

# **FORGING A NEW ERA**

THE 1990 REPORTS ON  
PEOPLE WITH DEVELOPMENTAL  
DISABILITIES

May 1990

National Association of Developmental Disabilities Councils

# **The 1990 Reports**

## **Forging A New Era**

A summary of the reports  
prepared by State and Territorial  
Developmental Disabilities Councils  
pursuant to the 1987 Amendments to the  
Developmental Disabilities Assistance and Bill of Rights Act

**May 1990**

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# FORGING A NEW ERA

## The 1990 Reports on People with Developmental Disabilities

### **Forging a New Era: The 1990 Reports on People with Developmental Disabilities**

brings together new ideas, new knowledge and powerful voices of people who themselves experience developmental disabilities. The timing of these Reports fits well into today's environment: civil rights for people with disabilities are at the top of our national priorities; new technologies, ideas and devices make participation possible; families and individuals with disabilities are speaking out about their achievements and their desires to be accepted as an active part of society.

The 1990 Reports capture this energy, describing what life is like in the United States now and defining a vision for a new era. The Reports clearly demonstrate that disability issues should be discussed as part of general social and economic policy. The Reports will assist federal, state and local governments in recognizing the achievements of people with developmental disabilities and in shaping an America which meets the challenges that remain.

43 million Americans have disabilities--3 million of those have developmental disabilities--disabilities which are severe, occur early in life, and usually require lifelong supports. These may include mental retardation, cerebral palsy, epilepsy, autism, head injury, deafness, blindness and others. The definition of developmental disabilities is contained in the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1978.

Developmental Disabilities Councils are advocates for people with developmental disabilities in each of the states and territories. Their members are appointed by governors and include people with developmental disabilities, their family members, state agency representatives, service providers and interested members of the public. These Councils were created by the Developmental Disabilities Assistance and Bill of Rights Act in 1971.

In amendments to this Act in 1987, Congress mandated that Councils prepare the 1990 Reports, looking at barriers to the achievement of independence, productivity and integration into the community by all people with developmental disabilities. Congress asked for a review of federal and state policies and for a survey of "consumers"--people with developmental

disabilities and their families--to ask them directly what their experiences have been. This became the National Consumer Survey, including nearly 14,000 respondents.

**Forging a New Era** illuminates some of the critical policy questions that emerged from the review of policies and from the Survey. It also reflects some of the successes and opportunities for tapping the potential of all people with developmental disabilities.

This summary includes references from the individual state reports, expressions of the visions for full participation the reports contained, quotes from people who participated in the survey and in public forums, and hallmarks of achievement in public policy.

## THE NATIONAL CONSUMER SURVEY

In developing the 1990 Reports, Developmental Disabilities Councils conducted a survey of people with developmental disabilities and their families to discover their views on services and also to determine the impact of services on their independence, productivity and integration into the community.

Working through the National Association of Developmental Disabilities Councils and with the technical support of Temple University, Councils developed a survey instrument which could be used nationwide. Nearly all Councils used this instrument to conduct their required survey, resulting in the collection of information on 14,000 people nationwide.

This information was key to the development of recommendations in the Reports. The survey emphasized how well policies and programs were meeting people's needs but also included many questions about everyday life: How much do you participate in your community? How do you feel about being a productive citizen? Do you have choices about your life? Many of these questions were constructed so that data about people with developmental disabilities could be compared to information about other Americans. Questions were taken from the U.S. Census and from other major national studies.

The voices of people are an important part of the public policy debate, reflecting the real needs and desires of people with developmental disabilities and their families.

Key findings of the Survey are identified in this summary. A full report, "Report on the 1990 National Consumer Survey," has been prepared by the Developmental Disabilities Center of Temple University in conjunction with the National Association of Developmental Disabilities Councils, under a grant from the Administration on Developmental Disabilities.

# **SUPPORTS TO FAMILIES AND INDIVIDUALS**

**"Technology has made it possible for us to express our ideas and feelings and let you discover that we do have things to say. Computer technology is one of the most important keys in making a person with a disability become more productive and independent."  
(Minnesota Consumer)**

**"An appropriate wheelchair is as important for mobility as legs are for walking; an augmentative communication device as important for talking as a voice." (Hawaii Consumer)**

## **1990 REPORT FINDINGS**

People with developmental disabilities can live in the community; many need supports to assist them. This is true both for adults living on their own or with others and for families of children with developmental disabilities. Service systems are gradually changing to offer supports to meet individual needs.

Medicaid optional services and the Medicaid Home and Community Based Services (HCB) waiver are being used by many states to provide individual and family supports. However, many states must use significant amounts of state resources in family support initiatives. Many unmet needs remain. Waiting lists are long and hold little promise of diminishing for critical services such as respite care for families.

Technology Related Assistance grants are helping some states to expand the availability of all types of mobility aids, computer based learning tools, communication aids and other innovations.

Transportation, one of the most needed supports, is still not available or accessible to many people with developmental disabilities. In the National Consumer Survey, transportation for activities needed for full participation in community life are particularly lacking.

While new models provide supports to individuals in their homes, meeting individual needs, there are major gaps in the availability of some supports: personal care assistance and some therapies are not required Medicaid services; technology and medical equipment are not

always reimbursable; independent living training is not widely used to help people with disabilities such as mental retardation live on their own.

In the National Consumer Survey, some of the most frequently identified needs were in the areas of self-help and support groups, family support groups, and companion/friend programs. This points out the importance of working to connect individuals and families to the natural support that is found in friends, family, neighbors and communities.

## **FORGING A NEW ERA**

**Individual and family supports will be an integral part of a new approach. Supports to individuals will enable choice and selection, help people to stay in their homes and communities, and empower people to obtain what they need to achieve the goals of independence, productivity and integration.**

- \*Promote the development of information and referral systems and the improved effectiveness of coordination assistance.

- \*Promote increased use of informal supports and involved communities, in addition to formal programs, helping people to help each other; support individuals to form meaningful friendships with people who do not have a disability.

- \*Expand the availability and scope of individual supports through Medicaid optional and waived services, including personal assistance, case management, technology and therapies.

- \*Expand the Independent Living Program which supports consumer-managed programs to provide assistance and training to individuals with disabilities to live on their own in the community.

- \*Restore funding levels for the Social Services Block Grant which has great flexibility and the goals of preventing unnecessary institutional services and promoting self-sufficiency.

# EDUCATION AND LEARNING

**"We all are prejudiced toward people with disabilities. It's the way we were raised. But I see the kids in Josh's class interact with him as another kid. Maybe future generations won't have that prejudice."  
(West Virginia Parent)**

**"I went to regular schools all my life. I wasn't treated any differently by my teachers and peers. I was accepted." (Louisiana Consumer)**

## 1990 REPORT FINDINGS

Children with developmental disabilities are now included in public school systems, but education now must reach further to achieve full development of each child's potential, inclusion of each child in school and community life, and transition of each student to adult life.

Since the enactment of P.L. 94-142 in 1975, more and more children have access to a free and appropriate education, but segregation in school programs is still the most common experience, especially for children with severe disabilities. In the National Consumer Survey, 38% of the children were completely segregated either in separate buildings, residential schools or in homebound education.

While more and more children are receiving an education, there are widespread concerns about insufficient funding resources for special education and related services. Supports such as technology, assistive devices, essential therapies and physical accessibility can be critical to achieving an optimum education for a child with a developmental disability. In the National Consumer Survey, summer school, which if provided prevents children from losing skills gained during the regular school year, was one of the most needed services.

Services for very young children received impetus and support with the provision of federal funding under recent amendments to the Education of All Handicapped Children Act. But there remains a shortage of early intervention, infant and toddler and other pre-school and early childhood services. Many children are on waiting lists and programs may be limited in many areas without resources (e.g., trained professionals). Early intervention is critical to prevent further problems and to achieve maximum development. Regular day care providers do not always accept children with special needs. Although Head Start has a requirement to offer 10% of its services to children with disabilities, this does not meet the need.

Preparation for adulthood--for jobs and adult responsibilities--needs considerable attention. There is little transition planning to assure that students exiting special education are linked to services which will assist them with work and other aspects of life. For those students who desire post-secondary education, opportunities are still limited. All of this often means that the investment in special education is wasted.

## **FORGING A NEW ERA**

**Every person with developmental disabilities from infancy through adulthood will receive an education in integrated environments with all other students.**

**Education will meet each person's needs to enable them to become accepted, contributing citizens.**

\*Increase federal funding support for special education to the level promised in the Education of All Handicapped Children Act.

\*Require the development and monitoring of clear policies on the promotion of full integration and meeting students' individual needs. Assist teachers to include students with developmental disabilities in classrooms and other school activities.

\*Use the school years to prepare students for adult life and work. Improve curricula to include career planning and work preparation. Increase coordination and transition planning when students are in school to assure that needed adult services are provided when needed.

\*Parents, students and educators will be full partners in decisions about the student's education.



# WORK

**"I want to work for the same reason other people want to work. Which is to support myself and to feel like part of the world. Why is that so hard for people to understand?" (Maine Consumer)**

**"Supported employment works. It allows school staff to train and place students in competitive work sites. We've done it in Waco. It must be more effective than any workshop." (Texas Parent)**

## 1990 REPORT FINDINGS

People with disabilities can become a part of the workforce. Having a job contributes to independence, empowering people to make contributions and to support themselves. Work enables participation and contact with people. The National Consumer Survey found that only 10% of the adults were unable to work; even people with substantial limitations had competitive jobs.

While supported employment is a recognized part of vocational rehabilitation programs, it is still limited in availability. With supported employment, an individual can receive assistance (such as a job coach) to get and keep a real job. This assistance is often provided only for a short time; many people need continuing or intermittent assistance for the entire time they are employed. Supported employment under the Vocational Rehabilitation Program is available but does not yet reach the majority of adults with developmental disabilities.

People with developmental disabilities earn very low wages even when working. In the National Consumer Survey, 75% of the adults earned minimum wage or less. Average weekly wages were \$60 and were particularly low in sheltered employment.

Cooperative programs with private industry have achieved a high level of success, integrating people with developmental disabilities into real jobs for real wages. The Job Training and Partnership Act has targeted people with disabilities and has been successful in educating private employers as well as providing training and supports.

Changes in income support programs, such as the establishment of the Section 1619

provisions in the Supplemental Security Income program which allow for continuation of Medicaid eligibility while working encourage employment. Participation in this program is growing but still only includes a small percentage of those eligible; education of individuals and families is needed.

Benefits, such as health insurance and retirement plans, are not available to many people with developmental disabilities. Frequently the reason is that they are only working part time.

## **FORGING A NEW ERA**

**All people with developmental disabilities will have an opportunity to work and will receive just wages and benefits. They will have a variety of occupational choices to empower them to pursue a productive, contributing life.**

- \*Improve and target job training and placement for people with developmental disabilities through existing programs such as the Job Training and Partnership Act and state job placement programs.

- \*Vocational Rehabilitation programs should focus on achieving job placement and retention and be flexible enough to meet the varied needs for long-term support, specialized technology and training of people with developmental disabilities.

- \*Provide economic incentives to service providers to move people in sheltered employment to the competitive labor force, assisting these providers to make the best use of their resources and to modify their services in order to find real jobs for people with developmental disabilities in the community.

- \*Increase the Substantial Gainful Activity allowance under SSI so more adults can try employment without sinking into poverty. Reassess the "catch 22" in income support programs which requires people to prove complete inability to work in order to be eligible.

- \*Provide education and incentives to private sector employers to hire people with developmental disabilities; provide funding for on-going, on-the-job supports to encourage employment in real jobs. Encourage state and federal governments to increase employment of people with developmental disabilities in the public sector.

# INCOME

**"The guidelines for what you can earn without losing benefits are too low. My guideline was set a long time ago and it doesn't reflect the earning power of today. I have a job I could do but it jeopardizes my SSI and I cannot risk that." (Maine Consumer)**

## 1990 REPORT FINDINGS

People's ability to be independent and productive is directly related to their income. People with disabilities often need income supports but those supports often pose many barriers to becoming employed. They restrict the amount that can be earned without jeopardizing cash and other supports, including eligibility for Medicaid.

Income support programs are insufficient to meet basic needs and limit the ability of adults to live independently. Many people with developmental disabilities live below the poverty line, even when receiving income supports.

Eligibility requirements fail to recognize that disability creates above average and often extraordinary expenses, especially for working families. Although children with developmental disabilities often require expensive care and equipment, eligibility for income support programs is often not available to families.

Income support programs frequently do not support people to live independently. State supplements to Supplemental Security Income and eligibility for food stamps are often available to some (i.e., those living in group homes) but are not available to those who live on their own or with families.

In the National Consumer Survey, 54% of those surveyed said they received Supplemental Security Income, 20% said they received Social Security Disability Income and 8% said they received Aid to Families with Dependent Children.

# FORGING A NEW ERA

**People will have income sufficient to provide for their basic needs, to maintain an adequate standard of living, and to save for old age and emergencies. Income supports will be available when needed, for emergency, short-term and long-term needs and be provided in ways that foster dignity and increase independence and autonomy.**

\*Increase income support levels to above the level of poverty and to achieve an adequate standard of living.

\*Improve flexibility of income supports to meet individual needs and to encourage employment and productivity, not create disincentives to work.

\*Increase the levels of substantial gainful activity so that people can continue to receive the additional income support they need even while working.

\*Remove eligibility barriers in income support programs, particularly for children.

\*Improve coordination of income supports so that an individual can obtain needed supports without losing other benefits and continuing the cycle of poverty.

\*Encourage use of tax credits (both income and property) to bolster independence and self-sufficiency and prevent impoverishment caused by disability.

# HOUSING

**"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)**

**"Our son is a walking miracle. He demonstrates the success of community living programs. They said it would never work, not for our son. They said it couldn't be done. Look at him now. We beat the doomsayers. Our son is a very loving and lovable human being who expects no more from life than so-called 'normal' people but deserves no less." (Wisconsin Parent)**

## 1990 REPORT FINDINGS

More and more people with developmental disabilities are living in homes, in communities but the need for adequate housing and supports has not yet been fully met.

Most states have reduced the use of large institutions and have developed community living alternatives. The number of people residing institutions has decreased by 50% (from a high of 194,650 in 1967 to 91,440 in 1989). New policies in several states have been especially effective in preventing institutionalization of children. States have developed state-financed community living programs and have used Medicaid waiver programs to fund necessary community supports. McKinney Act programs have begun to address the needs of homeless Americans, including those with developmental disabilities.

In order to live in homes, people with developmental disabilities often need supports. Families with children may need respite care, training, medical equipment and supplies. Adults need help to manage their homes and some need personal care assistance for daily activities. States are pursuing community services-provided to people in real homes--as a more appropriate, better way to meet people's needs; but all of the 1990 Reports indicate a serious shortage of supports, with very large waiting lists in many states and inadequate choices for families and individuals.

Foster families can provide a home for children with developmental disabilities, but recruitment is often hindered by limited supports available to families.

General housing is often not accessible to people with physical disabilities. Accessibility may be improved with the implementation of the Fair Housing Act Amendments but education is needed for real estate developers, landlords and community housing boards on ways they can help meet the housing needs of people with developmental disabilities.

Also, housing may be expensive for people on fixed incomes, such as SSI. Housing subsidy programs, like the HUD Section 8 rent subsidy, can assist people to live in community housing but there is a shortage of affordable rental units.

Although almost three-fourths of the adults with developmental disabilities in the National Consumer Survey live in the community, the rest live in institutions and other specialized facilities. 40% of the respondents living in nursing homes want to leave.

## **FORGING A NEW ERA**

**People with developmental disabilities will be in homes that they have selected, will live with people they have chosen to live with and in the neighborhoods and communities of their choice.**

**Children with developmental disabilities will grow up in family homes.**

**Community support and family support services will be available to enable people to live in homes and participate in their communities.**

\*Phase down Intermediate Care Facilities funding through Medicaid and redirect resources to community and family services and supports tailored to individual needs which enable families to keep their children at home and promote independence for adults.

\*Support new ideas for increasing the availability of accessible, affordable housing to meet the needs of people with developmental disabilities. These include housing loan programs, cooperative ventures, public/private partnerships, bond issues, vouchers and other ways to make the option of community living possible.

\*Encourage home ownership or renting by people with developmental disabilities themselves by lifting restrictions in income programs.

# HEALTH

**"We were told that our daughter would have to stay in the hospital for over two hundred more days before it would be 'cost effective' for her to go home." (Michigan Parent)**

**"Our disabled daughter is doing o.k. We seem to be able to meet her needs. But the other children need help for their feelings of anger and discouragement. I need counseling services but I cannot pay for it. There needs to be public funding for mental health care for the whole family. Even with an average income we can not afford the counseling we need and all the expenses for my daughter's special needs." (Maine Parent)**

## 1990 REPORT FINDINGS

Nearly one out of five individuals or families in the National Consumer Survey said they need health insurance but don't have it. There is a serious lack of coverage by private insurance providers. Exclusions and other practices in private health insurance programs (e.g., pre-existing conditions exclusions, capitated coverage levels, high premiums, limited coverage of certain services) have a devastating impact on working families with children who have disabilities.

Mental health services, both for those individuals whose primary disability is a mental illness and for individuals or families who experience another disabling condition are lacking. Services for children and adolescents are particularly scarce. 23% of the people in the National Consumer Survey said they need counseling services. 28% said they need self-help and support groups. 22% of caregivers said they need family support groups.

General health services often are not available in rural areas or because reimbursement levels are so low that few professionals are willing to provide services to people who receive Medicaid.

There are severe shortages of trained professionals in various therapies. This is exacerbated in areas with limited general health care services, such as rural and poverty areas. Many professionals, including physicians, dentists and mental health counselors, are untrained in disability issues and are unwilling to provide care to people who have physical disabilities, mental retardation or behavior problems.

Medical equipment is often not available or is not paid for by either public or private health insurance. This equipment can often be a critical support toward health and may make the difference between living at home or being placed in costly institutional care.

## **FORGING A NEW ERA**

**People with developmental disabilities will receive health care services they need to enjoy the best possible health. They will have access to and receive the same high quality care that is available to people in the community who do not have disabilities, including special health services and devices made necessary by the particular disabilities they may have.**

**People with developmental disabilities will be eligible to participate in public and private health insurance programs.**

- \*Redirect Medicaid resources from institutions to supports at home and in community settings.

- \*Broaden eligibility for Medicaid so that families and individuals need not become impoverished in order to receive assistance.

- \*Expand availability of and equal access to health insurance; require employers to provide equal access to health insurance programs; prohibit the use of the pre-existing condition clause for private health insurance and strengthen overall regulation of insurance.

- \*Ensure availability of quality health and allied health care provided by adequate numbers of people who are educated about the issues of disability and implications for appropriate health care, including through support to university affiliated programs for developmental disabilities.



# TRANSPORTATION

**"Had I not had a good friend to drive me, I would not have been able to testify. Transportation for social situations and other appointments is definitely needed." (Texas Consumer)**

**"When the school brings up community jobs there is no transportation. There is transportation to the workshop so (my son with a disability) will have to go to the workshop." (Ohio Parent)**

## 1990 REPORT FINDINGS

Inadequate transportation is a significant barrier to independence, employment and other productive activities, and to integration into society. Having transportation gives people choice and control over their lives and affects where they live, work and participate.

Transportation is not sufficiently available for people with disabilities in general and less so in rural areas. While improvements in public transportation and increased accessibility are recognized, lack of resources and the competition between accessible public transit and specialized services still remain problematic.

Many systems in the state network provide transportation: human services, aging systems, schools, and generic public transportation programs. Coordination of these efforts is needed.

Issues of individual transportation include lessening of restrictions on drivers' licenses, improving drivers' training (especially for students in the school system) and making vehicle modification support available to individuals and families.

In the National Consumer Survey, transportation was both highly used and greatly needed. Transportation for non-work, leisure activities is particularly lacking limiting the ability to participate fully in society.

Air, bus and rail systems which provide intercity and interstate transportation have attempted to meet the needs of people with disabilities but education about regulations and rights is needed to improve industry response and assist in meeting these requirements.

# **FORGING A NEW ERA**

**Transportation will be available to people with developmental disabilities that is accessible, convenient and affordable.**

**Transportation will be available for a full range of community living, social and business activities.**

**Individuals with developmental disabilities will have access to an array of affordable transportation supports.**

\*Increase availability and accessibility of transportation systems including air, rail and long distance bus transportation, urban mass transit, rural transportation systems, and connections between transportation modes.

\*Make available sufficient resources to assure that transportation needs are met; encourage coordination for more effective and efficient use of available resources.

\*Increase access to an array of affordable transportation supports, including mobility training, drivers education, vehicle modification and personal mobility technological aids.

\*Vigorously enforce laws and regulations regarding the right to accessible transportation.

# CIVIL RIGHTS

**"Discrimination occurs in every facet of our lives. There is not a disabled American alive who has not experienced some form of discrimination. This has serious consequences. It destroys healthy self-concepts and slowly erodes the human spirit. Discrimination does not belong in the lives of disabled people." (Georgia Consumer)**

## 1990 REPORT FINDINGS

Many citizens with developmental disabilities are unaware of existing protections, such as Section 504 of the Rehabilitation Act and the Fair Housing Act Amendments of 1988. Education can help to promote understanding and better protection for people with developmental disabilities.

In the National Consumer Survey, 23% of those surveyed need legal or protective assistance, but only 8% were receiving it.

Because people with developmental disabilities are often immersed in an array of services and people providing those services, their choices about their lives are often very limited. In the National Consumer Survey, only 16% of the adults chose where they lived. A service provider or family member usually made this decision, often without consulting the individual.

People with disabilities and their families are infrequently represented on governmental and other bodies which make decisions affecting their lives and are excluded from monitoring services. People who are not able to protect their own interests are vulnerable to abuse or inappropriate treatment such as aversive therapies involving drugs or physical harm. Although guardianship is an important protection for some people, the guardian may have limited knowledge of disability or may act in ways that conflict with the individual's rights. Many people who need guardians do not have them, particularly in institutions.

# FORGING A NEW ERA

**People with developmental disabilities will be afforded the same rights and responsibilities as all American citizens.**

\*Eliminate practices that discriminate on the basis of disability, such as barriers to voting and other forms of community participation, inaccessibility and lack of essential supports.

\*Make available an adequate supply of competent and affordable legal assistance, including protection and advocacy.

\*Fully enforce anti-discrimination provisions in federal and state law. Fully implement the Fair Housing Act and foster general public education about its requirements.

\*Require all public bodies which plan for services to contain representation of people with developmental disabilities and their families.

\*Guardianship should be used judiciously and not infringe unnecessarily on a person's life. National guardianship standards should be adopted

## **Further information on the 1990 Reports....**

This summary was based on several documents which are also available from the National Association of Developmental Disabilities Councils.

### **Forging a New Era: The 1990 Reports A Compilation**

- Part I: An Introduction**
- Part II: Life Areas: Supports, Education and Learning, Work, Income, A Home, Health, Transportation, Civil Rights and Empowerment**
- Part III: Cross-Cutting Issues**
- Part IV: Implications for Policymakers**

(This document summarizes Councils' findings in relation to the eligibility, scope, effectiveness and state agency responsibilities affecting people with developmental disabilities. It includes quantitative information on the barriers and recommendations from the individual reports.)

### **Forging a New Era: The 1990 Reports Appendix**

**Life Areas**  
**People Who Are Unserved and Underserved**  
**Effectiveness**  
**Funding**  
**Human Resources**  
**Quality**  
**Data Collection**  
**Coordination**

(This document catalogues all Barriers and Recommendations from the individual reports and references them by state and territory.)

### **Report on the 1990 National Consumer Survey**

(This document is a discussion of the process and outcomes of the National Consumer Survey conducted by Councils. The report was prepared by the Developmental Disabilities Center of Temple University.)