

Making Our Voices Heard...

s p e a k i n g o u t

Self-Advocates Speak Out About Quality in Services



*Self-advocates, realizing
their empowerment, are
seeking meaningful jobs,
active community lives,
lasting relationships, and
the respect they deserve.*

speaking out

This is one of a series of booklets that reflect the views and opinions of people concerning the quality of services they receive. NCOR conducted several focus groups to find out what people were looking for in a support network and this is what they had to say. People featured in the Speaking Out series include:

- Self-Advocates
- Adolescents with Disabilities
- People with Brain Injury
- People with Physical Disabilities
- Parents of Children with Disabilities

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NCOR gratefully acknowledges members of Self-Advocates Becoming Empowered (SABE) for their participation and opinions. It is their voices you hear.

Photography by Michelle Gienow

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introduction



As a self-advocate:

- **What do you expect from a high quality service or support?**
- **How do you define quality?**
- **What are the characteristics of a high quality service or support?**

The National Center on Outcomes Resources (NCOR), a division of the Council on Quality and Leadership, conducted a focus group with self-advocates at the Self-Advocates Becoming Empowered (SABE) Conference to listen to their thoughts and expectations about quality in service. This focus group was videotaped and highlights of the videotape were played for a panel of self-advocates at the Wingspread Conference. The panel was then asked to express their reactions to the comments they heard and to elaborate with their own experiences and feelings.

This booklet expresses the views of people with disabilities who advocate for themselves and others.

characteristics of a high quality service

1. Respect

Respecting people means putting people first. This requires valuing a person as an individual, with unique talents, abilities, and perspectives. Often individuals are categorized by their disabilities and not given credit for their personality, experiences, and contributions.

When a person with a disability needs support services they want the services to be tailored to their individual needs. Often times, the staff providing the service thinks that they know what is best for that person. One woman commented that, “they’re not looking at the whole person, they’re looking at things through their own eyes.” People from agencies often look at individuals through the lens of their own perception. They need to put that lens aside and see the whole person clearly.

“Attitudes are more important than all the money you could ever spend on programs. I have become completely indignant with the things that people have to go through to live what are called normal lives.”

Some agencies and staff in an effort to “protect” people with disabilities are not truthful with the person and may “shelter” a person from a painful experience. Treating a person with respect can sometimes mean being brutally honest.

It is respecting a person’s ability to hear the truth. Respect may also mean allowing a person to experience failure and learn from it.

“Have respect for me to let me make my own decisions; people act like parents by not letting us make our own decisions.”

Support staff sometimes see their role as a parental one. But staff shouldn’t act like parents; they need to provide information to individuals and teach people ways to make decisions. Then they need to step back and let people make their own decisions.

2. Communication

An attitude of respect becomes real through good communication skills. It is one of the first characteristics of quality services that self-advocates noted as important. One participant noted that “they need to understand you, while on the other hand, you have to understand them. You know, if you don’t have understanding, then you can’t work together.”

One of the most important skills of communication is listening. Listening to people with disabilities requires the same type of skills as listening to all people. It involves setting aside your own perceptions, paying attention to a person’s



“They will sit there and talk to you, but then you often wonder, do they listen to what I say?”

body language, tone of voice, and the meaning of what they are saying. People have different communication styles. Some people process thoughts quickly, while others need to ponder thoughts and ideas a little longer. It is important to understand the person’s communication style and allow people to process thoughts in their own way. As a part of a team or committee, a person may also have a different communication style. As one participant pointed out, “if you want our insights and input, you have to ask us how we will be willing to communicate that. Because we’ve been told all along that we’re not professionals, and that we don’t know how to function in meetings, so we try to use the politeness that we were taught, and that doesn’t always get us recognized.”

It is critical to accept the person’s perspective when he or she is speaking about his or her own life. Self-advocates often feel that their opinions are diminished and not taken seriously. One man noted that if you listen carefully to a person, “you will learn something new every day. It does not matter how large or small that something is, even if it’s

about another person’s feelings, you’re learning what is important.”

The most important skill to teach staff is how to discover what an individual wants. Many staff still think that their job is to tell the individual what he or she should do and what they should want in life. It needs to be flipped around so that staff know that their job is to really listen to the individual they support and learn what their dreams and goals are.

Self-advocates want clear answers. Often agencies and staff beat around the bush and give long-winded answers that don’t tell a person anything. A person with a disability is much more interested in hearing the honest truth than in hearing a sugar-coated version of the truth.

“We can’t even get a clear answer from any two people, if you ask it the same day, the same way, in the same words, you can’t get a clear answer.”

People with disabilities want staff to use language that is easy to understand. Staff may be trained to use professional jargon, but this does not help the individual with the disability. “Staff should be trained to communicate in ways that people can understand,” commented one focus group participant. This may involve using demonstrations, pictures, simple words and/or videotape.

3. Inclusion

There was a consensus from the self-advocates that everyone needs to be included. Everyone needs a seat at the table, but inclusion means far more than just a place to sit. It is often easy to say words like “inclusion,” but true inclusion means actual involvement in the process. Accommodations may need to be made and may involve physical changes such as ramps and communication devices. But more often, inclusion involves other people allowing the time for the person to communicate their needs and wishes. It may involve using pictures and videos to explain concepts. And it will definitely involve speaking in clear terms and avoiding professional jargon.

The self-advocates were also very clear that sheltered workshops and group homes were not what individuals wanted. They want to be a part of the community. They want real jobs and real homes. And they want choices about where those jobs are, where they live, and with whom they live.

“Be a good listener, be a good speaker, be a voter. Get involved. Get other people involved.”

4. Empowerment

Quality services empower the individuals they serve. Self-advocates see empowerment as people making their voices heard. It is agencies and support staff realizing that people are in charge of their own lives and staff’s role is to support them in living their lives to the fullest and realizing their dreams.

The focus group participants had some very specific and practical suggestions for how people with disabilities and their families can become empowered and change the system. Their first suggestion is to not let “anyone steal

“You’re the voice, you need to speak up and make the changes that you want in your life.”

your dreams.” Make an investment in your dreams of your time, energy, ideas, and commitment. When challenges to achieving your dreams present themselves, “make yourself a part of the solution or the whole solution.” There is a solution to every problem and sometimes it takes getting a lot of people together to find that solution. This takes teamwork and brainstorming.

For more complex challenges, self-advocates advise that individuals need to join together in organizations; network with other organizations and participate in political action when necessary. The first step in solving complicated issues at the agency level is to go to the agency director. Ask them what they would do if they were in your situation. Work together with them as a team player to come up with solutions that improve the quality of the service.

When an issue involves laws and state regulations, go to your legislators, either alone, with an organization, or with a coalition of organizations. You can do this by writing letters to them and by visiting them in their offices. Sometimes, it is helpful to participate in training on how to approach lawmakers.

One man is attending a class called “Partners in Policy-Making” where he is learning how the policies that run agencies are determined and how he can effect changes in these policies. Another man suggested starting an Americorps program in each state. The Americorps



program in his state trains case managers, personal care staff, and other support staff about what people want in their lives.

5. Committed Staff

Staff who support individuals with disabilities need to be in the job for more than a paycheck. They need to be committed to what they are doing. This is not something that can be taught; it has to come from within. In referring to her support staff, one woman commented, “I feel special because the lady that works with me goes the extra mile for me.” It’s that “extra mile” that can’t be trained — that comes from dedication.

Staff also need to make decent wages. Self-advocates noted that wages for staff have become worse over the years and therefore staff turnover is increasing. “Lack of staff effects my quality of life directly in that my case manager is being taken away,” one woman explained. This woman had formed a bond with her case manager over the years and now she would be losing that connection due to a re-assignment based on budgetary concerns.

Another woman pointed out that the staff who work with her are health care professionals, but they are not paid at a scale comparable to other professionals in that field. She also points out that “they do get a full education after they support an individual, and they should be recognized as the professional that they’ve become after having more job experience like everybody else.”

6. Flexibility

Often supports are provided in a way that is either “all or nothing.” One woman said that she is often seen as more capable than other people and thus isn’t given any support. She noted that she sometimes needs support however, but doesn’t need it all the time. The important thing in supporting a person is to be flexible and to give attention when needed. This again requires getting to know a person and discovering what he or she wants and needs. A person’s needs may change over time, so there should be flexibility in the system.

outcomes from services

1. Self Determination

Self-advocates were very clear that they want to be in control of their lives and have chosen the term “self determination” to express this desire. They want to choose where they work, the type of jobs they accomplish, and where they live. People want jobs and lives in the community. They want to choose how to spend their time.

“The individuals... have choices [about] where they want to live, where they want to work. They tell the providers. They tell whoever asks them. It’s their lives. Nobody else can talk you down. It’s their choice where they want to have fun and who they want to have in relationships.”

2. Leadership

The people who were interviewed for this booklet are all leaders in their communities. They have been involved with self-advocacy for many years and have seen quality change over the years. One change for the better is that there are more self-advocates in this country. These self-advocates are speaking up and making changes in the system for themselves and for other people. Many of the people in the focus groups were also making presentations at the SABE

Conference. They provide training for other self-advocates and for staff and policy-makers.

If services for people with disabilities are quality services, they will produce leaders. Not everyone will be a leader, but more people will be able to speak up for themselves and for other people. They will know how to access the system and make changes.

Self-advocates are concerned that there are not enough opportunities for leaders. They make the point that people with disabilities are often excluded from planning meetings because the people running the meetings assume that the information will be too technical and the meeting will be too long. Self-advocates make the point that, “if it’s too complicated for you to explain, it’s too complicated to use and to put into practice.”

3. Employment

Employment is a complex issue for self-advocates. People with disabilities are often pigeon-holed into particular types of jobs with little attention being paid to their own interests and desires. Many are under-employed and people with disabilities are often poor. Many people with disabilities still work in sheltered workshops and make fifty cents per hour. Self-advocates want real jobs.

sharing our lives: what self-advocates say

About Respect

“There are a couple of words that we need to always carry with us — that we honor and respect each other. And that we don’t compare people with disabilities to other people with disabilities and try to figure out how to categorize people. Then you’re honoring them as an individual and you respect their individuality, and you respect their wishes for their own future and the way their whole life would look for them.”

“Attitudes are more important than all the money we could spend on programs.”

“I wish my privacy was respected. If there’s a problem, they should come to me and not go to other staff to discuss the situation. The entire agency finds out if you have a problem.”

About Staff

“Quality services mean having a good relationship with the person giving the service.”

“It takes a lot of people to get to a person you finally, finally like.”

“I feel special because the lady that works with me goes the extra mile for me.”

“It’s very important to pay our staff a decent wage.”

About Employment

“Are workshops the answer to employing people with disabilities? No.”

“The quality of the jobs we are offered is not good.”

“Jobs paying fifty cents an hour are not the jobs for us. Work on our capabilities and put us in some type of training.”

About Leadership

“When we talk about leadership, we’re for everybody, and hopefully in the future these environments will be more accessible for more people to participate.”

“We {self-advocates} are probably your front line out there in the community, making those connections with the self-advocates and the families, and we really want to support you.”

“We’re always excited to have opportunities, so build us in to those opportunities.”

“I want to build a system that responds to each person’s needs, and treats each person with respect. Not one that requires spokespeople to tell me what all people need.”





Self-advocates feel that an important outcome of quality services is quality jobs. Some of the suggestions they made were to have more job fairs and to

“We’re horribly under-employed or unemployed, and we have issues trying to utilize the services that are out there.”

provide more job training. One man suggested that more attention be paid to people’s capabilities and not just look solely at educational requirements. He stated that he was a manager of a business without any formal schooling for the job. He learned the skills necessary through “on-the-job” training.

4. Achieving Dreams

Quoting Mary Wilson, one participant said, “Dreams don’t die, people just stop dreaming.” Self-advocates have many dreams. One man talked about his dream to become a professional baseball player. He realizes that his body may not be able to do that anymore, but he has more dreams. He dreams of being a lawyer and a politician. While he hasn’t entered law school, he is working through the political system to make changes for people with disabilities.

People with disabilities are often told that they can’t do certain things. This has a tendency to stop some people from dreaming. However, there are many role models and success stories that are encouraging. Support persons should encourage people’s dreams and then staff need to help each individual to make the connections necessary to live their dreams. Many of us may not achieve our “ultimate” dream, but it is our dreams that provide us with direction in life. As a self-advocate from New York said, “Dream it, do it!”

redesigning systems and services

“I’m very disappointed that I don’t get to evaluate them [staff] for a raise or an increase. I get to evaluate them on performance, but I don’t get to see them advancing in a career as a person who supports people with disabilities.”

Self-advocates think the system is upside down. When a diagram is made of the system, the individual is on the bottom and does not receive the money that is allocated for their services. The money should go from the government to the individual. This will “lead us to the power and control because we then know what money we have in the system.” When individuals have control of the money, they will have wider choices in who supports them.

The system is currently still focused on “slots” and fitting people into the slots that are available. The new system needs to focus on the individual and the best way to connect that individual to the resources that he or she needs to be able to live life to the fullest. This involves focusing on:

- INFORMATION
People need the best information available about money and where to obtain resources. The information needs to be organized in a way that is relevant and readable to people who need it to make decisions.
- CONNECTIONS
People need connections to resources within the community. One self-advocate

described the organization where she works. It’s purpose is to reach out into the community and to connect people to each other. She locates the resources and people in the community, tracks them in a database, and then is available to help people to make those connections.

- RELATIONSHIPS

Relationships are the key to fully utilizing the community resources and maintaining them for the long term. Relationships between individuals and staff can often be the most important determinant of quality services. These relationships are built over time and must be respected. But more importantly, the staff should be assisting individuals in making life relationships that last long after staff move onto another job.

- INTER-PERSONAL SKILLS

People need communication and conflict resolution skills to enhance their relationships. Many of the self-advocates talked about needing more effective ways to deal with conflicts. When conflicts arise with people in their lives, they want to be able to work it out. If the conflict is with staff, often the staff try to figure out how to “control” the person and the situation. Self-advocates would like to sit down and talk things out before they get out of control.



what does the future hold?

The individual should be in the middle of the whole system. They should be the ones driving the system and determining what supports and services are needed. The people who are supported by staff should be the ones hiring and evaluating the staff.



At the Wingspread Conference, there was much discussion about the meaning of the term “self determination” and whether words like self determination and empowerment had lost their meaning through overuse.

Through the work of self-advocates, words like “self determination” and “empowerment” may be used frequently but they will not lose their meaning if the concepts they embody have a life of their own. When people with disabilities are meeting with their legislators, testifying before government committees, hiring, training, and evaluating staff — they are empowered.

In the future, as more and more people choose where they want to live, are working in meaningful jobs, are actively involved in the community of their choice, and have deep and lasting relationships, they will be living the powerful word “self determination.”

these websites and national and international organizations

can help self-advocates find valuable information and resources

in their community:

Advocating Change Together (ACT)

1821 University Avenue
Suite 306-S
St. Paul, MN 55104
651.641.0297
800.641.0059 (Tools for Change)
Fax: 651.641.4053
www.selfadvocacy.com

American Association of People with Disabilities (AAPD)

1819 H Street, NW, Suite 330
Washington, DC 20006
800.840.8844
202.457.0046
Fax: 202.457.0473
www.aapd.com

American Disabled for Attendant Programs Today (ADAPT)

201 South Cherokee
Denver, CO 80223
303.733.9324
www.adapt.org

Americans with Disabilities Act/Olmstead Decision

DHHS Working Group for ADA/Olmstead
c/o Center for Medicaid and State Operations
HCFA, Room S2-14-26, DEHPG
7500 Security Blvd.
Baltimore, MD 21244-1850
www.hcfa.gov/medicaid/olmstead/olmshome.htm

Axis Disability Rights Web Site

Axis Consultation & Training Ltd.
340 Machleary Street
Nanaimo, BC, Canada V9R 2G9
250.754.9939
Fax: 250.754.9930
www.normemma.com

Bazon Center for Mental Health Law

1101 15th Street, NW
Suite 1212
Washington, DC 20005-5002
202.467.5730
Fax: 202.223.0409
TTY: 202.467.4232
www.bazon.org

The Consortium for Citizens with Disabilities

1730 K Street, NW, Suite 1212
Washington, DC 20006
202.785.3388
Fax: 202.467.4179
www.c-c-d.org

Council for Disability Rights

205 West Randolph, Suite 1650
Chicago, IL 60606
312.444.9484
TDD: 312.444.1967
Fax: 312.444.1977
www.disabilityrights.org

The Disability Rights Activist

www.disrights.org

Disability Social History Project

255 3rd Street, #202
Oakland, CA 94607
www.disabilityhistory.org/dshp.html

Disabled Rights Action Committee

3565 South West Temple
Suite 16
Salt Lake City, UT 84115-4493
801.685.8214
Fax: 801.685.8216
pws.prsv.net/drac

Individualized Funding

Information Resources
members.home.net/tsalisbury

National Program Office on Self-Determination

Self-Determination for Persons with Developmental Disabilities
7 Leavitt Lane, Suite 101
Durham, NH 03824-3522
www.self-determination.org

Not Dead Yet

Progress CIL
7521 Madison Street
Forest Park, IL 60130
708.209.1500
Fax: 708.209.1735
TTY: 708.209.1826
www.notdeadyet.org

The Oaks Group

P.O. Box 1913
Pollock Pines, CA 95726
530.647.8246
oaksgroup.org

People First International

P.O. Box 12642
Salem, OR 97309
503.362.0336
Fax: 503.585.0287
www.people1.org

People with Disabilities

U.S. Department of Housing and Urban Development
451 7th Street, SW
Washington, DC 20410
202.708.1112
TTY: 202.708.1455
www.hud.gov/groups/disabilities.cfm

Self-Advocate Leadership Network

Human Services Research Institute
850 Lancaster Drive, SE
Salem, OR 97301
503.362.5682
Fax: 503.362.7729
www.hsri.org/leaders/leaders.html

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www.selfadvocatenet.com

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TDD: 410.828.1306
www.tash.org



The National Center on Outcomes Resources (NCOR) is the research division of The Council on Quality and Leadership in Supports for People with Disabilities and provides leadership in outcomes research, analysis and dissemination. NCOR is a clearinghouse and information resource on outcomes data on all aspects pertaining to people with disabilities.



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