

People with Physical Disabilities are

# s p e a k i n g o u t

About Quality in Services



*People with  
physical disabilities  
seek solutions to  
achieve their  
goals, ambitions  
and outcomes.*

# 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:

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

For information about our resources, please contact:

The National Center on Outcomes Resources (NCOR)  
A Division of The Council on Quality and Leadership  
100 West Road, Suite 406  
Towson, Maryland 21204

410.583.0060

410.583.0063 fax

e-mail: [info@thecouncil.org](mailto:info@thecouncil.org)

[www.thecouncil.org](http://www.thecouncil.org)

[www.ncor.org](http://www.ncor.org)

NCOR gratefully acknowledges Independence Now for their participation and opinions. It is their voices you hear.

Photography by Michelle Gienow

©2001 by The National Center on Outcomes Resources

All rights reserved. Printed in the United States of America. Except as permitted under the United States Copyrights Act of 1976, no part of this publication may be reproduced or distributed in any form or by any means, or stored in a data base or retrieval system, without the prior written permission of the publisher.

# introduction

As a person with a physical disability:

- What do you expect from a high quality service or support?
- What does quality depend upon?
- How do you define quality?



**T**he National Center on Outcomes Resources (NCOR), a division of The Council on Quality and Leadership, held focus groups and interviewed people with physical disabilities and representatives of independent living centers to discover their answers to these questions.

This booklet presents the views of people with a variety of disabilities including: sight impairment, learning disabilities, and mobility impairment.

# characteristics of a high quality service

## 1. Communication and knowledge

The individuals we interviewed did not want to prioritize aspects of quality and determine which characteristic was the most important. However, repeatedly, those interviewed referred to a great need to have someone listen to their issues and be knowledgeable about resources. People with physical disabilities and people supported by indepen-

*“Quality staff have knowledge of the system and the services available and understand how to match those services to my needs.”*

dent living centers felt that these two characteristics were very closely linked. It is not helpful to have a good listener who doesn't know where to obtain the help and supports that are needed. Similarly, a staff person who is extremely knowledgeable about a wealth of resources will be apt to recommend the wrong ones if he or she doesn't listen to the individual and fully understand what is needed. Mary has such great difficulty in reading and spelling that it interferes with her job, for example. A rehabilitation counselor provided an assessment for Mary and recommended a device that has worked for other individuals. Mary knew from experience that this device was not appropriate for her and shared this information with the

counselor. The counselor didn't listen to Mary, but instead relied on her own list of resources. This device was purchased for Mary. Since it wasn't what she needed, it has not been used. Mary is still attempting to be matched with the device that will work for her.

## 2. Coordination

A very strong theme for people with physical disabilities is that quality services and supports need to work together in a coordinated fashion. These services form networks and attempt to serve people with physical disabilities and representatives of independent living centers through a “one-stop shopping” method. For many people with physical disabilities, transportation presents challenges. One woman we spoke with told of a day when she had to ride on 16 different buses to apply for services and attend required meetings.

Many people with physical disabilities are required to complete a different form for each service, which often means writing the same information numerous times. “One-stop shopping” should also include a universal form to apply for services and supports. Quality services use a standard form that has basic information and then may ask customers to add pertinent additional

information when needed.

Another woman told of the differences between two counties in applying for housing assistance. In one county, she looked at apartments and then had to travel to a different office to apply for funding assistance. This was very difficult as she was using a walker because of her disability. She later moved to a different county which provided the applications for funding on-site at the apartment building.

Some individuals with physical disabilities felt so strongly about collaboration that they believe networking between agencies should be mandated by policy. This would benefit the individual and save him or her, as well

as the system, time, and money. Most people with physical disabilities need more than one service, so it is imperative that these services are networked.

### 3. Easy access

Accessibility means more than simply meeting the Americans with Disabilities Act (ADA) requirements. For many people, it also means decreasing the red tape so that services can be used without the barriers caused by excessive rules. People should be treated as individuals, not as one member of an entire class of people. Rules and red tape usually exist because of difficulties caused by one individual and are then applied to all individuals in need of a program or supports. Ideally, each person would be treated as an individual, and services and supports would be tailored to that individual. Any limits would be made based on that individual and not a previous customer.

Funding is another issue that arose repeatedly. Many services lack quality because they are severely underfunded. People who were interviewed commented that a “grand influx” of money is needed. At the same time, this money must be spent wisely and focused mainly on improving direct care services and less on administration. Other programs limit people’s accessibility because of the person’s income and/or the spouse’s income. People interviewed have experienced situations where they had to separate from their spouse so that the income of one spouse wouldn’t affect the supports that the person was eligible



to receive.

People with physical disabilities need to know about a service in order to use it, thus it is imperative that a quality service market itself effectively. Many organizations that provide services to people with disabilities seem afraid of marketing for fear that they will have more customers than they can handle. However, people who need the service

*“...it was never explained to me that I had to claim my wife’s income, and now I’m being penalized and SSI is deducting penalties...”*

have to know it exists. One individual commented on the high quality booklet that one organization published. This booklet was widely available and listed the support services that its agency provided as well as other supports provided by both public and private agencies.

#### 4. Timeliness

A quality service responds quickly to the needs of its consumers. The staff stays on top of details and provides good follow-through. The time of people with physical disabilities is respected and if a service and/or support is not readily available, the staff person relays this information to the consumer. One woman stated that she had to wait almost two years to receive approval for adaptive equipment that she needed. Services that require the completion of duplicative paperwork also waste the time of people with physical disabilities and those receiving supports from independent living centers. Quality services

are continually searching for new and better ways to meet people’s needs in a timely manner.

#### 5. Stability and accountability

People with physical disabilities want to be able to count on a service or support being in existence for a long time. This requires good financial management and attention to customer and staff needs. The organization ensures that it has a depth of staff so that it can provide back-up when needed.

High quality services provide good supervision of staff and periodic review of staff’s work. This review must be based on how the work of the staff is affecting the person with the physical disability. Are the person’s goals being met? Does the person indicate that he or she is being treated with respect? Is staff listening to the individual’s needs and suggestions? Reviewing staff performance must be coupled with appropriate feedback to staff. This should include positive feedback, as well as corrective action when required. Staff should also be monitored for “burn-out” as their jobs may be very demanding. Managers should develop a variety of ways to “energize” their staff such as: cross-training workers for different jobs, personally commenting on positive staff performance, giving staff their anniversary date of service off as a holiday, recognizing staff for outstanding contributions to the individuals they serve and for helping people achieve their out-



comes. Supervisors need to listen to staff as much as the staff needs to listen to consumers.

Organizations that provide high quality services have a commitment to quality throughout the entire organization. The staff receives good direction from the top of the organization and is knowledgeable about the mission of the organization. A clear mission statement is important, but it is useless if all staff members are not aware of it and don't believe in it. Strategic planning based on the mission statement and the achievement of outcomes is key to success.

## 6. Respectful and well-trained staff

High quality staff members are well-trained and have a good basic understanding of disability issues. They are people who care deeply, are committed to work and have an energy born of their passion for the mission. These staff members constantly educate themselves, learning as much as possible about all types of disabilities and all levels of the system. Staff members must be sensitive to the needs of people with physical disabilities and willing to listen to the person.

The staff needs to be respectful and not patronizing. Being respectful involves truly listening to the person with the physical disability, both to discover the issues the person is dealing with and consider the individual's proposed solution. Too many staff members think that they have all the answers, or that they are required to have all the answers. What is more important is to truly LISTEN to the person and respect

**“It's not just a matter of finding qualified people; it's a matter of finding people that care.”**

the individual's ideas and opinions. People with physical disabilities feel that a high-quality organization has zero tolerance for disrespect.

A great staff person combines the skills of listening and networking with the knowledge of resources and technical assistance to address the needs of people with physical disabilities in a

timely manner. A quality staff person also follows through on actions that are promised and is accountable to the person with the physical disability. This follow-through may involve creative and



flexible thinking on the part of the staff person and the organization. One individual's income was \$2.00 over the limit to receive a particular needed service.

Rather than disqualify her, a case manager counseled her to ask her boss for a slight decrease in salary so that she would be eligible for a needed service. The boss complied and this helped the person to get on her feet enough to be able to earn more money in the future and not need the assistance that was temporarily provided.

Repeatedly, people with physical disabilities and independent living center representatives indicated that good staff people helped the person to have more self-confidence. Several people noted that quality staff people are creative and tenacious. They don't give up easily even when faced with the most difficult challenges.

## 7. Outcomes oriented

People with physical disabilities said that quality services promote personal goal attainment and help people to become independent. The individuals interviewed expressed a desire for more independence and to be able to help others. They wanted services that helped them to set goals and to identify the incremental steps that would help them to achieve their goals.

*"...services should have built-in incentives encouraging us to contribute rather than just consume..."*

# what people with physical disabilities say

## About Support Services

**“How are we supposed to understand what services are available to us? People who work in the system don’t even know their own programs.”**

**“Social services are making people more dependent on the system rather than helping people become more independent.”**

**“Service providers should focus on my ability rather than my disability.”**

**“Quality means getting the right type of services at the right time.”**

*“I will not allow bureaucratic barriers to keep me from achieving my outcomes.”*

**“...we need more guides through the system... people are often lost in the maze...”**

**“I used to just be grateful for any help at all I received... but now I expect more from services...”**

## About Staff

**“People who design services need to work from the viewpoint of a person with disabilities.”**

**“Staff need to be knowledgeable about diseases and disabilities... they need to understand both our physical and our emotional challenges.”**

**“Organizations should mandate a zero tolerance policy for disrespect from staff.”**



## About Funding

**“The financial incentives are to divorce and break-up the family. That needs to change.”**

**“There needs to be more supportive employment. My incentive is NOT to work. Once I'm employed and able to contribute my skills and abilities, my supports will end. I'm not left with a fair choice.”**

*“I don't want to have to give up things which are essential to me to maintain benefits. I was forced to sell my ten-year old car in order to continue receiving benefits because I was informed that to qualify, I was not allowed to own a vehicle.”*

## About Social Stigma

**“I was advised that I shouldn't show up in court with my wheelchair or a walker or I might be viewed as being unable to care for my children.”**

**“We're not thought of as equals, and all the legislation in the world can't change that.”**

**“Our concerns are often ignored because people with disabilities aren't often viewed as credible.”**

# outcomes from services

Most people with physical disabilities are not interested in receiving services. They expressed a desire to live free of services and supports. When this is not possible, they are looking for services and supports that will make a difference in their lives. None of the people interviewed asked for a 3-hour evaluation or a certain amount of time from any service provider. Their biggest complaint, as a matter of fact, was that services took up too much of their time. They don't want more time, they want results! The most common desired outcomes mentioned were:

- Equal participation in society
- Increased self-confidence
- Good jobs
- Ability to contribute to society
- Increased independence and choices

## Equal participation in society

People with physical disabilities want to feel a reduced stigma associated with their disability. Playing important roles in society and being able to participate on an “even playing field” were most often cited as being important. To do this, they said, the focus has to be flipped from one that centers on “disability” to one that draws attention to a person's

“abilities.” Services and supports can participate in this process by helping people to understand what they are capable of doing. Focusing people's attention more on their strengths and less on their deficits will increase self-confidence and independence. Improved technology can often provide assistance to people in achieving goals. For example, an individual who has severe dyslexia can use software that turns the spoken word into the written word on a computer so that reports can be completed.

**“I just don't want to feel excluded from society.”**

This person's abilities may be in problem-solving and creativity, but his or her “deficit” may be in written reports. With the help of technology, this “deficit” is no longer a barrier and the person's strengths can be utilized to assist other people with physical disabilities.

## Increased self-confidence

Several people spoke about the difference in how they feel about themselves based on the types of supports that they received. Services whose staff really listened to the individual and felt that they had pertinent information to contribute

to the best way to meet their needs, helped people to have more confidence in themselves. Staff who did not listen to individuals, or who down-played the individual's opinion, left the individuals feeling less capable of making their own decisions.



## Good jobs

Most people expressed the desire to work. They wanted jobs that interested them and that they felt would make a difference in society. They were not interested in using their disabilities to escape work, but often did need supports to help them break through barriers that exist in the work world.

“...we shouldn't exclude from our job search organizations that serve people with disabilities... if we seek leadership positions we can act as role models to others with disabilities...”

## Ability to contribute to society

When asked what difference quality services and success at meeting their personal goals would make in their lives, most people interviewed indicated that they would be able to help others. Most individuals with disabilities were interested in giving back to society. This was often their ultimate goal in achieving their own personal goals.

## Increased independence and choices

Most people wanted to have control over their lives. With more independence and choices, this control can become a reality. People with physical disabilities want to focus on their own personal goals and usually have concrete ideas of how to achieve these goals. They mainly expressed a need for the resources to support their attainment of their own goals. Many people were frustrated by staff and support organizations that didn't listen to the individual's needs and instead superimposed generic goals onto the person.

# self-advocacy: what can people with disabilities do to improve quality?

There are many things that an individual can do to promote quality services. The following are a few examples:

## Become knowledgeable

The first step to self-advocacy is to learn everything possible about your own disability. Next, learn about other disabilities. Sometimes, what works for one disability will also work for another.

Thirdly, learn about the system that has been set up to assist persons with disabilities and people receiving supports from independent living centers.

Although a service and support organization should know the available resources, the staff may not be aware of all that is available. Thus it is most help-

*“Learn about what’s out there. And that means go out and explore... leave the backyard.”*

ful for the individual to also learn as much as possible about available resources. The internet is often very helpful in this search. Using a search engine to investigate your particular disability or disability resources in general can turn up a wealth of information. Public libraries are also very useful.

## Speak up!

People with physical disabilities suggest that it is imperative not to become a victim. One individual suggested that

speaking up and becoming a “pain in the butt” in a respectful way is often effective. She noted that many people with physical disabilities don’t argue and they “go away” when they are told “no” by an organization. They need to hold the system accountable. This is easier to do when you have followed Step One and increased your knowledge of the system and your individual rights.

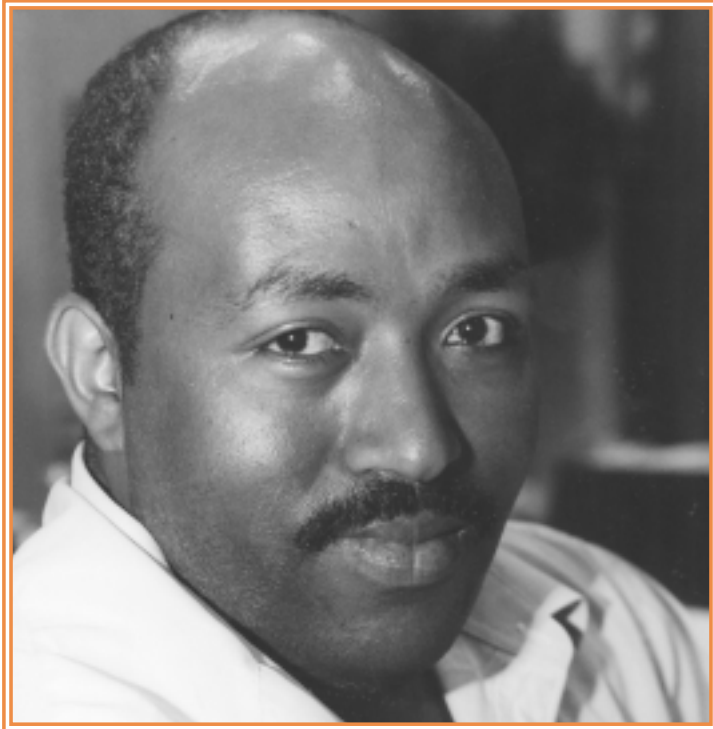
**“Contact the policy makers and make yourself a part of that power.”**

## Get organized and involved

It is important to work in coalitions so that many people can speak with one voice. There are many existing organizations such as ADAPT, Disability Rights Education and Defense Fund (DREDF), the Council for Disability Rights, and the Centers for Independent Living. If there isn’t an existing organization to serve your needs, see about developing one.

You might also consider working through political channels by contacting policy makers and elected representatives. Become qualified to work in an organization that serves people with physical disabilities and work toward assuming leadership positions.

“...look into building cross coalitions of people with varying types of disabilities... not limiting ourselves to specific disability groups...”



### Be creative

If you are being told all of the reasons why you can't have a particular service, start by asking the question: what are my options? Often staff people and organizations are working from a prescribed set of rules. Ask what would happen if a rule was broken for one individual. Ask the staff person to brainstorm with you about other alternatives.

Brainstorming doesn't involve coming up with the "right" answer, it involves coming up with a large quantity of potential answers. Creativity can often be enhanced by asking the question, "what is the wackiest solution to this problem?" It doesn't mean that the wackiest solution is the one that you will implement, but it can help you to come up with more solutions. For example, people who were working on the issues of increasing choices in housing in North Dakota were asked this question and they came up with a wacky solution of having people live in tents, that way if they changed their mind, it would be easy to move. The temperature on the day of that particular wacky solution was -20 degrees! This was not the final solution, but loosening up people's thinking in this way led to other more creative solutions.

### Summary

What is a quality service? One that is timely, creative, flexible and listens to the people who use its services and supports. A quality service connects a wealth of knowledge and resources with the individuals who need this information. The staff of a quality service listen to the individuals and provide timely solutions to any barriers (physical, psychological and bureaucratic) that stand between a person and his or her goals, ambitions and outcomes.

# these national organizations

can help families and people with physical disabilities find valuable resources in their community:

## 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.org

**ABLEDATA**  
www.abledata.com

## American Disabled for Attendant Programs Today

(ADAPT)  
201 S. Cherokee  
Denver, CO 80223  
303.733.9324  
Fax: 303.733.6211  
www.adapt.org

## Bazelon Center for Mental Health Law

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

## Center for Independent Living —

Berkeley, California  
2539 Telegraph Avenue  
Berkeley, CA 94704  
510.841.4776  
TDD: 510.848.3101  
Fax: 510.841.6168  
www.cilberkeley.org

**Presidential Task Force on Employment of Adults with Disabilities**  
(disAbility.gov)  
www.disability.gov

**The Disability Resources Monthly (DRM) Regional Resource Directory**  
www.disabilityresources.org/DRMreg.html

## Disabled Peoples' International (DPI)

www.dpi.org

**Independence Now**  
6811 Kenilworth Avenue  
Suite 504  
Riverdale, MD 20737  
301.277.2839  
Fax: 301.277.4587

**Independent Living Centers**  
[ILRU (Independent Living Research Utilization)]  
www.rtcil.org/directory/directory.htm

**Institute on Independent Living**  
www.independentliving.org

**MEDLINEplus: Disabilities (General)**  
www.nlm.nih.gov/medlineplus/disabilitiesgeneral.html

**NARIC's Instant Disability Information Center**  
www.naric.com/naric/search

**National Association of Protection and Advocacy Systems (NAPAS)**  
900 Second Street N.E.  
Suite 211  
Washington, DC 20002  
202.408.9514  
TTY: 202.408.9521  
Fax: 202.408.9520  
www.protectionandadvocacy.com

**National Council on Independent Living**  
1916 Wilson Boulevard  
Suite 209  
Arlington, VA 22201  
703.525.3406  
TTY: 703.525.4153  
Fax: 703.525.3409  
www.ncil.org

**National Council on Disability**  
1331 F Street, NW, Suite 1050  
Washington, DC 20004-1107  
202.272.2004  
TTY: 202.272.2074  
Fax: 202.272.2022  
www.ncd.gov

**The National Information Center for Children and Youth with Disabilities (NICHCY)**  
P.O. Box 1492  
Washington, DC 20013  
Voice/TTY: 800.695.0285  
Voice/TTY: 202.884.8200  
Fax: 202.884.8441  
www.nichcy.org

**National Institute on Disability and Rehabilitation Research**  
330 C Street, SW, Suite 3060  
Washington, DC 20202-2572  
202.205.8134  
TTY: 202.205.9433  
TTY: 202.205.8189  
Fax: 202.205.8997  
www.ed.gov/offices/OSERS/NIDRR/

**Rehabilitation International**  
25 East 21st Street  
New York, NY 10010  
212.420.1500  
Fax: 212.505.0871  
www.rehab-international.org

**World Institute on Disability**  
510 16th Street, Suite 100  
Oakland, CA 94612-1500  
510.763.4100  
TTY: 510.209.9493  
Fax: 510.763.4109  
www.wid.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, with a special focus on developmental disabilities.



100 West Road, Suite 406, Towson, MD 21204  
410.583.0060 phone, 410.583.0063 fax  
[www.thecouncil.org](http://www.thecouncil.org)  
[www.ncor.org](http://www.ncor.org)

The Council on Quality and Leadership provides world-wide leadership for greater accountability, responsiveness, and quality performance in human and social service organizations and systems.

NCOR operates under a cooperative agreement between The Administration on Developmental Disabilities – United States Department of Health and Human Services and The Council on Quality and Leadership in Supports for People with Disabilities. The views expressed herein, however, do not necessarily reflect the position of The Administration on Developmental Disabilities.