national gateway to







self-determination

riendships + social capital + community

self-advocacy + community + friendships +

ommunity + self advocacy + social capital

a national training initiative

funded by U.S. Department of Health and Human Services, Administration on Developmental Disabilities



mission

Fall 2010: The purpose of this booklet is to provide an overview of activities to date of the National Gateway to Self-Determination project and describe highlighted activities and products currently available.

The overall goal of the National Gateway to Self-Determination is "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." There are a number of important beliefs upon which the National Gateway to Self-Determination project is founded, as discussed below.

1. Scaling up efforts to promote self-determination (SD) are most effective when they are conducted in an enabling context focused on the people they are intended to benefit. In the case of this project, this context is established by a social-ecological framework that acknowledges the importance of the interactions occurring between people and their environments throughout their lifespan.

- 2. UCEDDs have a responsibility to develop evidence-based practices and to support the translation of research into practice. As such, it is important that scaling up efforts to promote self-determination be developed and tested within the framework of research-based models, theories of self-determination, and research-based or evidence-driven practices.
- 3. Within the context of the Gateway to Self-Determination, the development of self-determination is not an end in and of itself, but rather a viable means to accessing an improved quality of life. Thus, evaluation strategies incorporated into efforts to promote self-determination must address not only increased knowledge and skills leading to enhanced self-determination, but also include strategies for ongoing evaluation of improved quality of life outcomes for individuals with disabilities.
- 4. Finally, people with developmental disabilities must be equal partners in the planning, development, implementation, and evaluation of any effort to promote self-determination. Self-advocates will remain key partners throughout all aspects of the project's implementation.

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mission

leadership consortium

The Leadership Consortium is made up of five primary UCEDDs joining together with the Association of University Centers on Disability and Administration on Developmental Disabilities to lead this effort to scale up and promote SD nationally. The Leadership Consortium includes:

The University of Missouri Kansas City Institute for Human Development (the Missouri UCEDD), Carl F. Calkins, Director. http://www.ihd.umkc.edu

The Kansas University Center on Developmental Disabilities (the Kansas UCEDD), Michael Wehmeyer, Director. http://www.kucdd.org

Westchester Institute for Human Development (a New York UCEDD), in affiliation with New York Medical College,

Ansley Bacon, Director. http://community.wihd.org

The University of Oregon Center on Human Development (an Oregon UCEDD), Hill Walker, Director. http://ucedd.uoregon.edu

The University of Illinois at Chicago Institute on Disability and Human Development (the Illinois UCEDD), Tamar Heller, Director. http://www.idhd.org

The Association of University Centers on Disability, George Jesien, Executive Director. http://www.aucd.org

The Administration on Developmental Disabilities, Jennifer Johnson and Suad Jama, Program Leaders. http://www.acf.hhs.gov/programs/add

additional ucedd partners

The participation of additional UCEDDs is key to the success of this project. Other UCEDDs that provide substantial support include:

The University of Minnesota Institute on Community Integration, David Johnson & Brian Abery. http://ici.umn.edu/welcome/network.html

The University of Alaska Anchorage Center for Human Development, Karen Ward. http://www.alaskachd.org

Texas A&M University Center on Disability and Development, Dalun Zhang. http://cdd.tamu.edu

The University of Delaware Center for Disability Studies, Steve Eidelman. http://www.hdfs.udel.edu

Georgetown University National Center for Cultural Competence, Tawara Goode. http://www11. georgetown.edu/research/gucchd/nccc/index.html

The Missouri UCEDD serves as the lead organization and fiscal agent for the consortium, and Dr. Carl F. Calkins from the Missouri UCEDD and Dr. Michael Wehmeyer from the Kansas UCEDD serve as co-project directors.

For additional information on any aspect of the project, please contact Dr. Carl F. Calkins at 816.235.1755 or calkinsc@umkc.edu.



Mike Wehmeyer & Nancy Ward deliver a keynote address at SABE 2010.

self-determination alliance

A primary objective is the inclusion in every phase of the project of "all the players" in the disability community, from University Centers for Excellence in Developmental Disabilities, to government agencies, and most importantly to individuals and families. The Self-Determination Alliance supports and advises the project and is made up of the following organizations:

College of Direct Support is an internet-based curriculum for Direct Support Professionals creating a workforce to support individuals with disabilities - "Building Careers, Supporting Lives." The curriculum, values, and mission are based on the premise that all people should live life to its fullest in community-based settings. http://info.collegeofdirectsupport.com

Council on Community Advocacy assists AUCD to advance policy and practice for and with people with disabilities, their families, and communities. COCA serves as a model and resource for others desiring to infuse the participation of people with disabilities and family members into program planning, research, and evaluation. http://www.aucd.org

National Association of Councils on Developmental Disabilities promotes and enhances the outcomes of member councils in developing and sustaining inclusive communities and self-directed services and supports for individuals with developmental disabilities. http://www.nacdd.org

National Association of State Directors of Developmental Disabilities Services is a nonprofit organization, established in 1964, to improve and expand public services to people with intellectual and other developmental disabilities. http://www.nasddds.org

National Disability Rights Network works through training and technical assistance, legal support, and legislative advocacy to create a society in which people with disabilities are afforded equality of opportunity and are able to fully participate by exercising choice and self-determination. http://www.napas.org

National Family Voices

(including Kids as Self-Advocates) aims to Betty Williams, President of SABE, & Nancy Thaler, NASDDDS

achieve family-centered care for all children and youth with special health care needs and/or disabilities by providing tools to make informed decisions, advocate for improved public/private policies, build partnerships among professionals and families, and serve as a health care resource. http://www.familyvoices.org

National Leadership Consortium at the University of Delaware is committed to helping develop the next generation of leaders who are passionate about quality, have the necessary management and financial skills, are capable of assembling top-notch teams of caring staff, and have a solid commitment to progressive values. http://www.nlcdd.org

Self-Advocates Becoming Empowered (SABE) is the self-advocacy organization of the United States. Founded in 1990, they have been working hard for the full inclusion of people with developmental disabilities in the community. http://www.sabeusa.org

Sibling Leadership Network provides 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. http://www.siblingleadership.org

collaborations

definition

Much of the initial work of the project involved coming to a consensus on a philosophical approach and definition of self-determination and the various elements involved. Being able to articulate a common understanding of self-determination helps everyone involved in the project work more effectively toward the same goal. Included within this document are some definitions and conceptual elements:

We understand self-determination to refer to a characteristic of a person that leads them to make choices and decisions based on their own preferences and interests, to monitor



and regulate their own actions, and to be goal-oriented and self-directing.

The DD Act definition of self-determined actions, as noted below, suggests that both the abilities of the person and the opportunities presented by the environment contribute to the degree of self-determination that can be expressed.

In line with this approach, we have adopted a social-ecological approach by which we consider self-determination to reflect the interaction of factors in both the personal and environmental domains.

DD Act Self-Determined Actions:

an individual with developmental disabilites, with assistance:

- ✓ has the ability and opportunity to make choices & 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.

special journal issue

A major task of the initial phase of the project was the development of an evidence-based framework to guide the activities of the project and communicate the intended long-term outcomes associated with this initiative, which include improved opportunities to become self-determined, greater social inclusion, and enhanced quality of life for people with developmental disabilities. Through the development of this framework, a series of four in-depth articles was created to help define and clarify specific issues involved in self-determination.

These articles will be published as a Special Issue of *Exceptionality* entitled "Scaling Up Efforts to Promote Self-Determination" and reflect the consensus from the project partners on a social-ecological framework within which to focus efforts to scale up interventions to promote self-determination. This product provides the theoretical framework upon which a multitude of other products will be developed for a variety of audiences.

"A Social-Ecological Approach to Promote Self-Determination" This first article describes a social-ecological approach for promoting and enhancing the self-determination of people with developmental disabilities. A five-level model is presented, based upon the interaction of person and environmental factors, that identifies a series of social mediator variables (i.e. social effectiveness, social capital, social inclusion), which can successfully influence self-determination improvement efforts and enhance the efficacy of self-determination interventions.

"Personal Self-Determination and Moderating Variables that Impact Efforts to Promote Self-Determination" The second article provides detail with regard to how we understand the self-determination construct and discusses moderator variables and how such variables impact the design and implementation of interventions to promote self-determination. Importantly, this article discusses the role of culture as a critical moderator variable in considering interventions to promote the self-determination of people with developmental disabilities from minority or traditionally underrepresented groups.

"Self-Determination Across the Life Span: Issues and Gaps" This article synthesizes the literature on self-determination across the life span with a focus on identifying gaps that exist between theory, research, and evidence-based practices. Using a life-stages approach, it first examines issues across life phases, and then examines cross-cutting topics (employment, abuse and ne-

glect, and health) that are relevant during several age ranges. A life span approach to scaling up efforts to promote self-determination takes into account both the person's developmental stage and the social ecological conditions of his or her life. While its expression for individuals with developmental disabilities can begin at the earliest stages, the level of self-determination generally increases throughout adolescence and early adulthood.

"Lessons Learned in Scaling Up Effective **Practices: Implications for Promoting Self-Determination within Developmental Disabilities"** This final article examines how scaling up efforts should be conducted. Human service and educational professionals agree that implementation science is the missing link that connects research outcomes to the delivery of effective practices. Implementation science informs the scaling up of effective practices and addresses critical issues like social marketing, adoption decisions, capacity building, training, technical assistance, consumer participation and satisfaction, and long-term impact. This article defines scaling up, provides examples of practices that have successfully scaled up, examines levers and incentives for scaling up efforts to promote self-determination, and describes the Gateway to Self-Determination project's template for scaling up efforts to promote self-determination.

How are we learning about the importance of self-determination in the lives of self-advocates and their families?

Story-Telling Initiative: One important element of the project is the story-telling initiative through which self-advocates "write their own story." The story-telling session is perhaps best described as a guided interview through which different topics are introduced. The goal of the session is to allow the self-advocate to tell their own story as it relates to different topics, and describe their experiences in successfully (or maybe not successfully) living a self-determined life as it relates to the topic.

Regarding the topic of "housing" or "independent living" we have two stories - Megan who is living on her own and Chad who has found a great program that has allowed him to make his own choices.

Megan's story: I'm living on my own, after 20 some odd years,

the properties of the properti

and I had been been fighting with my parents. I'm really close to my dad, not as close to my mom, because my mom thinks of me as a "disability kid" not as a child. So it kind of tore me up inside. I talked to my case manager and said I have to get out before I go ballistic. Now I'm living closer to the city, because I like getting out and getting active. I moved into my own place on my birthday – the best birthday present ever. It's amazing.

Chad's story: I didn't know how to cook for myself or anything. I called up a resource and explained my situation. I said "Look - I can't live on my own anymore." He brought me to his support/resource program where I started a whole new life. I now have a whole new life for myself, I'm an advocate... I've done a lot of good work in the advocacy field. All this would never have hap-

pened had I not gotten into the program. I'm advocating for people to get the help that they should get. The program showed me how to cook, how to budget, helped me make something of my life. All this never would have happened without their help. I would have ended up in some institution. **Self-Administered Survey** on Self-Determination Using iPads at SABE 2010: One of the activities of the project was to examine opportunities for SD from items from the National Core Indicators. Twenty-seven items were selected that related to the concept of SD as defined by the project. These items were then reworded into a simplified survey that could be self-administered using Apple iPads operated by self-advocates themselves. Gathering data pertaining to self-advocates' reports of their opportunities for self-determination would prove valuable, allowing for collection of an extensive dataset without time-consuming interviews, and affording privacy and a sense of independence while taking part in a survey process.

The SABE conference provided an ideal opportunity to pilot the survey and collect baseline data on attendees' status relative to various indicators of opportunities for SD captured by the survey items (i.e., choice; employment; community inclusion; etc.). We could also test the viability of gathering responses to these questions directly in iPads rather than engaging in typical NCI face-to-face interviews. This will



Using iPad to take SD Survey

also prove useful in measuring the impact of various local and state interventions over time.

Working closely with AbleLink
Technologies (of Colorado Springs,
CO), a specially designed iPad
interface was developed that was
easy for self-advocates to understand
and navigate on their own. The
software displayed and read each
question and possible answer
out loud to the participant, who
then simply touched the answer
of their choice. With minimal
instruction, nearly three-quarters
of the participating self-advocates
were able to complete the survey
independently.

Volunteers from UCEDDs and other sources assisted the self-advocates in the survey. The research protocol allowed for informed consent and voluntary, anonymous participation. In a little more than two days, staff were able to support over 240 people to take part in the survey, yielding approimately 220 valid surveys. These data are currently being analyzed.

task forces

Through an extensive literature review, the Gateway to Self-Determination identified a number of barriers and training gaps. Based on this review, the Leadership Consortium developed five task forces, each of which will be responsible for outcomes related to one of the following areas:

- 1. **Aging and Life Span Issues:** Aging successfully evolves from exercising SD to create a successful and productive life. It is a dynamic process involving individuals in their environment including the historical and cultural context. The chair of this task force is Tamar Heller at the University of Illinois at Chicago, Dept of Disability & Human Development (UCEDD).
- 2. **Health:** SD has potential for improving the health of people with disabilities. People with disabilities are at greater risk for secondary and chronic conditions; have higher rates of preventable complications and premature death; are more likely to engage in poor health behaviors; and are less likely to obtain affordable and appropriate medical care, early disease identification or preventive screening, or access health promotion activities. The chair of this task force is Ansley Bacon at the Westchester Institute for Human Development (UCEDD) in affiliation with the New York Medical College.
- 3. **Employment:** SD is the essential element for enhancing individual control and involvement in employment, and ultimately job satisfaction and success. The chair for this task force is Michael Wehmeyer at the Kansas University Center on Developmental Disabilities (UCEDD) at the University of Kansas.
- 4. **Community Living:** In many places people with disabilities are institutionalized, denying them freedom and opportunity and excluding them from the fabric and mainstream of community life.

5. **Self-Advocacy:** Self-advocacy skills are critically important if adults with disabilities are to become independent, self-determined people who participate meaningfully in making major life decisions. The chair of this task force is Carl Calkins at the University of Missouri Kansas City Institute for Human Development (UCEDD).



The consortium will also focus on

cross-cutting themes that impact all five task force areas as they relate to self-determination: **social networks**, **technology**, and **cultural competency**.

The chair for each task force was chosen based on areas of expertise. They will determine and coordinate a plan to address the need for research, training, and development of interventions for their focus areas.

Each chair is also responsible for recruiting additional members and assigning tasks. Members will be drawn from other national UCEDDS, the National Self-Determination Alliance, and other state/national groups with expertise in the identified areas.

During Phase II of the project, each task force will be responsible for the following activities within its focus area: 1. Plan a scope of work for the task force; 2. Conduct a needs assessment/evaluation of SD resources within the focus area; and 3. Develop and publish a Special Topic Brief designed to provide strategies, discuss research, evaluate policy analysis, and tell success stories for self-advocates, families, and practitioners.

resource guide

Currently under development is the Resource Guide, comprised of approaches, strategies, resources, and curricula to promote self-determination. We are actively seeking materials for possible inclusion in the guide.

This resource guide will be a valuable tool for use by a broad audience of individuals including people with developmental disabilities, professionals, direct support personnel, parents and siblings, educators, and self-advocates. A web-accessible, national listing of recommended programs and resources to promote self-determination that can be utilized by all constituencies is in development.

The resources included in the guide meet the following criteria:

- ✓ Address one or more of the person-specific elements of self-determination and/or enhance the social or physical environment so that it is likely to support a person to be more self-determining;
- ▼ Be likely to result in personal outcomes and quality of life improvement consistent with self-determination (e.g., opportunities for supported living, employment, community participation and membership, and personal relationships);
- ✓ Have been used successfully by or with people having developmental disabilities, their families, or their support professionals;
- → Have some formative or summative evaluation data associated with them;

→ Be consistent with prevailing approaches and values in the field of developmental disabilities.

If you would like to submit a resource for consideration in the guide, please visit www.aucd.org/ngsd/nom for complete details or contact: George Gotto, UMKC Institute for Human Development (UCEDD), 816.235.5334, gottog@umkc.edu.

Be a part of this important product by submitting your materials for review and possible inclusion. If you are aware of other authors who have developed similar materials to promote self-determination, please pass this information on to them.

Have you developed or implemented effective interventions or practices to promote self-determination? If so, submit them for possible inclusion in the Resource Guide!

web site

http://aucd.org/ngsd

A major product of the project is the National Gateway to Self-Determination Web site. The Web site is a portal to information, stories, resources, training, and much more. The site provides a single access for self-advocates, professionals, policy-makers, and the general public on current best- and evidence-based practices in enhancing self-determination in the lives of people with developmental and intellectual disabilities, as well as any individual.

The **Listserve** is an open listserve, meant to facilitate communication regarding self-determination. Your emails and responses to this listserve will be viewed by all listserve members. Log on to the Web site and join the listserve now.

The **SD** in **Practice** section features video interview and stories. Examples of current video postings include:

- ✓ Dreams: This video shows children and adults who have Down syndrome talking about their dreams and what they're proud of in their lives.
- ✓ Success & Self-Determination: Individuals with disabilities talk about living self-determined lives in high school, college, and careers.

Related Material includes fact sheets, calendar postings of special events, research, and more, all organized by topic (aging, abuse & neglect, health, technology, etc).



Scaling Up SD refers to many processes and procedures that

help organizations at the community, state, and national level to sustain best- and evidence-based practices to promote self-determination over time. These policy and organizational supports to promote self-determination occur through a number of initiatives by a variety of stakeholders and are highlighted in this section of the Web site.

SD News & Events includes news about conferences, AUCD upcoming events, and recent NTI accomplishments. Past events and postings are archived in an easy-to-use format.

SD Links provides convenient links to organizations and self-determination related Web pages.

Visit the Web site often, as it is continually evolving and expanding. As always, if you have comments or suggestions on how the site can be more effective, please drop us a note to: calkinsc@umkc.edu.

additional resources for ucedds & professionals

Practice Guidelines: Promoting self-determination has become best practice in the education of students with intellectual and developmental disabilities. The purpose of this practice guide is to review and summarize existing practices that enhance self-determination and the empirical support associated with those practices. SD is a construct with multiple facets and as such there will be no single practice or package of practices for achieving self-determination that applies to all people or all contexts. We offer in this practice guide first a summary of the way in which self-determination has been conceptualized for the purposes of this Practice Guide and by the Gateway to Self-Determination project, then an organizational framework for linking practices that will enhance self-determination, and finally a brief summary of the research literature supporting use of these practices. Our hope is that this guide will not only provide recommendations for educators, but also prove useful in fostering research, policy, and systems efforts to expand the role of self-determination in the lives of people with disabilities.

White Paper on Social Capital: A series of scholarly papers will be developed on various topics. To date, the first paper on the topic of Social Capital is complete. This paper discusses a systematic approach to develop social

capital for people with disabilities. As Portes (1998) observed, social networks are not a natural given but must be constructed through systematic effort and the development of appropriate investment strategies. To fully realize the potential benefits of social capital for persons with developmental disabilities, it is essential that systematic steps be taken to operationalize this construct in a way that creates a path for developing strategies to access and increase it.

Lectures & PowerPoints: These products provide excellent professional level introductions to self-determination.

"What is Self-Determination & Why is it Important to People with Developmental Disabilities?" This video lecture and PowerPoint by Michael Wehmeyer give an in-depth introduction to self-determination with discussions around expectations, definitions, and philosophical doctrine, as applied to disability, supports, outcomes, research, and more. This lecture is targeted to graduate level students and professionals interested in a thorough introduction to the subject.

"Self-Determination and People with Intellectual and Developmental Disabilities: What Does The Research Tell Us?" There exists an already substantive and still growing literature base pertaining to self-determination and people with disabilities. The intent of this slide show is to provide a synthesis of major findings in the area of self-determination pertaining to youth and adults with intellectual and developmental disabilities. The findings in this slide show come from a comprehensive review of the literature on self-determination published in 2007 in the journal *Exceptionality*, as well as from a comprehensive review of the research published subsequent to this review.

Sustainability

By providing valuable resources to the field, the Gateway to Self-Determination project will remain a viable presence in the disability community long after the conclusion of the project. Major activities planned for the latter portion of the project will enhance the long-term impact to the field and include:

State Summits & Pilots: A limited number of pilot summits are planned to develop the scaling up options for states.

Scaling Up UCEDDs Symposium: to be presented at AUCD at the start of the final year of the project providing UCEDD faculty and staff with in-depth training methods and strategies to scale up efforts to promote self-determination in their state or territory. A "Train the Trainer" Implementation Manual will be a product from this activity.

additional resources for individuals & families



"What is Self-Determination and Why Is It Important?" is a multimedia product consisting of a print-based, 16-page full-color publication and an accompanying Web-presence that elaborates on stories and themes introduced in the print publication. The product, both print and Web-based,

provides a user-friendly, attractive introduction to self-determination and its importance in the lives of people with developmental disabilities by relating the stories of self-advocates, as well as their family and support staff. These stories, presented in pictures and narrative in the print product and via videos streamed online, provide information about the role of self-determination in the lives of people interviewed across multiple domains, including employment, independent living, self-advocacy, and health and recreation, and emphasize the importance of friendships, social capital, and social inclusion.

This multimedia product provides a user-friendly introduction to SD and to the Gateway to Self-Determination project and will be used and distributed in all of the project's activities, including workshops, presentations, trainings, and in Web-based dissemination to individuals and families as well as other groups.

Upcoming Resource for Individuals, Families, and Providers:

"Social Capital Implementation Practices (SCIP)" In the context of disability, social capital can be thought of as a personal resource for individuals, analogous to financial capital, which can be earned, accumulated, and expended over time. In the most fundamental context, persons with developmental disabilities place the highest priority on having family and friends in their lives. Much like social status, social capital is a construct that operates pervasively in social relations but does not have a tangible, physical reality.

The SCIP tool presents a five-stage model or road map for conceptualizing and addressing social capital within the larger context of disability. Environmental contexts or settings are identified in which social capital serves as a mediator of self-determined behavior: home, school, work, social media, and community organizations. Across environmental contexts, an array of activities and strategies will be identified that share numerous features and elements but that will be contextualized for each of the five developmental steps of the tool. A pool of activities and strategies for use by parents, advocates, and professionals in fostering the development of social capital will be developed. Implementation guidelines, recommended resources, and a discussion of cautions and limitations in reference to each context will also be provided.

Information about how to find any of the products and resources described in this booklet can be found on the Gateway to Self-Determination Web site at: http://aucd.org/ngsd. For additional information, questions, or suggestions, contact Dr. Carl Calkins at 816.235.1755 or calkinsc@umkc.edu.





Sharing Our Life Experiences

Learning About Self-Determination

Having Fun

Hearing from the ADD Commissioner

Volunteering

Celebrating Eunice Kennedy Shriver Day

In September 2010, The Gateway to Self-Determination was a major sponsor of the SABE National Conference held in Kansas City. The theme of self-determination was infused into every aspect of the conference. Keynote speakers spoke about self-determination, social capital, inclusion, family, and community.

Over 800 self-advocates, family members, support providers, and professionals gathered to celebrate 20 years of the self-advocacy movement and focused on individuals having a greater voice in decisions that affect their lives. Break-out sessions focused on how to have that more effective voice in specific situations - buying a house, dating, being involved in your community, and more. By increasing the capacity of SABE, the Gateway to Self-Determination is able to touch countless lives.











capacity building

Increasing the capacity of stakeholder groups at every level is of primary importance, not just for the project and its related activities, but also for the long-term sustainability of the initiative. The importance of scaling up efforts to promote self-determination is clear and, through the activities and products of the project, is becoming a reality. State agencies are expressing interest in scaling up at the state level, national organizations are focusing on the concept of self-determination, local family groups use the products to help individuals



become more self-determined.

It is through the capacity building of stakeholder groups at all levels that the Gateway to Self-Determination project will be most effective. All of the activities and products are geared toward building the capacity of some specific element of the disability community - from state Developmental Disability Divisions, to state P&As, to UCEDDs, to national agencies, to community consumer agencies, and to invidividuals and families. By collaborating with and impacting each of these, we are ultimately impacting the individual self-advocate.

capacity building with the sibling leadership network

The Sibling Leadership Network (SLN) provides 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 National Gateway to Self-Determination has played a major role in supporting the development of the SLN, including supporting strategic planning, the development of the Web site, several national and international conferences, and the development of its incorporation as a not-for-profit organization. Over the past year, the SLN has grown and developed by electing a dynamic Board of Directors including a representative from Self-Advocates Becoming Empowered (SABE) to guide the direction of the SLN.

With support from the Gateway to Self-Determination, the SLN is also engaged in strategic planning. Chapters are the grassroots of the organization and maintain personal and consistent contact with people, ensuring that they obtain the information and support they need. The SLN Web site was developed to provide information about policy, advocacy, services, and supports, as well as research related to siblings: www.siblingleadership.org. Presentations and trainings about the SLN and sibling issues have reached audiences across the country to increase awareness of the importance of siblings and educate people on ways to support siblings of people with disabilities across the lifespan.

capacity building



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