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Facts You Can Use— People with Disabilities

Background data on people with disabilities that you can use in your community education programs

Who Are the People with Disabilities?

There are many different ways of defining and counting people with disabilities. This fact sheet offers a variety of research data from different perspectives.

The Americans with Disabilities Act covers people whose disabilities typically cause great difficulty in such daily activities as walking, talking, seeing, hearing, communicating, learning, or working.

The National Center for Health Statistics, in its annual National Health Interview Survey of U.S. households, estimates the prevalence of various types of impairments. All ages are surveyed, and the impairments reported may cause mild as well as severe difficulties in daily activities.

Total Number of People Who Reported Impairments	No. Per 1000
People with hearing impairments.23,296,000	94.7
People with visual impairments.7,525,000	30.6
People with speech impairments.2,285,000	9.3
People with arthritis.30,833,000	125.3
People with epilepsy.1,174,000	4.8
People with missing extremities (excluding toes & fingers).1,232,000	5.0
People who have partial or complete paralysis.1,445,000	5.9

In addition, many people in the households surveyed reported health conditions often considered "impairments" or "disabilities." Examples include:

People with diabetes.6,232,000	25.3
People with hypertension.27,129,000	110.2
People with heart disease.19,307,000	78.5
People with kidney trouble.3,061,000	12.4
People with back injury.17,308,000	70.3

The Centers for Disease Control estimate that one percent to two percent of the noninstitutionalized population are persons with **mental retardation** and that two out of every one thousand people have **cerebral palsy**. A soon-to-be published survey from the National Center on Health Statistics reports approximately 1.4 million people in the United States use **wheelchairs**. The Interagency Committee on Learning Disabilities, in its 1987 report to Congress, estimates that between five and ten percent of the United States population—or approximately 12 to 25 million people—have **learning disabilities**. And according to the Center for Psychiatric Disabilities at Boston University, 2.5 million people have severe, long-term **mental illness**.

Who Are the Working-Age Adults with Disabilities?

- They are Americans with a “work disability,” defined by the U.S. Census Bureau as a “yes” answer to the following question:

“Does anyone in this household have a health problem or disability which prevents them from working or limits the amount or kind of work they can do?”

The Census Bureau poses this question each year in the March supplement to its monthly *Current Population Survey* of approximately 60,000 households. The main purpose of the survey is to gather statistics on employment, unemployment, income, and poverty. The figures in this fact sheet come from the March 1991 *Current Population Survey*.

- Most working-age adults with disabilities live and work in metropolitan areas in . . .
 - the South: 5,359,000
 - the Midwest: 3,339,000
 - the West: 3,055,000
 - the Northeast: 2,894,000
- 14,648,000 have a work disability; 4,250,484 are employed; 10,397,000 are not employed.

How Many Adults with a Work Disability Are Employed?

Here is the latest census data showing how many civilians with disabilities, age 16 to 64, are employed either full or part-time:

Sex	Total No. Who Have A Work Disability	Total No. Employed Full- or Part-Time
Both sexes	14,648,000	4,250,484 (29.0%)
Women.	7,380,000	1,830,240 (24.8%)
Men	7,268,000	2,420,244 (33.3%)
White women	5,690,000	1,581,820 (27.8%)
White men	5,853,000	2,077,815 (36.6%)
Black women	1,455,000	194,970 (13.4%)
Black men	1,207,000	217,260 (18.0%)
Women, Hispanic origin	568,000	86,336 (15.2%)
Men, Hispanic origin	620,000	151,900 (24.5%)

What Has Been the Hiring Trend?

This chart shows an UPWARD trend in employment of **women** with and without a work disability and a DOWNWARD trend in employment of **men** with and without a work disability.

Percentage Employed Full-Time	1981	1986	1991
Women with a work disability	11.4	11.3	15.1
Women with no work disability	41.6	44.8	49.1
Men with a work disability	29.8	25.8	25.3
Men with no work disability	74.1	73.6	72.4

For more information...

Copies of "Current Estimates From the National Health Interview Survey, 1990" can be ordered from the Superintendent of Documents, U.S. Government Printing Office, Washington, DC, 20402. The cost is \$11.00 and can be ordered using Stock Number 0170220114912. If you have any questions about the statistics from the National Health Interview Survey, call 301-436-8500.

To obtain disability statistics from the U.S. Census Bureau, write to:

Disability Statistics
Housing and Household Economic Statistics Division
U.S. Bureau of the Census
Washington, DC 20233

Words with Dignity

Guidance on how to write and speak about people with disabilities

Choosing Words with Dignity

People with disabilities, like other minority groups, are actively seeking full civil rights. They want to be accepted in their communities as equals.

Your portrayal of individuals with handicapping conditions can greatly affect the public's perception of their worth. What you write and what you say can enhance the dignity of people with disabilities and can promote positive attitudes about their abilities.

Let your descriptive words emphasize the person's worth and abilities, not the disabling condition. Refer to the person first rather than the disability. The phrase "people with disabilities" is preferred, for instance, over "the disabled" which tends to emphasize disability and to create the image of an unusual and homogeneous group.

Affirmative Phrases

- person who is blind; person who is visually impaired
- person who is deaf; person who is hearing impaired
- person who has multiple sclerosis
- person affected by cerebral palsy
- person who has muscular dystrophy
- person with mental retardation
- person with epilepsy; person with a seizure disorder
- person who uses a wheelchair
- person without disabilities; non-disabled person
- physically disabled
- unable to speak; non-verbal
- seizure
- successful, productive

Negative Phrases

- the blind
- suffers a hearing loss
- afflicted by MS
- CP victim
- stricken by MD
- retarded; mentally defective
- epileptic
- confined or restricted to a wheelchair
- normal person (implies person with a disability isn't normal)
- cripple; lame; deformed
- dumb; mute
- fit
- courageous (implies the person is a hero or martyr)
- drain; burden; poor; unfortunate

President's Committee on Employment of People with Disabilities
1331 F Street, NW • Washington, DC 20004-1107

CHARTBOOK

SUMMARY OF DATA ON CHILDREN & YOUTH WITH DISABILITIES IN THE UNITED STATES

National Institute on Disability
and Rehabilitation Research

SUMMARY OF DATA ON CHILDREN AND YOUTH WITH DISABILITIES

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INTRODUCTION

Background

Disability among children and youth in the United States is a serious social and public health issue. As medical care continues to improve, mortality rates of children have declined. However, many of these survivors are living with serious chronic disabling conditions. Twenty million children and youth live with chronic illnesses (Newacheck & Taylor, 1992), 10.7 million have developmental, learning and emotional problems (Zill & Schoenborn, 1990), and 3.4 million have activity limitations (Disability Statistics Program, December 1991). A significant number of children are now being born with HIV infection and cocaine addiction. These conditions are associated with a range of physical and mental limitations and the numbers are steadily growing.

The effect of these increasing numbers of children with disabilities on the children themselves and on society is significant. Analysis of disability years, a measure of the number of years people survive with disabilities, suggests that childhood disabilities account for 35% of all disability years (Pope & Tarlov, 1991). Children with disabilities use more medical services than other children, resulting in higher health costs for this group. An average of \$1406 was spent on each child with a chronic disabling condition compared to \$487 for other children. These costs are going up as the number of children with disabilities increases (Newacheck & McManus, 1988). Special education programs showed a 30% increase in enrollment from 1976 to 1992 (Office of Special Education Programs, 1993). As schools are beginning to serve younger children and providing a wider range of mandated services (i.e., assistive technology), their budgets are being stretched to the limit.

Disability is a complex phenomenon. The Independent Living movement, initiated by disability advocates in the early 1970s, asserts that attitudinal and environmental barriers in society are major obstacles to independence and inclusion for people with disabilities. Lack of access to resources and the "medicalization" of services reflect these barriers (Daniels, 1990). Among children, disability has been found to be associated with low socioeconomic status, low educational attainment, lack of access to health care services, generally poorer health, and non-intact families, although the exact nature of these associations has not been clarified by research. These factors form the basis for the "new morbidity model" which seeks to analyze childhood health and disability in terms of the interaction of environment, behavior, biology, and health and social resources (Baumeister, Kupstas, and Woodley-Zanthos, 1993).

Significant legislation has been passed in recent years to increase the participation of people with disabilities, including children with disabilities, in society and support enhanced independence and quality of life. The Americans with Disabilities Act of 1990 (ADA) bans discrimination in employment, public and private transportation, public accommodations, telecommunications, and local and state government activities. It requires public accommodations to become physically and programmatically accessible to individuals with disabilities. The Technology Related Assistance for Individuals with Disabilities Act of 1988 (Tech Act) provides funds for states to increase access to assistive technology devices and services for individuals with disabilities of all ages. These laws reflect the movement toward recognizing the impact of the environment on disability. Attention to such quality of life issues is critical to understanding and measuring disability.

Other recent federal legislation and policy has mandated improved access to services for children with disabilities. The Individuals with Disabilities Education Act of 1990 (IDEA), formerly the Education for All Handicapped Children Act, mandates a free and appropriate public education for all children and youth with disabilities. The 1989 amendments to the Omnibus Reconciliation Act and the 1990 Supreme Court decision in *Sullivan v Zebly*, mandated that for certain services and benefits, a noncategorical rather than a disease-specific approach be applied by federal programs. In *Sullivan*, the court found that the Social Security Administration had denied Supplemental Security Income benefits to children with serious disability because of its reliance on condition lists to determine eligibility. The court ruled that equity could best be accomplished by assessing the consequences of disability on functioning (Stein et al., 1993).

Disability prevention is a national health priority. Specific goals for children were included in the Healthy People 2000 initiative (U.S. Department of Health and Human Services, 1990). These goals are: reducing disabilities, impairments and limitations in activities associated with chronic conditions, and increasing provider services and service systems for children with special health care needs. Valid and reliable data on disability are needed to assess progress in disability prevention.

Despite the significance of disability issues, the increasing prevalence of disabling conditions, and the accompanying annual disability-related expenditures approaching \$200 billion, little comprehensive demographic and epidemiologic research on disability has been conducted. Even less research has focused on children with disabilities. Research has shown that conditions leading to disability are different for children under 18 than for adults (LaPlante, 1991b; Disability Statistics Program, December 1991) which suggests the need for research devoted specifically to children and youth.

Currently, there is no regular and systematic collection of data on the population of disabled children and youth in the United States. Studies that are done tend to focus broadly on disability or narrowly on specific programs and services. Because the data are collected for different purposes and with different methods, it is difficult to interpret and compare findings.

Purpose

The purpose of this Summary is to compile existing statistical data on children and youth with disabilities into a single source and to provide guidance in using the data appropriately. Children and youth are defined as any neonate, infant, child, or adolescent under the age of 21. This Summary will:

- present the major sources of data on disabled children and youth in the U.S.
- describe the various definitions of disability used in data collection
- outline issues in the measurement of disability among children
- explain the strengths and limitations of data sources
- identify gaps in current data collection efforts
- provide an overview of current prevalence estimates and characteristics
- describe future needs

This section of the Summary presents detailed statistical tables from various data sources. Most of the data presented are from sample surveys and therefore the estimates are subject to sampling variability. Sampling variability occurs when estimates are based on sample data rather than the entire population of interest. Estimates based on samples may differ from figures that would have been obtained had the entire population been used. The standard error is a measure of sampling variability. Estimates derived from small sample sizes tend to have large standard errors and are therefore unreliable. These estimates should be interpreted with caution. In some sources, authors have omitted estimates that are based on sample sizes of fewer than 30 because the large standard error makes the estimate unreliable.

Statistics based on federal reporting requirements, or child counts, represent the entire population of interest, for example, all children receiving special education services in a given school year, or the number of cases of HIV reported to AIDS surveillance. While not subject to sampling variability, the data presented can still be incomplete or biased. Although most programs specify definitions and guidelines, these data sources are still subject to underreporting and misclassification. The possible sources of bias for each data source are described in the explanatory notes for each table and also in the inventory section.

Tables are reproduced from the original sources. Information on standard errors of the estimates have been omitted, but are available in the original source material cited at the bottom of each table. When presenting findings from various surveys, we retained the terminology used in the original survey.

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Supported Employment in Illinois: Benefits versus Costs

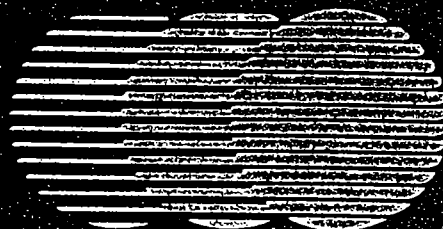
Volume 5

Jeffrey Tines

Frank R. Rusch

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**With an Introduction by
Ronald W. Conley**



**TRANSITION
INSTITUTE
AT ILLINOIS**

The following principles guide our research related to the education and employment of youth and adults with specialized education, training, employment, and adjustment needs.

- Individuals have a basic right to be educated and to work in the environment that least restricts their right to learn and interact with other students and persons who are not handicapped.
 - Individuals with varied abilities, social backgrounds, aptitudes, and learning styles must have equal access and opportunity to engage in education and work, and life-long learning.
 - Education experiences must be planned, delivered, and evaluated based upon the unique abilities, social backgrounds, and learning styles of the individual.
 - Agencies, organizations, and individuals from a broad array of disciplines and professional fields must effectively and systematically coordinate their efforts to meet individual education and employment needs.
 - Individuals grow and mature throughout their lives requiring varying levels and types of educational and employment support.
 - The capability of an individual to obtain and hold meaningful and productive employment is important to the individual's quality of life.
 - Parents, advocates, and friends form a vitally important social network that is an instrumental aspect of education, transition to employment, and continuing employment.
-

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Project Officer: William Halloran

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**Supported Employment in Illinois:
Benefits versus Costs
Volume 5**

**Jeffrey Tines
Frank R. Rusch,
and
Wendy B. McCaughrin**

With an Introduction by Ronald W. Conley

**The Secondary Transition Intervention Effectiveness Institute
University of Illinois at Urbana-Champaign**

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Discussion

The success of supported employment can be measured by a number of different outcomes, such as participant satisfaction, associating with co-workers, and/or program costs versus benefits. This study focused on the longitudinal comparison of program costs versus benefits from society's perspective for individuals participating in supported employment in Illinois.

The current analysis projected benefits and costs for the statewide supported employment initiative in Illinois over an eight-year period based upon McCaughrin's average yearly fluctuations for each of three benefit-cost variables used in the first analysis. The projected longitudinal benefit-cost analysis from society's perspective suggest that if the number of individuals who were placed in supported employment in the first year remains constant each year over an eight-year period, then society will benefit economically. The projections indicate that during the fourth year (FY 1990), benefits to society will be greater than the annual expense to fund the program. The projected rate of return on society's investment in supported employment in Illinois over the next eight years, given the parameters identified in this model, suggest for every \$1.00 invested, \$1.70 will be

Table 3

Projected Cumulative Benefits and Costs for the ISEP Project for 224 Full-time
Equivalents for FY 1987 - 1994

	Discounted Benefits	Discounted Costs	Net Benefits	Benefit-cost Ratio
1987	\$ 1,309,626	\$1,632,229	\$ (322,603)	.80
1988	2,732,261	3,084,913	(352,562)	.89
1989	4,289,400	4,377,802	(88,402)	.98
1990	6,008,151	5,528,473	479,678	1.09
1991	7,922,791	6,552,570	1,370,221	1.21
1992	10,076,754	7,464,016	2,612,738	1.35
1993	12,525,178	8,275,203	4,249,975	1.51
1994	15,338,167	8,997,160	6,341,007	1.70

Benefits versus Costs/74

returned to society on the average each year.

This study, along with previous benefit-cost analyses completed to date (Hill et al., 1987; McCaughrin, 1988), provide administrators and legislators with a firm basis to make financial decisions. If we could take yet another step in evaluation research and incorporate these financial findings with participant satisfaction as well as employment rate, we would then truly have comprehensive evaluations of supported employment programs (Conley, this volume; Rossi, Freeman, & Wright, 1979) and make much better decisions for individuals with handicaps expecting the opportunity to participate in the American workforce.

Statistical Brief

Americans With Disabilities

Due to a variety of physical, mental, and emotional conditions, an estimated 49 million noninstitutionalized Americans (about 1 in 5) have a disability. Of these persons, 24 million have a "severe" disability.

The first section of this Brief describes the disability status of persons aged 15 years and older; the last section details children's disabilities. The box on the back defines "severe" disabilities.

This Brief examines the number of persons with specific types of disabilities, their demographic characteristics, the impact of having a disability on employment status and health insurance coverage, and more. The data were collected in the Survey of Income and Program Participation (SIPP) between October 1991 and January 1992.

Difficulty with a functional activity is the most common type of disability for adults.

Functional activities include lifting and carrying a weight as heavy as 10 pounds, walking 3 city blocks, seeing the words and letters in ordinary newsprint, hearing what is said in normal conversation with another person, having one's speech understood, and climbing a flight of stairs.

Thirty-four million adults aged 15 and older had a functional disability — *difficulty* performing at least one of these tasks; for 15 million of them, the disability was severe — they were *unable* to perform one or more activities. The latter figure includes 1.6 million who *could not* see words or letters in ordinary newsprint and 900,000 who were *completely unable* to hear what was said in normal conversation.

Fewer adults have trouble with ADL's and IADL's than with functional activities.

Activities of Daily Living (ADL's) consist of getting in or out of a bed or a chair, bathing, getting around inside the home, dressing, using the toilet, and eating. About 8 million adults had difficulty with at least one of these tasks; 3.9 million of them required the assistance of another person, making the disability severe.

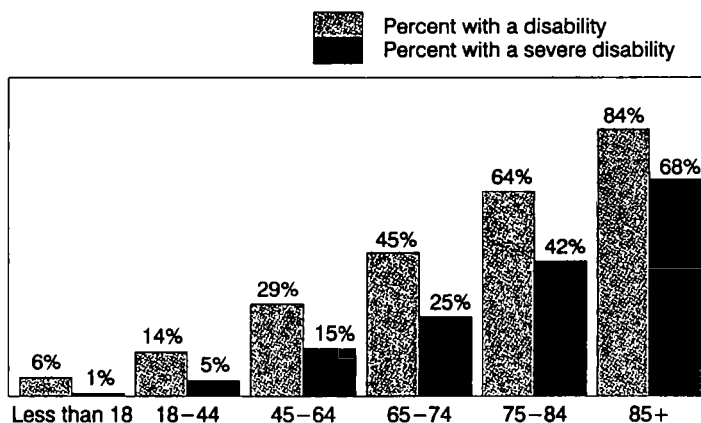
Physical Conditions That Cause Disabilities

Conditions most frequently cited by persons 15 years old and over with a functional, ADL, or IADL limitation as a cause of the limitation(s): 1991-92

Condition	Number with condition (millions)
Arthritis or rheumatism	7.2
Back or spine problems	5.7
Heart trouble	4.6
Lung or respiratory trouble	2.8
High blood pressure	2.2
Stiffness or deformity of extremity	2.0
Diabetes	1.6
Blindness or vision problems	1.5

With Increasing Age Comes A Greater Likelihood of Having a Disability

Percent of persons with a disability and percent with a severe disability, by age group: 1991-92



SB/94-1
Issued January 1994

U.S. Department of Commerce
Economics and Statistics Administration
BUREAU OF THE CENSUS

Instrumental Activities of Daily Living (IADL's) include going outside the home to shop or visit a doctor's office, doing light housework (such as washing dishes), preparing meals, keeping track of money and bills, and using the telephone. Twelve million adults had trouble with one or more of these activities; nine million needed assistance.

Not only were adults with functional, ADL, and IADL limitations considered to have a disability, but so too were those who —

- Used a wheelchair (1.5 million did so).
- Used a cane, crutches, or a walker for 6 months or longer (4 million).
- Had a mental or an emotional disability, such as Alzheimer's disease or mental retardation (6.9 million).
- Had a condition that limited the kind or amount of work they could do at a job (19.5 million aged 16 to 67).
- Had a condition that made it difficult to do housework (18.1 million aged 16 and over).

The elderly comprise a disproportionate share of persons with disabilities.

As the graph on the front illustrates, the chances of having a disability increased with age; most persons aged 75 or older had a disability. In fact, those aged 65 or more comprised a far larger share of those with disabilities (34 percent) than of the total population (12 percent); they constituted an even greater percentage (43 percent) of persons with severe disabilities.

Disability rates are higher among those with low levels of education.

Adults with a disability comprised a much larger share of persons without a high school diploma than of persons with higher levels of education. For example, 23 percent of adults aged 25 to 64 who had not completed high

What Is a Severe Disability?

Adults aged 15 and over were classified as having a severe disability if they used a wheelchair or had used another special aid for 6 months or longer, were *unable* to perform one or more functional activities or *needed assistance* with an ADL or IADL, were *prevented* from working at a job or doing housework, or had a selected condition including autism, cerebral palsy, Alzheimer's disease, senility or dementia, or mental retardation.

Disability and Health Insurance Coverage

Health insurance coverage patterns for persons 15-64 years old, by disability status: 1991-92

	No disability	Non-severe disability	Severe disability
Private insurance	80%	74%	48%
Government insurance	5%	7%	36%
No coverage	15%	19%	16%

school had a severe disability; for persons who were high school and college graduates, the respective figures were 9 percent and 3 percent.

Severe disabilities reduce employment chances.

Those with disabilities constituted 13 percent of all employed persons; those with a severe disability comprised 3 percent. Although having a less-than-severe disability does not have a large effect on one's chance of being employed, having a severe disability does. Among persons 21-64 years old, 81 percent without a disability and 76 percent with a disability that was not severe were employed. However, just 23 percent with a severe disability worked. Data show that persons with a disability — particularly a severe one — earn less than those without one.

Disabilities affect 3 million children under age 15.

Disability rates were 2 percent among children under 3 years old, 5 percent among those aged 3-5, and 6 percent among children aged 6 to 14.

The definition of disability was different for children than for adults. For those under age 6, a limitation in the usual kinds of activities

done by most children that age and the receipt of services or therapy for developmental needs were considered disabilities. Children 3-14 limited in their ability to walk, run, or use stairs were categorized as disabled, as were 6-to-14-year-olds whose ability to do regular school work was limited.

More information:

Americans With Disabilities: 1991-92. Current Population Reports, Series P70-33. Contact Customer Services (301-763-4100) for ordering information.

Contacts:

Persons with disabilities —
John McNeil
301-763-8300
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Robert Bernstein
301-763-1584

This Brief is one of a series that presents information of current policy interest. It may include data from businesses, households, or other sources. All statistics are subject to sampling variability, as well as survey design flaws, respondent classification errors, and data processing mistakes. The Census Bureau has taken steps to minimize errors, and analytical statements have been tested and meet statistical standards. However, because of methodological differences, use caution when comparing these data with data from other sources.

STATISTICAL REPORT: THE STATUS OF PEOPLE WITH DISABILITIES

The census report *Americans With Disabilities: 1991/1992*, published January 1994, gives us some in-depth data on the status of people with a disability who are not residing in an institution. The Bureau of the Census defined an individual with a disability as a person having difficulty in performing one or more functional or daily living activities, or one or more socially defined roles or tasks. Persons who are completely unable to perform an activity or task, or who must have personal assistance, were considered to have a severe disability.

In 1991-1992, 48.9 million Americans (or 19.4 percent of the total population of 251.8 million) reported on the U.S. Department of Commerce's survey that they had a disability. This survey sampled about 30,000 households between October 1991 and January 1992.

WHO ARE THE 48.9 MILLION PERSONS WITH DISABILITIES?

* under age 15:	6%
* between age 15-64:	60%
* between age 21-64:	56%
* 65 and over:	34%
* men:	22.9 million
* women:	26.0 million
* people with severe disabilities:	24.1 million
* men:	9.9 million
* women:	14.2 million

RACE AND ETHNIC GROUPS AGE 15-64

* Blacks:	4.1 million
* Asian and Pacific Islanders:	515,000
* Persons of Hispanic origin:	2.4 million
* Whites not of Hispanic origin:	22.6 million
* American Indian, Eskimo or Aleut:	285,000

WHAT IS THE EMPLOYMENT STATUS?

EMPLOYED PERSONS AGE 21 TO 64:

* total:	108.7 million
* people with disabilities:	14.3 million
* men:	7.9 million
* women:	6.4 million
* of 14.3 million people with disabilities, those with a severe disability:	2.9 million
* men:	1.3 million
* women:	1.6 million

WHAT ARE THE LEADING CAUSES OF DISABILITY AND THEIR IMPACT?

Over 27 million individuals age 15 and over reported having a limitation in a physical or daily living activity, causing a disability. Following are the leading causes:

* arthritis/rheumatism:	7.2 million
* back /spinal problems:	5.7 million
* heart trouble:	4.6 million
* lung/respiratory trouble:	2.8 million
* high blood pressure:	2.2 million
* stiffness or deformity of the foot, leg, arm, or hand:	2.0 million
* diabetes:	1.6 million

THOSE INDIVIDUALS AGE 15 AND OVER REPORTED THE FOLLOWING:

* used a wheelchair:	1.5 million
* women:	919,000
* men:	575,000
* used a cane, walker, or crutches for six months or longer:	4.0 million
* even when wearing corrective lenses, had difficulty seeing words or letters in ordinary newsprint:	8.1 million
* even when wearing corrective lenses, could not see the words or letters in newsprint at all:	1.6 million
* had difficulty hearing a normal conversation with another person:	10.0 million
* could not hear what is said in a normal conversation:	924,000

WHAT IS THE HEALTH CARE PICTURE?

The status of health care insurance coverage for 29.5 million Americans with disabilities between the age of 15 to 64 showed:

* people without a disability:	135.6 million
* private insurance coverage:	80.0%
* government plan coverage:	5.2%
* no coverage:	14.8%
* people with a disability:	16.3 million
* private insurance coverage:	74.1%
* government plan coverage:	7.2%
* no coverage:	18.7%
* people with a severe disability:	13.2 million
* private insurance coverage:	48.1%
* government plan coverage:	36.2%
* no coverage:	15.7%

**WHAT PROFESSIONS ARE MOST ATTRACTIVE
TO PEOPLE WITH DISABILITIES?**

Careers & the disABLED magazine's Third Annual Reader Survey reports that college students and professionals with disabilities indicated that the following are the top 10 professions in which they will be seeking employment:

- | | |
|---------------------------|-------------------------|
| Counseling/Rehabilitation | Computer Science |
| Teaching | Business Administration |
| Health Care | Law |
| Human Resources | Accounting |
| Communications | Engineering |

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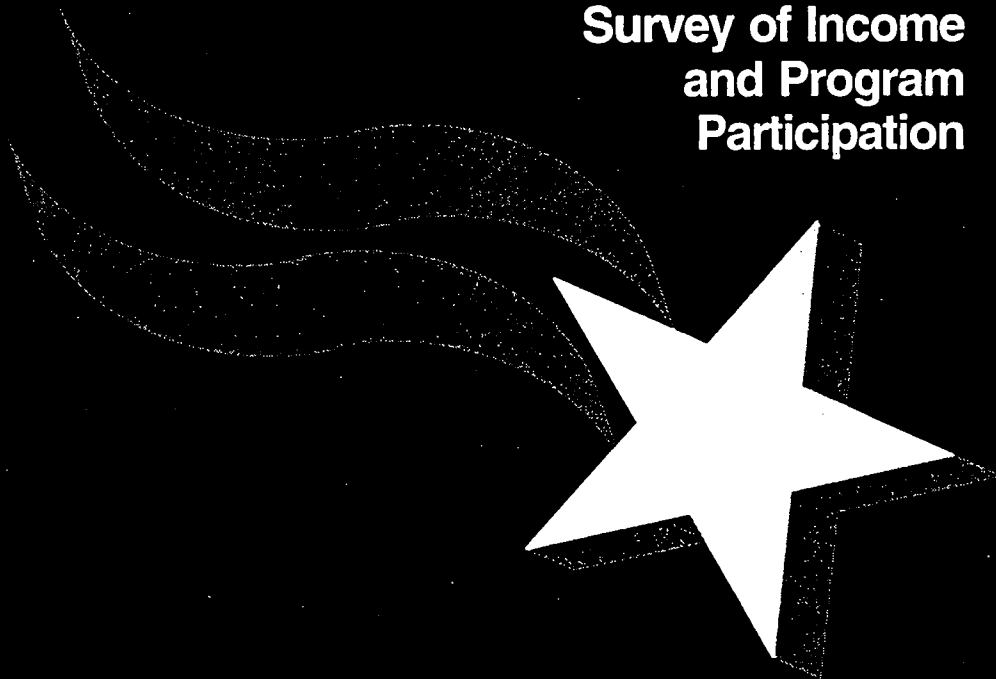


CURRENT POPULATION REPORTS
Household Economic Studies

P70-33

Americans With Disabilities: 1991-92

**Data From the
Survey of Income
and Program
Participation**



by John M. McNeil

U.S. Department of Commerce
Economics and Statistics Administration
BUREAU OF THE CENSUS



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Consortium for Citizens with Disabilities

Kathy McGinley (202) 785-3388

Peter Thomas (202) 466-6550

November 22, 1995

VIA TELEFAX

The Honorable William Jefferson Clinton
The White House
1600 Pennsylvania Avenue, N.W.
Washington, D.C. 20500

Re: **Disability Community's Recommendations on Medicaid and Medicare Reform**

Dear President Clinton:

On behalf of the Health and Long Term Services Task Forces of the Consortium for Citizens with Disabilities (CCD), comprised of over 50 national associations interested in disability policy, we request a meeting with you and your staff to discuss the attached Medicaid and Medicare recommendations from a disability perspective. We are currently drafting a detailed analysis of the Congressional leadership's reform proposals which we intend to forward to you within the next week.

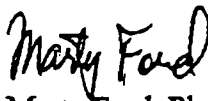
We strongly support your position that the current version of the budget bill must be vetoed in order to protect these two vital programs. We welcome the opportunity to discuss with you and your Administration substantive alternatives to the current proposals to reform these programs that will be acceptable to all Americans, particularly people with disabilities.

CCD representatives are available at any time to meet and discuss these important issues. Thank you for your consideration.

Sincerely,



Peter W. Thomas, J.D.
Health Task Force Co-Chair



Marty Ford, Ph.D.
Long Term Services Task Force Co-Chair

cc: Marilyn Yeager
Chris Jennings
Diana Fortuna

To: Chris J.

Ten K

Debbie Fine

Marilyn Yeager

Nancy Ann Mc

Fr: Diana Fortuna

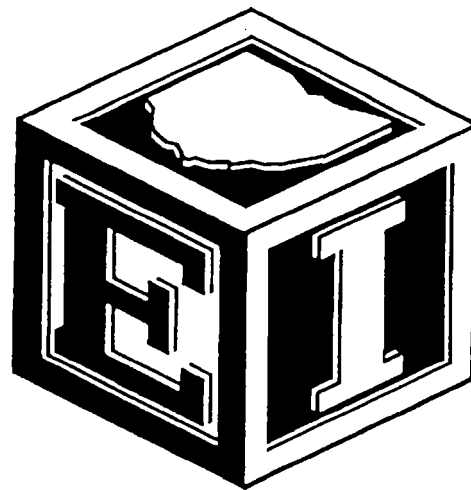
They want a meeting. Maybe Friday's
meeting w/ disability advocates would suffice.

Nancy Bloch
WAB
Bazelon

Final Report of the Target Populations Sub-Committee on

COST EFFECTIVENESS OF EARLY INTERVENTION

Presented to The Ohio Interagency Early Intervention Council



May, 1989 (revised)



*At the heart of it all -
a healthier Ohio.*

RICHARD F. CELESTE
Governor

RONALD L. FLETCHER, M.D.
Director of Health

JAMES F. QUILTY JR., M.D.
Chief, Division of Maternal and Child Health
Chair, Ohio Interagency Early Intervention Council

Final Report of the Target Populations Sub-Committee on

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Ohio Department of Health
Division of Maternal and Child Health

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EXECUTIVE SUMMARY

The Cost Effectiveness of Early Intervention

"...the most important part is the beginning." - Plato

Early childhood is a special time. The development of physical, mental and social skills/competencies early in life affects later ability to function at or near one's potential.

Children who are most likely to have difficulties in development include:

- children with clear handicapping conditions, e.g. cerebral palsy, Down Syndrome (at established risk)
- children who have a difficult start medically (at biological risk)
- children who live in a non-stimulating environment (at environmental risk)

For children falling in these categories, early intervention services may be needed to:

- **prevent** disabilities;
- **lessen** secondary effects of existing impairments;
- **improve** developmental outcomes.

EARLY INTERVENTION

Early intervention is a system of developmental services and programs which are designed to meet the needs of infants or toddlers at developmental risk in any one or more of the following areas: physical development, cognitive development, language and speech development, psycho-social development, or self-help skills.

Early intervention services include: family training, counseling and home visits; special instruction; speech pathology and audiology services; low vision services (including orientation and mobility instruction); occupational therapy; physical therapy; psychological services, including school psychological services; service coordination (case management) services; medical services only for diagnostic or evaluation purposes; early identification, screening and assessment services; health services necessary to enable the infant or toddler to benefit from other early intervention services; and respite care.

Early intervention services are provided by qualified personnel who represent a variety of disciplines and a variety of service settings.

Not all at-risk children and their families need the same level of early intervention. Services should be matched with the need. Collaboration among established agencies, private practitioners, volunteers, parents, and other consumers will maximize existing services and reduce the number of needed new services.

P.L. 99-457, Part H, of the Education of the Handicapped Act Amendments provides seed money for the planning and provision of early intervention services in Ohio for eligible infants and toddlers with special needs and for their families. Ohio must NOW design its own system of early intervention service delivery and develop its own resources to support that system. Policy makers involved in this design of system and resources must constantly weigh the costs and benefits of each in order to maximize the use of limited resources. These policy makers are encouraged to keep in mind the various points in the definition of cost effectiveness, as well as points made throughout this paper, in making their decisions.

COST EFFECTIVENESS ANALYSIS

Cost effectiveness analysis estimates the cost of providing each child born in Ohio the opportunity of achieving his/her potential by comparing the costs of a number of alternative routes. Cost effectiveness of early intervention needs to estimate all of the positives (benefits) and negatives (costs) of a course of action, and to place a money value



on those outcomes. In addition, cost effectiveness analysis needs to consider the productivity losses for society, as well as personal losses for individual children and families if early intervention services are not available from birth.

It is difficult to place a dollar figure on the future of children who are at-risk. Each child is too important to be reduced to that level. As we look at the limited amounts of money we have to spend on early intervention, we need to ask how early intervention money can best be spent to maximize the developmental potential for Ohio's children and their families.

FOUR EXAMPLES SUMMARIZING THE COST EFFECTIVENESS OF EARLY INTERVENTION

The following case studies of four children in Ohio who have special needs (detailed in the Changing Predictions Through Early Intervention section of this paper) illustrate that serving children at-risk at an early age does cost less than a life-time of special services which are likely to be needed if they do not receive early intervention services. The social and personal benefits to the children and their families of these early detection and treatment services cannot be quantified in terms of dollars and cents but their impact will last for a lifetime.

Case 1: Established Risk

Theresa is a child born with phenylketonuria (PKU), a metabolic disorder, who will become severely mentally retarded and experience behavior difficulties unless she receives a very controlled diet from birth for most of her life. The costs of early detection and life long treatment for Theresa is \$227,000 while the costs of institutionalizing the person with severe retardation she would have become is \$2,678,350. Life long community care for a person with severe retardation costs less than institutionalization, but it is still estimated to cost \$1,089,853.

Case 2: Biological Risk

TK was born prematurely and weighed only two pounds. At thirteen months of age at a screening in his community, TK was found to be delayed in language and to have mild cerebral palsy. TK and his mother received early intervention programming which included infant stimulation, physical, and speech therapies until he was age four. He was improved enough to enter Head Start at that point and then regular public school classes with some support services. The cost of these services was \$176,752. Without early services he would probably have needed special education services throughout his school years at a cost of \$233,000 to \$253,000.

Case 3: Biological Risk

Erin was barely 3 months old when she began suffering from numerous middle ear infections. Although she was treated promptly by her family doctor with antibiotics and the insertion of drainage tubes in her ears, by the time she was two and one half years old, she showed delays in talking and in social and cognitive development due to a hearing loss from her ear infections. She was quickly enrolled in an early intervention program where treatment by an audiologist, and language development classes as well as later participation in Head Start began to help Erin recover from the secondary effects of her ear infections. Although such treatment is not inexpensive - \$15,220, the long term special education and/or grade retention that would have ensued without the early intervention services would be far more costly, \$35,710- to \$83,938.



Case 4: Environmental Risk

Joey was born to Joann when she was fifteen years old. His birth weight was low and he exhibited "tremors" of unknown cause. Joey and Joann lived in a very stressful home environment. Joann had begun attending a special school for teen mothers when she knew she was pregnant where she received many services to support her in her dual role of parent and high school student.

This included Joey's participation in a quality nursery program during school hours. In two years, Joann will graduate from high school and Joey will enter a Head Start program. Continuing early intervention services for Joey and Joann have probably helped to prevent both of them from becoming lifetime cross-generational welfare recipients. Joey initially was a high risk for developmental delay, and with early intervention, currently has no delays that would limit him to special education classes. The early intervention costs for both children, Joann and Joey, cost an estimated \$26,050 while Public Assistance and Special Education for them would have cost \$330,000.

OHIO'S EARLY INTERVENTION SERVICES

The preceding case histories describe some of the health-related, educational, and support services available in Ohio which were accessed by four specific families of young children at risk for developmental delay or disability. The Ohio agencies that currently provide various early intervention services, the benefits of those services to children, their families, and their communities, and examples of cost effectiveness data are provided in the full length paper.

The categories of various early intervention services are organized into:

HEALTH RELATED SERVICES

- prenatal/perinatal services
- pediatric services
- at-risk pediatric services

EDUCATIONAL SERVICES

- infant stimulation & early childhood education
- parent education

SUPPORT SERVICES

- licensed/certified child care
- family support
- child abuse prevention

While there are a number of programs/service providers in each of these categories of services, they do NOT currently reach all children/families in need of these services. Furthermore, few, if any, of these programs provide comprehensive services that are available in every community. Limitations may be geographical, based on eligibility criteria (e.g. diagnostic labels or socioeconomic status), or limited by funding constraints.

