advocates to read or listen to questions and answer them independently and in complete privacy. The Apple iPad seemed to be the perfect device for this.

We chose questions that were brief and clearly worded. AbleLink Technologies of Colorado Springs, Colorado took the questions and incorporated them into a cognitively accessible software design they developed for use with iPads. The software read each question and the possible answers aloud. The person pressed the iPad touch screen to record his or her answer. Some questions (e.g., “Who decides what you buy with your spending money?”) were answered either by choosing, “I decide,” “People help me decide,” or “Someone else decides.” Other questions (e.g., “Do you like your home, or where you live?”) were answered by selecting “Yes” or “No” on the touch screen. To take the survey, participants wore headphones, read or listened to the questions, read or listened



to the possible answers, and then touched the screen to select an answer. Only one question and set of answers appeared on each screen. Navigating the screens was easy for most self-advocates, even those with a physical disability, as the iPad touch screen requires very little pressure.

We field-tested the survey with a group of self-advocates who told us they found the iPad easy and fun to use. They also made suggestions about changing the wording on some items to make them more easily understood. We then developed a detailed set of procedures for the survey process to ensure that it was private and confidential, and that participants would understand their rights as well as how to use the iPad. We thought it was important to have self-advocates as part of the survey team, so we recruited and trained a group of self-advocates to support participants and make them feel comfortable with the process. These survey mentors were a vital part of the survey process.

Collecting Data at the 2010 SABE Conference

SABE 2010 was great opportunity to test out our self-administered iPad survey. We knew that SABE members have a strong interest in self-advocacy and self-determination, and we thought they would consider this survey to be important. We also know that SABE is often attended by self-advocates who could likely participate independently. Since SABE has a conference every two years, we have the opportunity to repeat the survey on a similar group frequently to see if self-advocates' experiences change. The SABE board was very supportive of our project. During the conference, we had a separate room set aside for people to take the survey, and SABE helped promote completion of the survey.

The self-advocate mentors were a vital part of the process. They recruited participants for the survey by mingling among the attendees and inviting people to take the survey. They explained the survey's purpose, what taking the survey would be like, and assisted with informed consent.

Once the person consented to participate, he or she was escorted to one of the private stations that were set up in the room. The person put on a set of headphones, as did a survey assistant, so that



A SABE participant completes a survey using the iPad.

the questions could be heard in private without disturbing the other people in the room who were taking the survey. The survey assistant showed the person how to use the iPad as they answered the first few demographic questions. These questions allowed us to gain valuable information about the people who were taking the survey, and also served as a training experience in using the iPad. At the conclusion of these demographic questions, participants were asked if they felt comfortable doing the rest of the survey – the part on life experiences related to self-determination – by themselves. Nearly all of the self-advocates indicated that they wanted to complete the survey independently, and did so successfully. Survey assistants remained nearby in case people needed any help, but few people required any significant additional assistance.

In total, over 240 self-advocates attending the conference took the iPad survey.

We were happy with the cooperation and support of all the attendees, and we were pleased with how well the iPad technology worked. Only one person dropped out before completing the survey, and only 24 surveys had to be removed because they were incomplete or because they did not meet our pre-determined validity requirements. After completing the survey, most self-advocates who participated said it was an enjoyable experience. They liked the type of questions in the survey and very much liked using an iPad.

What We Learned

We're still in the process of analyzing the iPad survey information collected at the SABE Conference. One thing the data confirmed was that the self-advocates attending SABE 2010 were indeed a very special group. The vast majority of survey participants live on their own or with their

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Using PAR...
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that increases the information's social validity as well as the sense of urgency among committee members to address concerns or promote promising practices.

Eventually, the development of educated allies is something to celebrate—members of advisory groups who initiate advocacy for disability and health issues. For example, it is extremely gratifying to attend public health meetings and see policy makers advocating for the adoption of strategies to increase the accessibility of communities, programs and services to senior citizens and persons with disabilities. In one instance, a mayor of a small Montana town invited the NAPA and MTDH programs to provide technical assistance on improving the accessibility of his town's recreational trail for seniors and persons with disabilities. He applied the information provided by local consumers and program staff to improve the local trail and now actively disseminates this success. In another instance, a member of the Montana Board of Housing stood with those organized to advocate for the addition of the zero-step entrance to the Montana QAP and said, "We have been discussing this requirement for a number of years now, and after the presentations by members of the Montana disability community at the Affordable Housing Conference this year, I am persuaded that this requirement will improve the quality of housing in Montana and the time to add it is now."

The Disability Advisors program reflects a policy to integrate disability issues into the policy development and advisory group activities of public health programs.

Conclusion

Montana stretches 630 miles across and 280 miles north to south. The key strategy for building our large state's capacity to improve the health of Montanans with disabilities is to involve individuals with disabilities who are already organized to advocate for self-determined disability service improvements to also advocate for self-determined public health services. While this article has discussed specific state-level activities important to our program, the use of social planning advocacy to engage individuals with disabilities with public health professionals has translated to local-level advocacy activities and will have sustainable outcomes for years to come.

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iPads...
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families. Many have jobs in the community. And most participants said they made many of the decisions that affected their lives. These indicators suggest that this group experiences a high degree of self-determination, and that their independence and self-determination is likely greater than others who have intellectual and developmental disabilities.

We will continue to modify the questions on the survey with the goal of developing a tool that can validly measure how specific self-determination outcomes people experience may change over time. This will require us to refine questions and compare our results to other survey tools until we have an accurate and reliable measure for use in our project.

The other major lesson from the SABLE survey was that many people with intellectual and developmental disabilities are capable of answering questions about themselves on an iPad. The iPad provided the support most people needed to use the device independently, with very little training or assistance. Using technology allowed them to answer in private, expressing their own opinions, without being influenced by others. In other words, the survey process itself with usable technology allowed for self-advocacy and the opportunity for independent and self-directed action. In the years to come, we hope to improve and repeat this survey, as part of the exciting movement to expand the use of technology for the benefit all people, including those with intellectual and developmental disabilities.

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Daniel K. Davies – AbleLink Technologies, Inc. Dan is Founder and President of AbleLink Technologies, Inc., a small business in Colorado Springs, Colorado providing national leadership in the area of research development of cognitively accessible technologies.



...Post Script

In the fall of 2010, we celebrated the 20th Anniversary of the DD Act and 20 years of Self-Advocates Becoming Empowered at the SABE National Conference. With over 1000 people in attendance, we heard Commissioner Sharon Lewis talk 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 letting risk! It’s actually really simple, but it’s not easy...”

Commissioner Lewis went on to discuss working in partnership with self-advocates, sometimes supporting, and sometimes getting out of the way. She outlined the framework in the system and how it works together to create this effective support system from the ground up. Self-advocates and their families work for change in the community, working to positively have a voice in their own life. The state support organizations are charged with

developing and supporting systems change and capacity building efforts that help with self-determination, integration, and inclusion. State agencies also make sure our legal rights are protected. They help us stay safe and protect all of our civil rights. At the national level, the ADD network is focusing on supporting not only the letter of the law but the spirit of the law.

The articles in this Issue of Research to Practice in Self-Determination review self-advocacy and self-determination in areas of relevance mentioned by the Commissioner. Included are articles about concepts, personal reflections by self-advocates about experiences, articles about research, and articles about systems. In this summary article, we will re-visit several of the key concepts and reflect on how these concepts were illustrated by contributing authors.

Self-advocacy and self-determination are critical to the empowerment of people with developmental disabilities.

Concepts: Self-Advocacy and Self-Determination

The opening article by Carl F. Calkins discusses the relationship between self-advocacy and self-determination. Self-determined people act as causal agents in their lives - they are actors and active players in their lives instead of being acted upon. When a person has a voice in the decisions that affect his or her life, then that person is practicing self-determination. 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 needs and desires (or those of a collective group) to assure their access to and full participation in the community.

Self-advocacy and self-determination are critical to the empowerment of people with developmental disabilities. To best promote self-determination, opportunities should be provided within multiple social contexts. At work, school, home, or in the community, efforts can be made to support the self-expression of individuals with disabilities through technology and other tools, support meaningful participation on boards, target the development of self-advocacy skills, and promote building wide social networks and opportunities for social capital.

Self-advocacy skills need to be developed over time. Self-advocacy skills include assertiveness, rights and responsibilities, communication, and leadership (Wehmeyer, 2007). This notion is illustrated throughout this Issue with a number of self-advocates sharing their stories.

Self-Advocacy and Self-Determination in Action

A number of national self-advocacy leaders share stories in this issue about



Sharon Lewis, Commissioner of the Administration on Developmental Disabilities, speaks about supporting self-determination at the 2010 SABE conference.



learning self-advocacy skills and developing these skills over time. In the article “Self-Advocates Leading Self-Determined Lives,” Self-Advocates Becoming Empowered (SABE) leaders Nancy Ward and Tia Nelis discuss this process (page 6). Nancy said, “It took me five years to gain the confidence through practicing speaking up for myself and not be afraid to ask for support.” Tia related that as a young person, her tendency was to react in an angry way. An advisor helped her build positive self-advocacy skills. Tia said, “Self-advocacy helped me learn how to communicate my opinions and needs in a positive way.” In this article, the SABE leaders advocate for additional opportunities for people with disabilities to learn these skills, stating that “There needs to be a range of leadership and self-determination training available.”

In a story focused on the role of supports in self-advocacy and self-determination (page 8), Mia Peterson also describes how she gained self-advocacy skills through a number of formal and informal channels. She worked to overcome her shyness and develop assertiveness skills with family and mentors, and she also improved communication through participation in courses, school activities, and practicing writing and public speaking. Amy Sharer described development of self-advocacy skills through a positive employment experience at a UCEDD (page 20). She describes her evolution, from hesitancy at raising her hand to express interest in a position to confidence in her leadership role in a num-



Nancy Ward and Mike Wehmeyer co-presenting on the meaning of Self-Determination at the 2010 Self Advocates Becoming Empowered conference in Kansas City, MO.

ber of research tasks. She credits acceptance, accommodation, and training as key contributors to success and confidence she found in the employment that she chose.

Concept: Social Ecological Approach

Self-advocacy and self-determination are best supported through social ecological approaches - the multiple environmental contexts in which a person lives his or her life, including home, school, work, and community organizations. A number of the articles in this issue illustrate how a person’s needs, wants, and aspirations can be matched with opportunities and supports in the environment that meet these desires.

Social Ecological Approach in Action

Contributors relate stories of opportunities arising through family, work, school, home, and mentors in the community, and through participation in self-advocacy organizations, boards, and committees.

Concept: Social Capital

A final key concept is the importance of building social capital within the environmental contexts in which people live and operate. Hill Walker and George Gotto expand upon the concept of social

capital as a vehicle to expand opportunities for choice-making and increase individual options (page 17). They outline several steps to increase social capital in the lives of individuals with developmental disabilities: family and/or parent participation and advocacy in the lives of people who are just developing their own social capital are vitally important; develop and sustain as many peripheral ties as possible—or develop ties with individuals outside the family, in the larger community; and connect with or join important social structures. Illustrations supporting each of these steps can be seen throughout this brief.

Social Capital in Action

Katie Arnold talks about the important role of adult siblings in supporting the self-advocacy and self-determination of siblings with developmental disabilities (page 14), and Mia Peterson describes the role of her parents in introducing her to eventual mentors during her transition to a self-determined adult life (page 8). Bryon Murray and Chester Finn had members of their social networks outside of their families facilitate introductions to others, fostering important opportunities for participation and leadership (page 6). Nearly every self-advocate contributing a perspective to this brief mentions benefits he or she has enjoyed as a result of connections to important social structures.

Self-determined people are active players in their lives - instead of being acted upon.



These connections have led to opportunities to build self-advocacy skills, gain new employment, become involved in important policy change, and realize varied opportunities for community participation, inclusion, and self-determination.

Community Participation

Several authors reflected on representing the needs and desires of people with disabilities through participation on boards. In his article, “Beyond Tokenism” (page 24), Bill Krebs offers a set of guidelines to help self-advocates fully participate in boards and policy groups. He directs these guidelines toward multiple audiences, offering advice to self-advocates participating on boards, but also emphasizing steps that can be taken by boards to more fully include and support self-advocates. In an article describing the roles and

Self-advocates and their families work for change in the community.

boards can address to make full participation by all board members possible.

Systems Change

The University of Montana Disability and Health Program involves people with disabilities in shaping the agenda and advocating for action throughout the Montana state public health program. Meg Traci and Tom Seekins share successful strategies they have used to develop social planning and community-level advocacy movements to promote the health of people with disabilities in their state. These strategies have led to important outcomes for disability and public health, but they have also provided opportunities for participation, created important partnerships, and resulted in self-determined public health programs that are in line with priorities of individuals with disabilities (page 27).

Tools That Promote Self-Advocacy and Applied Research

This Issue of Research to Practice in Self-Determination also includes several articles that focus on tools that promote expressions of self-advocacy and full participation in applied research. Allen Schwartz (page 30) reported on the use of

Apple iPads to support independent completion of a survey by individuals with disabilities. He described how this technology allowed for self-advocacy and practice of an independent and self-directed action, offering individuals a vehicle by which to express ideas more independently.

Spencer Hunley discusses the importance of access to technology to support self-advocacy and self-determination (page 12). He advocates for the use of Linux-based operating systems to decrease cost of assistive technology, improve accessibility, and provide greater selection of products to meet the needs of individuals. Kyla Eversman discusses a different type of tool to support self-expression (page 11). She describes the use of Lifebooks as a fun, low-tech tool that can help individuals communicate their needs and interests, build social capital through positive interactions, and enhance self-determination. In this piece, she shares several examples of individuals who have used Lifebooks and had positive outcomes which have enhanced their self-determination.

Conclusion

Coming full circle, from individual advocacy to systems change, we hope that this opening issue of Research to Practice in Self-Determination has communicated the importance of promoting self-advocacy and self-determination so that, as Commissioner Lewis noted, “people can live in supported communities where they are welcomed, happy, and loved, and where we can all take chances together.”

Our best supports came from other self-advocates who are great mentors.

responsibilities of UCEDD Community Advisory Committees (page 22), Cathy Enfield offers an additional self-advocate perspective regarding board participation. While she enjoys providing the voice of a person with a disability through board service, she experiences problems which make participating difficult. She describes several practical issues that

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The National Gateway on Self-Determination

To establish a sustainable,
evidence-based training
system that enhances self-
determination training programs
that lead to quality of life
outcomes for individuals with
developmental disabilities
throughout the lifespan.



COMING IN THE NEXT ISSUE:

Self-Determination and Employment
edited by Michael Wehmeyer and Wendy
Parent from the Kansas University Center on
Developmental Disabilities (UCEDD)