

UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES  
THE ADMINISTRATION FOR CHILDREN AND FAMILIES  
JO ANNE BARNHART, ASSISTANT SECRETARY

# EMPOWERMENT

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A Brief Report from the 1990 Consumer Survey and Policy Data Sets

THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES  
DEBORAH L. McFADDEN, COMMISSIONER

This is the third in a series of brief reports that combines information from two sources: the 1990 National Survey of People with Developmental Disabilities, and the 1990 Reports submitted to the Federal government by the States. The series is intended to highlight cutting edge issues, by combining information from more than 13,000 face-to-face interviews with people with developmental disabilities, with the information from the reports of 55 states and territories.

In the 1987 amendments to the Developmental Disabilities Act, the United States Congress required each state to:

- Conduct a survey of people with developmental disabilities concerning their satisfaction with services and supports;
- Perform a policy analysis of publicly funded programs and;
- Hold public hearings on critical issues.

Each state was advised to interview about 300 consumers. When this task was completed, more than 13,000 Americans with developmental disabilities had been interviewed face to face.

Policy analyses had been performed by 55 states and territories. Public forums and hearings had been held in each state in a variety of settings and formats. The information from all three sources was used to prepare a "1990 Report" in each state.

With the assistance of the Administration on Developmental Disabilities and the National Association of Developmental Disabilities Councils, the states developed a standardized consumer interview form, as well as consistent procedures for performing the policy analyses.

The National Survey data have been compiled by the University Affiliated Program at Temple University. The final data set includes 13,075 completed interviews. The policy information has been compiled by the National Association of Developmental Disabilities Councils and Jaskulski & Associates into a computerized file of over 7,000 statements abstracted from the individual reports.

## WHO IS THE SUBJECT OF THIS REPORT?

This report is about Americans who have developmental disabilities. Developmental disabilities are severe physical and/or mental conditions that begin before age 22. Most experts believe that about two to three million Americans have developmental disabilities. The Consumer Survey included 13,075 of them. This means that the States surveyed about one out of every 200 Americans with developmental disabilities.

The youngest people in the survey are under half a year of age; the oldest respondent is 90. The average age is 25.0 years.

The survey group is 55% male and 45% female. The great majority of people (92%) have never been married; 4% are currently married, and 4% are separated, divorced, or widowed. The self-reported ethnic makeup of the sample is 79% "white," 11% "black," 3% "hispanic," and 7% a variety of others, including various Asian, Pacific Island, and other ethnic groups.

Empowerment is important for everyone, both children and adults. However, many of the questions in the National Survey on choice and control were in areas more applicable to adults, for example, banking and consent to medical care. Therefore, National Survey data presented in this report are only for the 7,196 adults (age 22 and older).

## WHAT IS EMPOWERMENT?

Empowerment by definition means "authorization" or "to invest with power." For people with disabilities, empowerment stresses choice for the individual, and the use of personal goals to guide the course of the

individual's future. It means the use of new technology to maximize individual mobility and expression. In a more global sense, empowerment means having people with disabilities in leadership positions that shape everyone's future.

Empowerment is closely related to independence, a topic addressed in the National Survey. The Developmental Disabilities Act defines "independence" as "the extent to which persons with developmental disabilities exert control and choice over their own lives." The elements of choice and control are crucial to both empowerment and independence.

*"Somehow there seems to be a silent debate about whether I should really be assisted in living independly or whether I should live in a group home. And that should be my decision." (Maine consumer)*

Empowerment comes from within. It is not something which can be given by one person or group to another. Empowerment happens for the person with a disability when he or she recognizes his/her own value as a human being and begins to exercise choice and control in life. Parents, professionals, and others can help people with disabilities to become empowered by providing them with the tools they need to exercise this power, i.e., information, access, and the support services which will make equal opportunity a reality.

## EMPOWERMENT—POLICY

Virtually all the 1990 Reports—48 in all—addressed the issue of empowerment and independence for people with developmental disabilities. These findings reflect the broad based input of people with developmental disabilities in the public forums, surveys and policy reviews that were the basis for the reports.

*"Vision: people with developmental disabilities . . . have control over their services, thereby directing their own lives." (Guam 1990 Report)*

At the heart of these discussions of empowerment were such essential principles as seeing each individual's goals, preferences, and desires as the starting point; making sure that people have power over their lives; supporting people to meet their personal goals; and recognizing that these principles apply to all people with developmental disabilities, regardless of the severity of their disability or the "labels" that have been applied to them.

*"It is the State Council's vision that all people with developmental disabilities shall have the same rights as individuals without disabilities." (California 1990 Report)*

Most of the 1990 Reports further emphasized that these kinds of principles need to be applied in all the activities affecting people with developmental disabilities, from individual advocacy to overall system design and monitoring. A program based on the empowerment model centers its design on individual choices, desires and goals as well as "needs," rather than the traditional approach that establishes services and then places people with developmental disabilities into service "slots," without regard to people's personal goals for the future.

## EMPOWERMENT—THE NATIONAL SURVEY

In order to understand how adults with developmental disabilities feel about empowerment and independence, the National Survey asked "how independent do you think you are?" and "how important is it to you to be independent?" The results are shown in Figure 1.

Additional areas of concern included inaccessible programs, housing and community resources; and inadequate due process to address limits on individual rights. Also addressed was the absence of people with developmental and other disabilities in positions of influence, as employees and as citizen volunteers.

People with developmental disabilities, their family members, and others concerned about them provided information across the nation on the barriers associated with these issues. Four major barriers were identified:

- (1) People with developmental disabilities and their families do not have a meaningful role in the planning and decision-making that affects their lives.
- (2) Principles of empowerment are not being observed.
- (3) There are low expectations of people with developmental disabilities, and, in many cases, actual discrimination which limit people's empowerment and independence.
- (4) Many people with developmental disabilities are unaware of their rights.

One of the key aspects of empowerment is self advocacy: the opportunity for people with developmental disabilities to be informed and take action in support of their rights and carry out their responsibilities as individuals, citizens, and members of their communities. Although some reports highlighted the growth of People First and other self advocacy organizations, several of the 1990 Reports also noted a lack of resources, support, and training in self advocacy.

*"People with disabilities are seldom asked to participate on boards of voluntary organizations, advocacy groups, or on local and state commissions. When they do participate, some report that they do not receive significant assignments or encouragement for active participation."*  
(Michigan 1990 Report)

## WHERE BARRIERS TO EMPOWERMENT ARE FOUND

Empowerment concerns were found in the 1990 Reports across a wide range of activities and publicly funded programs. Some programs were criticized because they perpetuated the segregation of people with developmental disabilities and reduced their ability to become more independent or to participate as citizens of their community. For example, inaccessible polling places prevent people with disabilities from voting.

Several 1990 Reports identified problems in the individual program planning process, including the Individuals with Disabilities Education Act (IDEA), the ICF/MR program within Medicaid, and Vocational Rehabilitation programs. The primary barrier is the lack of meaningful participation by the person with the disability, and the failure to focus the plan on how to help the individual reach his or her personal goals.

The media's role in limiting empowerment also was identified, in particular the portrayal of people with disabilities as helpless, dependent, and different from other people.

## STRATEGIES TO EMPOWER PEOPLE WITH DEVELOPMENTAL DISABILITIES

Forty-five reports included recommendations on empowerment strategies. Five types of strategies were recommended in particular:

- (1) Change service and support systems to an empowerment model—one that emphasizes choice and control by individuals with developmental disabilities. Specific strategies include increased involvement of people with developmental disabilities and family members in decisions (25 states); giving people more choices (15 states); and development of voucher or direct cash benefit systems to give people choice and control (8 states).
- (2) Involve people with developmental disabilities and families in planning, policy development, and quality assurance/program monitoring (28 states).
- (3) Increase opportunities for self advocacy—provide supports and training, and make self advocacy available to more individuals with developmental disabilities (20 states). Related strategies are to educate people with developmental disabilities on their rights (16 states) and to register people to vote and make voting accessible (8 states).
- (4) Provide more information on services; do more outreach (16 states).
- (5) Improve images of people with developmental disabilities—in the media and through other broad based public education activities (11 states).

The 1990 Reports provided several additional suggestions, such as increased advocacy on behalf of individuals with developmental disabilities; enactment of state "Bill of Rights" similar to the Federal articulation of rights in the Americans with Disabilities Act proposed at that time; addressing the need for conflict of interest protection; widespread employment of people with developmental and other disabilities; and the appointment of people with disabilities to local and state commissions, such as the zoning commission.

"Futures planning" and other similar person-centered approaches also were recommended in several reports. This process systematically identifies a person's individual goals, desires, and choices. These are then used as the basis for defining a plan for their supports and services.

## SUMMARY

- Empowerment is important to all people with disabilities, regardless of age or the severity of the person's disability. Choice and control are crucial to both empowerment and independence.
- Empowerment issues in the 1990 Reports have been identified, along with barriers to empowerment and strategies to empower people with disabilities.
- Independence is very important to more than half of the people with developmental disabilities who were surveyed, yet only a third of the people say that they are independent.
- People living in the community, whether or not they receive residential services, are more independent than people living in institutional settings.
- People who work in regular jobs or do volunteer work have the highest independence levels, and people who participate in adult day services or who are home during the day have the lowest independence levels.
- Most people with developmental disabilities need transportation to work or day activity, but there is a 15% gap in service regarding transportation. That is, of all the people with disabilities who need transportation, 15% do not get the service.
- Most people with disabilities have choice and control in regard to friends and day-to-day activities, such as what to wear, what to buy, and what to do on weekends. However, less than half of the adults surveyed have a choice about where they live, and less than a quarter chose the support staff who assist them.

For more information about the Administration on Developmental Disabilities' (ADD) Empowerment initiative, contact ADD, Room 336D, 200 Independence Avenue, S.W., Washington, DC 20201, (202) 245-2890.

This report was produced for the Administration on Developmental Disabilities by the Temple University Institute on Disabilities, a University Affiliated Program, in conjunction with Jaskulski & Associates.

**Figure 3**

Independence By Where Adults Spend Their Weekdays

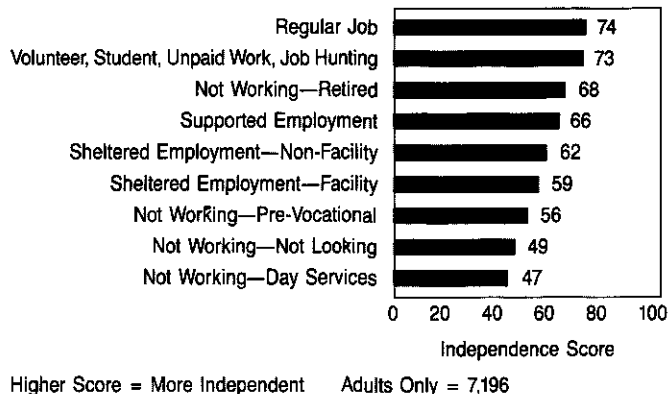


Figure 3 shows that the people who are the most independent are those working in regular jobs (74 on the Independence Scale), in volunteer or unpaid work, in school, or job hunting (73), in retirement (68), and in supported employment (66). The people who are in sheltered employment and pre-vocational programs are slightly less independent. By far, the people who are the least independent are those who are not working and not looking for work (49), and those in adult day services (47).

Support services are essential if people with disabilities are to be truly empowered, particularly in the areas of transportation and communication. If people with disabilities have no way to get from place to place, and no means of communication, their independence is severely limited.

For many people who have disabilities, transportation is a top priority that must be addressed. In the part of the National Survey that deals with supports needed, 62% of all adults told us that they need transportation to and from work or day activity. Of the people who need this service, 85% receive transportation service to their job or day activity. This means that 15% of the people who need transportation to get to work or day activity don't get it.

*"Continuous public transportation must be a top priority, if we honestly want people with disabilities to feel like contributing members of society." (New Jersey consumer)*

Another important aspect in the empowerment of people with disabilities is communication. The National Survey reveals that 38% of all adults need a lot of assistance (from people or devices) in communicating with others. Furthermore, 28% told us that they need communication and language services. Of the people who need communication and language services, only 42% are actually receiving the service. This reveals a 58% gap between the number of people who need this particular communication support and the number of people who receive it.

These gaps in service in transportation and communication represent two of the greatest barriers to increased independence, productivity, and integration for people with developmental disabilities. Filling these service gaps would go a long way toward the empowerment of people with disabilities.

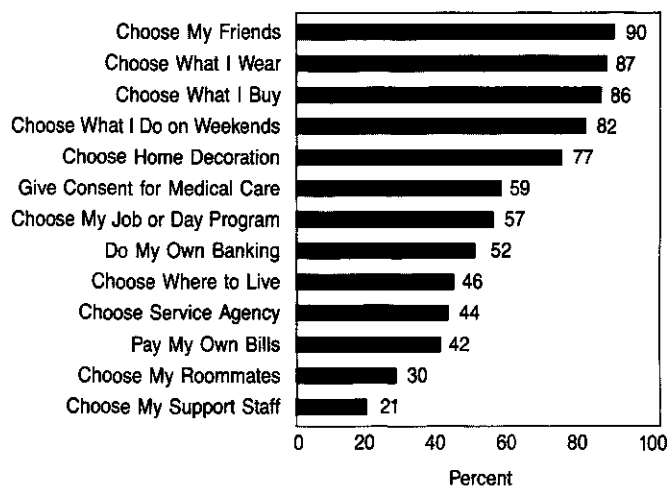
## EMPOWERMENT AND CHOICE

Because choice is such a necessary component of empowerment, we examined what people in the National Survey told us about choice in various aspects of life. The Survey asked many questions about choice and control. The responses to all these questions about choice

can be categorized as "yes, unassisted," "yes, assisted," and "no." Figure 4 presents the percentage of adults who answered "yes," either assisted or unassisted, to various questions on control and choice.

**Figure 4**

Assisted Or Unassisted, I



The figure shows us that there is a great deal of variability in the amount of choice and control that people with developmental disabilities have over various aspects of their lives. A large percentage of people do choose their friends (90%), choose what clothes to wear (87%), decide what things to buy with spending money (86%), choose what to do on weekends (82%), and choose how their personal space is decorated (77%). A smaller percentage of people told us that they give their own consent for medical care (59%), choose their jobs or what they do on weekdays (57%), do their own banking (52%), choose where to live (46%), choose who provides their services and supports (44%), and pay their own bills (42%). Areas where the fewest people have choice and control are in choosing their roommates (30%), and choosing their attendant and/or residential support staff (21%).

While many of these numbers are lower than expected, one figure that really stands out is that less than half of all adults with developmental disabilities choose where they live. This figure is low, especially when it is compared to the non-disabled adult population, in which nearly all adults choose where they live.

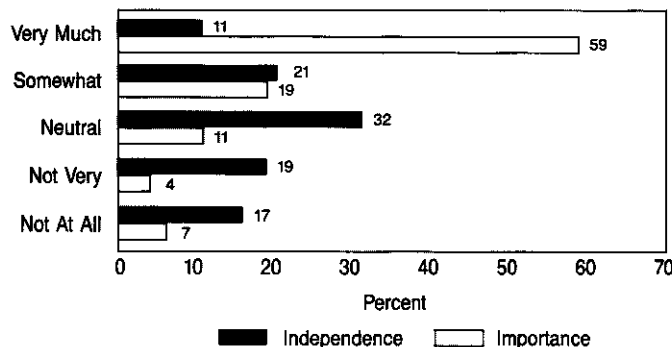
*"In the last year or so, Jylle has been telling us what she wants to do . . . She would like to live in an apartment. She would like to choose with whom she lives. I think she has the right to do that." (Alaska parent)*

## BARRIERS TO EMPOWERMENT AND INDEPENDENCE

The 1990 Reports provide a wealth of information on the barriers to empowerment and independence being encountered by people with developmental disabilities. The primary concern was the lack of opportunities for people with developmental disabilities to make choices about their lives. Related issues identified include poor "fit" between services/supports and individual needs, lack of control, and difficulties in obtaining information ("knowledge is power").

**Figure 1**

How Independent Are You vs. How Important Is Independence?



As the figure shows, 32% of the people told us that they are independent, as opposed to 36% who do not feel that they are independent. In contrast, 78% of the people with developmental disabilities feel that it is important to be independent, as opposed to only 11% who told us that independence is not important to them. In fact, more than half of the people (59%) say that independence is "very important" to them. While independence is clearly important to most people who have developmental disabilities, the percentage of people who say they are independent lags far behind.

*"As an adult, I have the right to live my life as independently as everyone else. That right and my desire to exert that right should never be questioned."* (Maine consumer)

Again using the person's rating of his/her own independence, the National Survey data show that some people with the most severe disabilities are independent. We examined the independence ratings of 475 adults in the Survey with substantial functional limitations in each of seven life areas. Of these people with the most severe disabilities, 3% say that they are "totally independent" and 5% rate themselves as being "independent." While these numbers are not large, they do show that it is possible for people who have severe disabilities to feel they are "independent." This finding should encourage all people with disabilities to strive for their highest possible level of independence and empowerment.

*"I lived at Dixon Developmental Center for 28 years . . . now I have moved to my own apartment . . . I signed my own lease, pay my own bills, and for the first time I can stay home without staff. This is the best place I have lived so far. I like my roommates, and this is our place."* (Illinois consumer)

For the purpose of group comparison, we created a scale which summarizes the independence level of each individual. The scale is composed of 10 different ratings of the amount of choice and control that people have over various aspects of their lives.

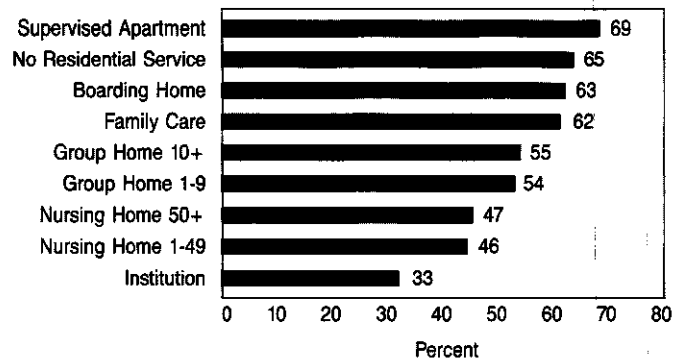
Examples of these include choice over where to live, choice over where to work, giving consent for medical care, and control over how people spend their own money. These 10 items are combined to produce the Independence Scale. The Independence Scale ranges from 0 to 100,

with a higher score indicating a higher level of choice and control (i.e., the person is more "independent"). The Independence Scale can best be used to compare different groups of people within the National Survey data set.

Figure 2 presents the average independence score for adults living in various residential situations, using the Independence Scale described above.

**Figure 2**

Independence By Where Adults Live



Higher Score = More Independent Adults Only = 7,196

The figure shows that adults living in community settings are "more independent" than those in institutional settings. The highest independence scores are measured for people living in supervised apartments (69), people living in the community without residential services (65), people in community boarding homes (63), and people in substitute/foster family settings (62). People living in group homes are slightly less independent (55 for larger group homes and 54 for smaller group homes). The people living in larger nursing homes (47), smaller nursing homes (46), and institutions (33) are the least independent, according to the Independence Scale.

Many people throughout the country have moved from institutions to community settings and have flourished, regardless of the severity of their disability. This indicates that the independence score is, to some extent, a function of the setting, as opposed to people suddenly learning to be independent after moving to their new home. By the very nature of the environment, people in institutional settings cannot attain the level of independence that can be reached in community settings.

*"I live in a group home with a roommate. I don't like my roommate, but I have no choice. I want my own place and my own job. I am 57 years old . . . I think that I should have some choice in things."* (Oklahoma consumer)

In order to compare independence levels for adults in different work situations, National Survey data were used to categorize adults according to their employment situations. The categories of employment are: regular job (12%), supported employment (6%), non-facility based sheltered employment (3%), facility based sheltered employment (17%), volunteer workers, unpaid workers, students, and people looking for work (9%). In addition, people who are not working included: retired (1%), pre-vocational program (21%), adult day service (11%), and not looking for work (21%). Figure 3 presents the Independence Scale scores for people in these employment categories.

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