THE ADMINISTRATION ON DEVELOPMENTAL DISABILITIES
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INCLUSION

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

The Administration for Children and Families
United States Department of Health and Human Services

This is the second 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 2 to 3 million Americans have developmental disabilities. The Consumer Survey included 13,075 people. 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.

WHAT IS INCLUSION?

Inclusion by definition means "being a part of a whole." For people with disabilities, the whole is a community, and inclusion means living among others and being a part of the life of a community. It means having the opportunity to participate in the everyday activities of a community with other citizens. Inclusion stresses the importance of family and friends, of performing real work for real pay, and of giving and receiving the benefits of being a community member.

Inclusion is closely related to integration, a topic included in the National Survey. The Developmental Disabilities Act defines integration as "the use by persons with developmental disabilities of the same community resources that are used by and available to other citizens, participation by persons with developmental disabilities in the same community activities and integrated employment in which citizens without disabilities participate, together with regular contact with citizens without disabilities, and use of the same community resources by persons with developmental disabilities living, learning, working, and enjoying life in regular contact with citizens without disabilities, and development of friendships and relationships with persons without disabilities, and the residence of persons with developmental disabilities in homes which are in proximity to community resources, together with regular contact with citizens without disabilities in their communities."

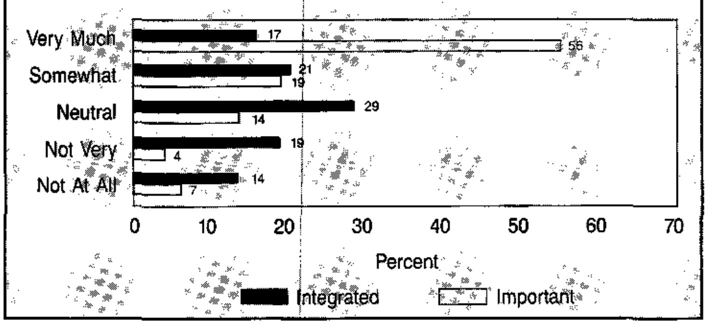
INCLUSION—THE NATIONAL SURVEY

This section uses data from all people interviewed for the National Survey, both adults and children. While nearly all responses for people age 21 and under came from surrogates (95%), the same patterns of response were found for adults and children on these items. We have therefore combined the data in this part of the report.

In order to get an understanding of how people with developmental disabilities feel about integration and inclusion, the National Survey asked "how integrated do you think you are?" and "how important is it to you to be integrated into the community?" The results are shown in Figure 1.

Figure 1

How Integrated are You vs. How Important is Integration?



As the figure shows, 38% of the people told us that they are integrated in their community, as opposed to 33% who do not feel integrated into the community in which they live. In contrast, 75% of the people with developmental disabilities feel that it is important to be integrated in the community, as opposed to only 11% who feel it is not important. In fact, more than half of the people (56%) say that integration is "very important." While inclusion is clearly important to a large percentage of people with developmental disabilities, the percentage of people who feel included in their community lags far behind.

> *"Friendship and support are important to everyone, regardless of their age or circumstances."* (Georgia 1990 Report)

In a related National Survey analysis, we examined the integration ratings of people with developmental disabilities by how satisfied they are with life in general. The percent of people who felt "integrated" is as follows:

OF THE PEOPLE WHOSE SATISFACTION WITH LIFE IS:	THE PERCENT WHO FEEL INTEGRATED IS:
Very Satisfied	45%
Somewhat Satisfied	36%
Neutral	29%
Somewhat Dissatisfied	28%
Very Dissatisfied	19%

The table shows that people who were most satisfied with their lives also had the highest percentage of people who feel "integrated." Conversely, the people who were least satisfied with life in general had the lowest percentage of people who felt integrated. Thus, there appears to be a significant relationship between community inclusion and satisfaction with life.

Again using the respondent's rating of his/her own integration, the Survey data show that some people with the most severe disabilities are included in their community. We examined the integration ratings of 680 people in the Survey with substantial functional limitations in seven life areas. Of these people with the most severe disabilities, 7% say they are "very integrated" and 10% rate themselves as being "integrated." This finding should encourage all consumers, advocates, families, and professionals to strive for the goal of community inclusion and integration for all people, regardless of the severity of their disabilities.

> *"Social and recreational opportunities must be considered on an equal basis with other program resources in providing for full life experiences for people with developmental disabilities. This form of full integration should help enable people with developmental disabilities to make friends and establish support groups among people without disabilities.* (California 1990 Report)

COMMUNITY INCLUSION OF CHILDREN

This section uses data from the 5,852 people interviewed for the National Survey who were age 21 and under. We will examine community inclusion by where these children live and by where they go to school.

The National Survey data reveal that most of the people age 21 and under do not receive residential services. A breakdown of where children live is presented in the following table.

WHERE CHILDREN LIVE	PERCENT
With Family—No Residential Service	72%
Family Care—Residential Service	17%
Community Residential Facility	6%
Institution	5%

Nearly three-quarters of the children live with family and do not receive any residential services at all. The rest do receive formal residential service. 17% are in situations defined as family care settings (substitute or foster family). Only 6% of the people under age 21 live in community residential facilities (group homes, apartments), and 5% live in institutional settings.

For the purpose of group comparison, we have created a scale which summarizes the integration level of each individual. The scale is composed of the frequency ratings of 13 different community activities for each individual. Examples of these activities are visiting friends, going to a restaurant, and going to the movies. Combined, these 13 ratings yield the Integration Scale. The Integration Scale ranges from 0 to 100, with a higher score indicating a higher frequency of community activity (i.e., a person is "more integrated"). The Integration Scale can best be used to compare different groups of people within the National Survey data set. The perception of inclusion may vary, based on the respondent (the consumer or the family/surrogate).

The following table presents an integration score for each of the four residential situations presented for people age 21 and under.

WHERE CHILDREN LIVE	INTEGRATION SCALE
With Family—No Residential Service	29
Family Care—Residential Service	28
Community Residential Facility	30
Institution	21

By far, the lowest score is found for children living in institutions, indicating that they are the least integrated. Integration Scale scores for the other three settings are similar, with children living in community residential facilities being the "most integrated." It is clear, almost by definition, that community inclusion for children can most likely happen when they live with family, or in a home in the community.

> *"Well, it seems if they have the money for group homes, why can't they have that for the child at home where he's happy and not take him out of his home surroundings?"* (Utah parent)

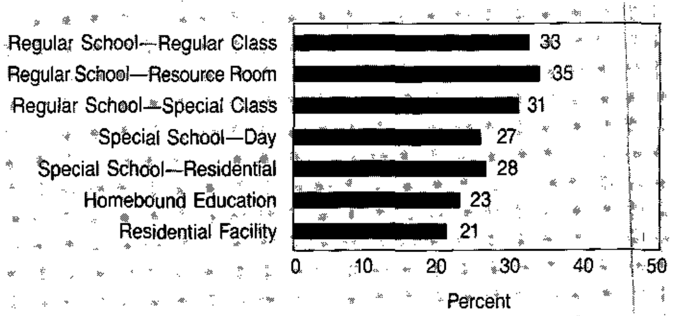
An important aspect of the lives of children is education. The National Survey asked, "In what setting did you receive most of your education?" 55% of the children go to a regular school (11% in a regular class, 5% in a resource room, and 39% in a special class). Another 39% of the children go to a special school (34% in school during the day and 5% in a residential school). 3% receive homebound education and 3% are educated at a residential facility. Only 11% of all the children are truly integrated, attending a regular class in a regular school.

> *"We are all prejudiced toward people with disabilities, whether we want to be or not. It's just the way we were raised and what we saw growing up . . . But I see the kids in Josh's class just interact with him as another kid. And I think, and maybe I'm optimistic, that future generations won't have that prejudice."* (West Virginia Parent)

Using the Integration Scale described earlier in this report, we rated the community inclusion of the various educational settings the children attend. The data are presented in Figure 2.

Figure 2

Integration Score by Where Children Go to School



Ages 1 to 21, N = 5327 Higher Scale = More Integrated

The figure shows that people age 21 and under who attend regular school are "more integrated" than those in other settings, as indicated by higher Integration Scale scores. The highest Integration scores are measured for children in regular school resource rooms (35), regular school regular classes (33), and regular school special classes (31). The children in special schools were less integrated, with special school—day scoring a 27 and special school—residential a 28. The children receiving their education at home or in residential facilities were the least integrated of all, with Integration scores far below the rest.

The same pattern is found when the parents rating of their child's integration is examined by educational setting. Children in regular schools are more frequently described as being "integrated" than children in special schools or residential facilities.

> *"Our son has always been in regular classes with his age group. Initially we had our reservations, but we've been really pleased. It's just incredible to me to go into the classroom and see these kids interacting with each other. They know how to communicate with him; they show him how to do his science experiments. It's incredible."* (New Hampshire Parent)

COMMUNITY INCLUSION OF ADULTS

This section uses data from the 7,196 people interviewed for the National Survey who were age 22 and over. We will examine community inclusion by where the adults live and by where they work, as well as several other indicators of community inclusion.

The National Survey asked, "During the past few weeks have you ever felt very lonely or remote from other people?" More than half of the adults in the Survey (56%) said "yes," indicating that they had felt very lonely recently. Comparison data are available from "The Quality of American Life" Study by Campbell and Converse in 1984. Only 22% of all non-disabled adults in this study ever "felt lonely." Adults with developmental disabilities are more than twice as likely to feel lonely as non-disabled Americans.

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> *"I just sit in my room, listen to the radio, have a cigarette, go out to church once a week—that doesn't cost anything. It's like a prison."* (New Hampshire consumer)

Adults in the National Survey live in a variety of residential settings. Most adults live in the community without residential services (46%). Residential service options in the community include group homes (23%) and supervised apartments, boarding homes, and family care settings (18% combined). The remaining people live in institutions and nursing homes (13%). Figure 3 shows the Integration Scale scores for adults according to where they live.

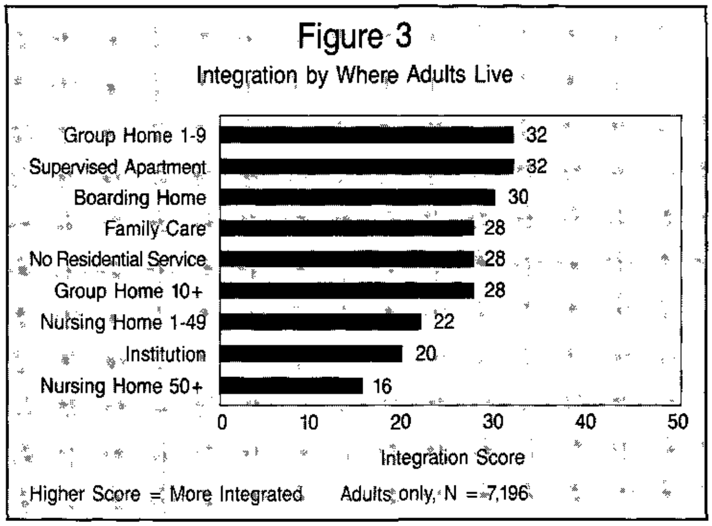

Figure 3

Integration by Where Adults Live

The figure shows a wide variation in community inclusion based on the type of residence. All adults living in the community scored 28 or higher on the Integration Scale, indicating that they are "more integrated" than adults living in institutional settings (who had average scores of 22 or lower). People living in small group homes, supervised apartments, and boarding homes were the most integrated. Next were people living in family care settings, large group homes, and people living in the community with no residential services. Adults living in nursing homes and institutions have by far the lowest levels of community integration.

In order to compare community inclusion 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/unpaid workers, students, looking for work (9%), and not working (53%). The table below presents the Integration Scale scores for people in these employment categories.

WHERE ADULTS WORK	INTEGRATION SCALE
Regular Job	34
Supported Employment	34
Sheltered Employment-Non-Facility	32
Sheltered Employment-Facility Based	31
Volunteer, Unpaid Work, Student, Job-Hunting	30
Not Working (Home, Pre-Vocational, Day Service)	25

The table shows that the people who are not working are "less integrated" than everyone else. There was little variability in the average Integration Scale score for the other 5 groups. The people who are "most integrated" are those in supported employment and regular jobs. The basic finding here is that adults with developmental disabilities who are working are more "included" than those who are not working.

The National Survey collected a great deal of information on how frequently the person with developmental disabilities participated in a variety of community activities, and used community resources, like everyone else in the community. Figure 4 presents the percentage of adults who participate weekly in each of seven activities. Comparative figures for people without disabilities are presented whenever available.

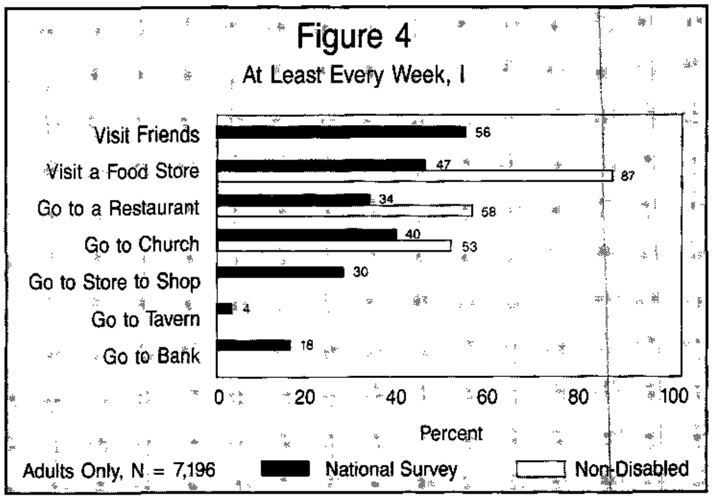

Figure 4

At Least Every Week, I

As the figure shows, the activities that the highest percentage of adults participate in weekly are visiting friends, relatives, or neighbors (56%), visiting a supermarket or food store (47%), and going to church (40%). Less than 20% of the adults in the National Survey go each week to the bank (18%) or to a bar or tavern (4%).

For comparison, Figure 4 also includes the percentage of non-disabled adults who participate each week in the same activities. These figures come from the International Center for the Disabled's Survey of Disabled Americans, conducted by the Harris organization in 1986. On all three comparative items, a higher percentage of non-disabled people participate weekly, compared to people with developmental disabilities. A higher percentage of people visit a food store weekly (87% to 47%), go each week to a restaurant (58% vs. 34%), and go every week to church (53% vs. 40%).

Perhaps through providing community supports to people with developmental disabilities, and through education and changes in attitude of the general public, and through the improvement of accessibility to community resources, these differences in community inclusion between people with disabilities and people without disabilities can become smaller or disappear.

BARRIERS TO COMMUNITY INCLUSION

Concerns about barriers to community inclusion were identified in 44 of the 1990 Reports. Barriers were found affecting the lives of people with developmental disabilities in the following areas:

- Inclusion as a neighbor (36 states): reliance on segregated living arrangements, use of ICF/MR facilities and other "medical models," lack of opportunities for integrated and accessible community recreation activities
- Inclusion in education (28 states)
- Inclusion as a co-worker (15 states)
- Inclusion as a citizen (8 states): voting barriers; barriers to participation on planning boards, in monitoring activities
- Inclusion in life in general (24 states): lack of friends; poor preparation for community participation, especially in the education system; physical proximity in housing, education, and work that does not equate with inclusion; "client mentality"

The 44 reports with findings on community inclusion also identified five types of factors associated with barriers to inclusion:

(1) Lack of supports to individuals specifically relevant to the promotion of community inclusion (35 states)—transportation (e.g., to community

leisure activities), related services that support integrated education, supports for making friends and building relationships, assistive technology, interpreters

(2) Other systems factors (33 states)—provider traditions; lack of awareness of the importance of inclusion, public education, other support to communities; shortage of knowledgeable professionals; generic provider resistance (e.g., in senior centers); use of the continuum model in employment and living arrangements; weak enforcement of standards (e.g., of "least restrictive environment" requirements in education); poor use of generic services; lack of support to generic service providers

(3) Community factors (27 states)—prejudice, negative public attitudes; inaccessible community facilities

(4) Resource factors (27 states)—relative lack of resources for services that *promote* community inclusion in contrast to those available for services that *restrict* community inclusion such as institutional care; financial disincentives (e.g., higher rates of state aid to local school districts for out of state school placements than for education in the child's home community)

(5) Policy factors (21 states)—inappropriate standards, approaches to monitoring that do not emphasize community inclusion; lack of explicit policies on inclusion; lack of data on inclusion (e.g., on outcomes for individuals)

STRATEGIES TO REDUCE BARRIERS AND PROMOTE INCLUSION

The 1990 Reports are a "gold mine" of ideas on strategies to promote community inclusion; 49 states and territories included information and recommendations in this area. Some recommendations were made by large numbers of states (e.g., 30 states recommended that community inclusion be identified explicitly as a policy goal); other strategies were identified by only one or two states (e.g., that American Sign Language be taught to students in classes with non-hearing peers).

The majority of reports (31 states) recommended *public education* strategies, including providers, both generic service personnel (e.g., health, public transportation) and those in the specialized developmental disabilities service system, as well as peers and community members. Specific strategies to reach providers included the following recommendations:

- Emphasize community inclusion (its importance, ways to support inclusion) in professional education.
- Add requirements on community inclusion to professional certification standards.
- Provide training and technical assistance on inclusion to generic service providers.
- Change the role of special education teachers to facilitators and consultants on "mainstreaming" and inclusive education.
- Identify the competencies needed for promotion of community inclusion.
- Provide scholarships to providers for additional training on inclusion.
- Improve dissemination of "best strategies."
- Increase resources for education and training on inclusion

Strategies recommended to reach peers and community members included, in addition to the teaching of American Sign Language noted above, the employment of people with disabilities (e.g., in community recreation programs); improved use of the media; participation of people with developmental disabilities in community organizations; and the establishment of a community council on developmental disabilities in each county of the state.

Many 1990 Reports recommended *local initiatives* on community inclusion, targeted either to individuals or to communities. Supports to individuals with developmental disabilities to enhance their inclusion included increased use of informal supports, building "circles of friends," the development of other friend-advocate programs, targeted provider efforts to help people increase their community connections, increased use of the Foster Grandparent Program, peer tutoring and cooperative learning programs in the schools, and the use of smaller community residences. Recommended supports to communities, in addition to increased resources for such supports, included the provision of incentives for local initiatives, greater involvement of communities and local governments, and the expansion of opportunities for community members to know and form relationships with people with developmental disabilities.

Eight additional types of strategies were recommended by the states and territories in their 1990 Reports:

(1) **Policy strategies** (39 states), including the definition of community inclusion as an explicit policy goal, recognition of its significance in developmental disability policy, and greater emphasis on inclusion in following existing policy.

(2) **Individual support strategies** specific to the promotion of inclusion (34 states), such as better preparation for community participation (e.g., in the education system), transportation, interpreters for people with severe hearing impairments, assistive technology, and architectural modifications to increase accessibility

(3) **Research and planning** (28 states), in particular research on community inclusion outcomes and ways to promote inclusion

(4) **Resource strategies** (24 states), including increased resources for the supports that promote community inclusion and for accessible community recreation, creation of incentives for community inclusion and reduction of financial disincentives, redirection of funding from segregated services to those that promote inclusion, and resources for professional and public education

(5) **Quality assurance** (23 states), in particular the improvement of monitoring and enforcement to emphasize community inclusion outcomes as well as such suggestions as the development of state mandates for integration and inclusion, the recognition of excellence in community inclusion, and the creation of a "segregation complaint procedure"

(6) **Service system strategies** (20 states), such as expanded opportunities for participation in community recreation, integrated child care, preschools, and adult education, the use of team teaching, elimination of the use of segregated facilities, and the specific addressing of community inclusion goals in individual program plans

(7) **Strategies to increase inclusion as citizens** (17 states), including greater participation of people with developmental disabilities on boards and committees responsible for service system planning and oversight, increased voter participation, and the development of statewide citizen participation initiatives

(8) **Coordination strategies** (7 states), including inter-agency collaboration on the promotion of inclusion, support to coordination among providers, and statewide coordination of local initiatives on inclusion

Strategies specific to inclusive living arrangements may be found in the "Home of Your Own" brochure available from the Administration on Developmental Disabilities.

STRATEGIES ALREADY IN PLACE

Fourteen 1990 Reports included information on existing strategies that had been found to be effective in promoting community inclusion. Similar to the recommendations outlined above, they may be characterized as follows:

- **Policy and systems strategies**, including explicit goals of community inclusion in developmental disability policy, inclusion of such goals in individual program plans, and standards of community inclusion as part of the quality assurance system
- **Supports to individuals that emphasize promotion of community inclusion**, such as friendship building, assistive technology, informal supports, "functional" curricula that emphasize community participation, and supported living approaches
- **Support of local initiatives** (e.g., demonstration projects)
- **Public education**, such as evidence of the benefits of community members' experience as co-workers of people with developmental disabilities

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