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ABSTRACT

This policy research brief summarizes changes in out-of-home placements of children and youth with mental retardation since the implementation of the Supplemental Security Income (SSI) and Individuals with Disabilities Education Act (IDEA) entitlements. Statistics are reported for 1977, 1987, and 1997 to show trends. Statistics were obtained from three surveys, a 1977 survey of state-financed settings for persons with mental retardation; estimates from the 1987 National Medical Expenditure survey, Institutional Populations Component; and a direct survey in 1997 of all 50 states and the District of Columbia (DC) regarding the number of children and youth with mental retardation/developmental disabilities receiving out-of-home residential services. Analysis indicates a substantial decrease (70 percent) in the number (now 25,842) of children and youth with mental retardation placed in residential mental retardation/developmental disability settings, possibly due to SSI and IDEA policies to support children and youth in their own homes and communities. Concerns are raised about new legislation which could result in loss of SSI benefits for up to 45,000 children and youth with mental retardation, and possibly increase future out-of-home placements. Other findings indicated a total estimated annual cost of $1.3 billion for out-of-home placements, an estimated $3.5 billion less than estimated expenditures if the placement rate had remained at the 1977 level. (Contains 14 references.) (DB)

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UNIVERSITY OF MINNESOTA

Policy Research Brief

RESEARCH AND TRAINING CENTER ON COMMUNITY LIVING
UNIVERSITY OF MINNESOTA

Children and Youth Receiving Residential Services for Persons with Developmental Disabilities Outside Their Family Home: Trends from 1977 to 1997

This Policy Research Brief was prepared by K.Charlie Lakin, Lynda Anderson, and Robert Prouty of the Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota. This brief summarizes changes in out-of-home placements of children and youth with mental retardation since the implementation of the SSI and IDEA entitlements. Very special thanks go to the many state officials who generously responded to a request for the reported data on a very short timeline.

Introduction

Since 1974, the Supplemental Security Income (SSI) program has been administered by the Social Security Administration (SSA) to provide cash assistance to persons who are aged, have disabilities, or are blind and who meet standards of financial need. In most states, SSI recipients are also automatically eligible for Medicaid and for all medical and rehabilitation services included in the state Medicaid benefit package. Persons eligible for SSI include children with mental retardation who live in families that meet the established standard of financial need. Children's SSI has been one of the cornerstones of a national commitment to support children and youth with disabilities in their families and communities. Another key entitlement program in the national commitment to children, families, and community has been the Individuals with Disabilities Education Act (IDEA). Since 1976, IDEA has assured a free and appropriate public education to all children with disabilities to the largest extent possible in the least restrictive educational environment of their local communities.

In recent years, there has been growing concern and sometimes outright skepticism within Congress and from other critics of U.S. domestic policy as to whether these national commitments to children and youth with disabilities yield tangible and valuable results. Presumably based on the assumption that they do not, Congress in Public Law 104-193, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, established a stricter standard for disability among children and youth to reduce enrollments and expenditures in the Children's SSI program.

The Social Security Administration estimated that approximately 135,000 children and youth would lose their benefits as a result of these changes. The single largest group of children and youth receiving SSI are those coded as having mental retardation. They made up approximately 41% of the nearly one million Children's SSI recipients in 1996. In 1997, based on its interpretation of Public Law 104-193, the Social Security Administration notified approximately 80,000 of the 407,000 Children's SSI recipients indicated to have mental retardation that their eligibility would be re-evaluated. Initial redeterminations denied continua-

A summary of research on policy issues affecting persons with developmental disabilities. Published by the Research and Training Center on Community Living, Institute on Community Integration (UAP), College of Education and Human Development, University of Minnesota.

The College of Education & Human Development

tion of benefits to about 57% of those who were reevaluated.

Substantial debate about SSA's interpretation of Congressional intent and about its specific methodologies of assessing mental retardation has ensued. Often lost in these debates is the more general discussion of social outcomes that may derive from societal commitments to supporting children and youth with mental retardation in their families and communities.

This brief report summarizes changes in out-of-home placements of children and youth with mental retardation since the implementation of the SSI and IDEA entitlements. Specifically, these statistics show the numbers of children (0-14 years) and youth (15-21 years) with mental retardation living in out-of-home residential settings provided under the administrative authority of state mental retardation/developmental disabilities (MR/DD) agencies. Statistics are reported for 1977, 1987, and 1997 to show trends in such out-of-home placements. These statistics in each of the three reporting years exclude those children and youth with mental retardation placed out of natural or adoptive homes into foster care financed by local child welfare agencies, residential schools financed by education agencies, juvenile correction facilities, and other residential settings other than those financed by state MR/DD agencies. The statistics reported do include the out-of-home placements of a substantial majority of children and youth with mental retardation living outside of their natural or adoptive homes and they include statistics for the same types of programs in all three years reported. They do, therefore, provide a key indicator of one of the most important outcomes intended in the enhanced support for children with mental retardation and their families since the mid-1970s.

■ Method of Study

Statistics contained in this report derive from three distinct data collection efforts. Statistics for 1977 were gathered as part of a national survey of all state MR/DD agency financed, licensed or operated residential settings for persons with mental retardation operating on June 30, 1977. This survey, conducted by the Research and Training Center on Community Living at the University of Minnesota, yielded state-by-state and national population statistics on the number of persons ages 0-14, 15-21, and various adult age categories living in "MR/DD residential settings" (Lakin, Hill & Bruininks, 1985). The statistics for 1987 are based on estimates from the 1987 National Medical Expenditure Survey (NMES), Institutional Populations Component (Lakin, Hill, Chen & Stephens, 1989). This study, sponsored by the federal Agency for Health Care Policy and Research, included a random sample of 3,618 residents of a stratified sample of 700 state licensed and state-operated residential facilities. Individual records for each of the sample members included date of birth. An age was computed for each subject from this variable and categorized into the same age breakdowns available from the 1977 survey. The NMES was a national sample that did not permit state-by-state estimates. Because the NMES sample frame excluded settings with two or fewer residents and underrepresented those with six or fewer residents, NMES age distribution estimates were applied to national statistics for the total number of persons receiving MR/DD residential services outside their family homes from a separate survey of each individual state (Lakin et al.,1989).

The statistics for 1997 were gathered from a direct survey of all 51 states. This survey was conducted in response to a request from the Social Security Administration to update statistics from 1977 and 1987 regarding numbers of children and youth receiving out-of-home MR/DD residential services. Specifically, state officials were asked to provide 1997 statistics on the number of children and youth 0-14 years and 15-21 years receiving out-of-home residential services through agencies licensed, operated, or funded by the state MR/DD program agency. Concurrently, states were reporting statistics on the total number of persons receiving residential services as part of an annual residential services data collection program (Prouty & Lakin, 1998). The survey of the number of children and youth receiving out-of-home services was conducted over a six-week period in December and January 1997-1998. It requested statistics as of June 30, 1997. Altogether, 49 states with 97.2% of the nation's total population of persons receiving MR/DD residential services responded to the request. Estimates of the number of children and youth in the non-reporting states (with 2.8% of residents with MR/DD nationwide) were made applying the same average ratio of children and youth to total residents as reported by the other 49 states.

The response rate to the 1997 survey was remarkably high, given the detail and timelines of the data request. It demonstrates how in recent years states have substantially increased the capacity of their management of information systems to provide such specific information. The fact that the responding states provide residential services to 97.2% of the total number of people receiving such services nationwide suggests that national estimates derived from the reported data should be considered highly reliable.

■ Results of the Study

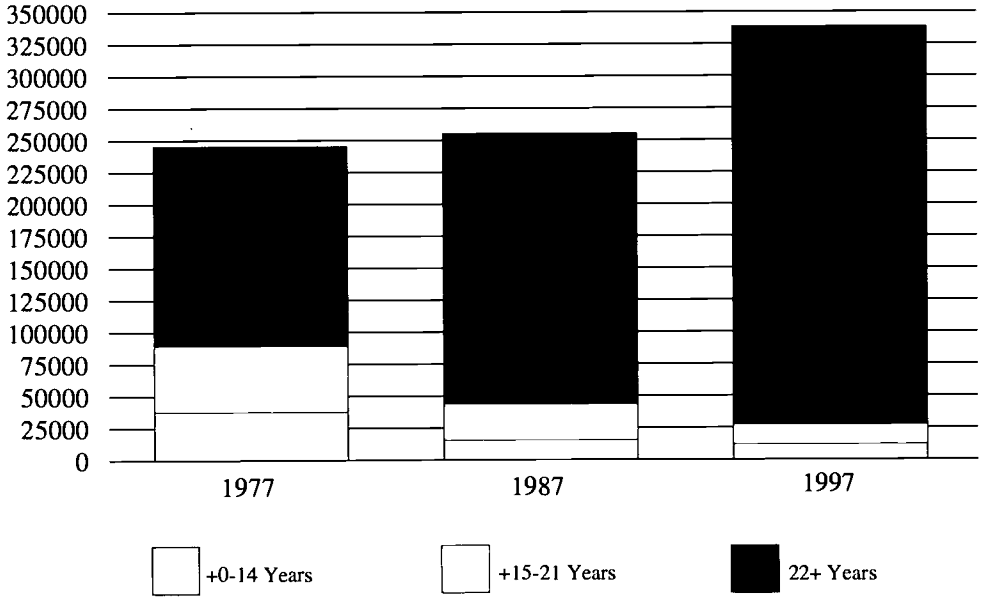
Table 1 and Figure 1 present the total number of children (0-14 years), youth (15-21 years), and adults receiving MR/DD residential services in 1977, 1987, and 1997. As shown in 1977 (at the very beginning of the federal commitment to supporting children and youth in their families and communities), there were 90,942 children and youth in MR/DD residential settings. Of these young persons, about 38,200 were 14 years or younger and 52,800 were 15-21 years old. In 1977, children and youth made up 36.7% of the 247,796 persons receiving MR/DD residential services, and 15.4% of all persons in MR/DD residential settings were children 14 years and younger.

Table 1: Children, Youth, and Adults Receiving Public and Private Out-of-Home Residential Services Sponsored by Developmental Disabilities Agencies

Age	1977	1987	1997
0-14	38,161 (15.4%)	15,085 (5.9%)	11,403 (3.4%)
15-21	52,781 (21.3%)	31,448 (12.3%)	14,438 (4.3%)
22+	156,854 (63.3%)	209,140 (81.8%)	312,641 (92.3%)
Total	247,796 (100%)	255,673 (100%)	338,482 (100%)

By 1987, just over a decade into the major national commitment to supporting children and youth with mental retardation in home and community, the number of children and youth living out-of-home in MR/DD facilities had decreased by nearly one-half (48.8%) to an estimated 46,533. Even more impressively, the number of children 14 years and younger had been reduced to an estimated 15,085. This was only 39.5% of the 1977 total. The number of youth with mental retardation 15-21 years old living out-of-home decreased by about 21,000 to an estimated 31,450. In 1987, children and youth 21 years and

Figure 1: Children, Youth, and Adults Receiving Public and Private Out-Of-Home Residential Services Sponsored by State Mental Retardation/Developmental Disabilties Agencies



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younger made up only 18.2% of all persons receiving out of home MR/DD residential services. This compares with 36.7% in 1977.

Between 1987 and 1997 the earlier trend continued. In 1997, there were an estimated 11,403 children 14 years and younger and 14,438 youth 15-21 years in out-of-home MR/DD settings. The estimated total of 25,842 children and youth 0-21 years living in out-of-home MR/DD residential settings was 44.5% less than in 1987. The rate of decrease between 1987 and 1997 was only slightly less than the rate of decrease between 1977 and 1987 (48.8%).

In the 20 years between 1977 and 1997, the number of children and youth receiving out-of-home MR/DD residential services decreased by over 65,000 persons and 71.6 %. The number of children birth to 14 years decreased by 70.1% to 3.4% of all people receiving MR/DD residential services. The number of youth 15-21 years decreased by 72.6% to 4.3% of all people receiving MR/DD residential services. As shown in Table 2, decreases occurred in every state. (Idaho's lower reported number of children in 1977 was due to partial reporting.)

Discussion and Recommendations

The statistics reported in this *Policy Research Brief* document a substantial decrease in the number of U.S. children and youth with mental retardation removed from their families and placed in residential settings for persons with mental retardation and related conditions.

The steady decline in the number of children and youth receiving out-of-home MR/DD residential services demonstrates powerful effects of social policies introduced in the mid-1970s to support children and youth in their own homes and communities. The number of children and youth receiving out-of-home MR/DD residential services in the U.S. has been reduced to less than 30% of the number 20 years earlier, even as the total number of children and youth less than 22 years old increased by 4% and the total number of persons receiving out-of-home MR/DD residential services increased by 37%.

Another indicator of the impact of the mid-1970s commitment to children and youth with mental retardation was that in just 6 years between 1972 and 1978, the average age of first admission to MR/DD residential settings increased from 13.95 years to 18.02 years (Lakin, Hill, Hauber & Bruininks, 1982).

In 1996, there were an estimated 87,000 people with mental retardation waiting for out-of-home residential services in the United States (Prouty & Lakin, 1997). Waiting lists are viewed as a growing national problem. It is remarkable to consider what would be the lengths of waiting lists today if MR/DD residential settings still housed the 91,000 children and youth who lived in them in 1977. If it were not for the success of SSI, IDEA, and other federal and state programs that have assisted families to keep their children with mental retardation at home, the number of people waiting for MR/DD residential services might be nearly double what it is today.

When Congress was considering Public Law 104-193, the Congressional Research Service estimated that the bill would yield "savings" of about $7.4 billion over 6 years, or about $1.23 billion per year (Soloman-Fears, 1996). Based on Social Security Administration projections, about 45,300 of the projected 135,000 discontinued children and youth would be individuals listed as having mental retardation, although these original estimates have since been revised downward by about one-quarter (Social Security Administration, 1998). Therefore, about one-third of the 6-year SSI savings or $1.9-2.5 billion or $310-415 million per year might be assumed to come from discontinued benefits to children and youth with mental retardation. But what is overlooked in these estimated "savings" is the surety that there are also "costs" associated with the discontinuation of important cash assistance. Although Medicaid eligibility was restored for SSI children whose cash benefits were discontinued, such is not the case for those children and youth denied SSI in the future.

Because of the reduced commitment to children and youth with mental retardation, some unknown number of them will enter out-of-home residential care. One way to examine the potential impacts of such outcomes is to consider the cost-related benefits and the expenditures for the programs and policies that have contributed to the remarkable decreases in the number of children and youth with mental retardation receiving out-of-home residential services. (Unfortunately, it is impossible to isolate individual programs such as SSI from the broad set of commitments that this society has made to children with disabilities and their families. However, SSI and IDEA are, by far, the largest and broadest in scope of those commitments

Table 2: Children and Youth with MR/DD Living Outside the Homes of Their Natural or Adoptive Families as a Percentage of All People with MR/DD Receiving MR/DD Services in 1977 and 1997

	1977			1997				
State	Total Residents in MR/DD Services	0-21 Year Olds in MR/DD Residential Services	0-21 as % of Total	Total Residents in MR/DD Services	Ages Birth -14 Years	Ages 15-21 Years	0-21 Year Olds in MR/DD Residential Services	0-21 as % of Total
AL	2,106	415	19.7%	3,210	19	108	127	4.0%
AK	243	169	69.5%	697	18	39	57	8.2%
AZ	1,453	667	45.9%	3,016	378	281	659	21.9%
AR	1,901 b	1,150	60.5%	2,822 a	130	267	397	14.1%
CA	26,179	12,644	48.3%	41,584	4,587	2,360	6,947	16.7%
CO	2,651	1,052	39.7%	3,910	DNF	DNF	263	6.7%
CT	4,497	1,533	34.1%	6,326	50	158	208	3.3%
DE	810	412	50.9%	752	19	6	25	3.3%
DC	75 e	64	85.3%	1,875	2	6	8	0.4%
FL	8,103	4,295	53.0%	10,463	370	527	897	8.6%
GA	3,327	1,251	37.6%	3,557 a	175	221	396	11.1%
HI	384 e	98	25.5%	1,071	20	31	51 i	4.8%
ID	811 d	173	21.3%	2,417	DNF	DNF	321	13.3%
IL	13,398	4,756	35.5%	13,077 a	463	678	1,141	8.7%
IN	4,856	1,923	39.6%	7,600	400	458	858	11.3%
IA	3,499	1,410	40.3%	8,048 a	168 f	295 f	463	5.8%
KS	2,706	980	36.2%	2,783 a	46	180	226	8.1%
KY	1,659	667	40.2%	653 h	DNF	DNF	25 h	3.8%
LA	4,449	2,171	48.8%	8,011 a	196	581	777	9.7%
ME	1,493	372	24.9%	2,314	DNF	DNF	94	4.1%
MD	3,372	1,281	38.0%	4,880	25	78	103	2.1%
MA	7,723	2,016	26.1%	8,602	67	251	318	3.7%
MI	12,648	4,111	32.5%	11,890	127	394	521	4.4%
MN	6,182	1,626	26.3%	10,990 a	170	545	715	6.5%
MS	2,138 c	671	31.4%	2,860	74	118	192	6.7%
MO	6,505	2,700	41.5%	6,611	180	366	546	8.3%
MT	765	194	25.3%	1,752	121	68	189	10.8%
NE	2,298	678	29.5%	2,359 e	44	98	142	8.1%
NV	247	144	58.4%	653 a	12	23	35	5.4%
NH	836	275	32.9%	1,628	7	52	59	3.6%
NJ	9,314	3,502	37.6%	9,432	176	450	626	6.6%
NM	793	370	46.6%	2,038 a	35	64	99	4.9%
NY	26,552	6,824	25.7%	34,782	537	1,201	1,738	5.0%
NC	4,424	1,637	37.0%	7,566	DNF	DNF	DNF	DNF
ND	1,376	299	21.7%	1,922	DNF	DNF	DNF	DNF
OH	10,818	3,689	34.1%	15,891	203	457	660	4.2%
OK	2,132 b,d	1,671	78.4%	4,439	99	117	216	4.9%
OR	2,607	1,004	38.5%	3,900 a	190	300 j	490	12.6%
PA	16,705	6,014	36.0%	18,275	244	513	757	4.1%
RI	992 d	183	18.4%	1,351	0	0	0	0%
SC	4,126	1,593	38.6%	4,592	103	351	454	9.9%
SD	1,177	395	33.6%	2,031	24	202	226	11.1%
TN	3,205	1,125	35.1%	4,386	47	126	173	3.9%
TX	14,906	6,052	40.6%	17,571	DNF	DNF	1,423 g	8.1%
UT	1,380	472	34.2%	2,378	73	183	256	10.8%
VT	921	281	30.5%	915	16	48	64	7.0%
VA	4,717	1,665	35.3%	3,373 a	DNF	DNF	387 g	11.5%
WA	4,428	1,519	34.3%	6,626	16	105	121	1.8%
WV	1,006	374	37.2%	1,917	1	9	10	0.5%
WI	5,649	2,192	38.8$	17,468	261	213	474	2.7%
WY	631 c	115	18.2%	976	18	21	39	4.0%
Reported U.S. Total	247,796 c	90,942	36.8%	327,106	9,911	12,549	24,973	7.6%
Estimated U.S. Total				338,482	11,403	14,438	25,842	7.6%

a indicates 1996 data
b excludes facilities with 1-6 residents
c excludes facilities with 16-63 residents
d excludes facilities with 64-299 residents
e excludes faciltities with 300+ residents
f indicates estimate
g 1997 statistics include ICF/MR Residents only
h indicates only children and youth living in state-operated facilities
i does not include birth through three years of age
j does not include people over age 18
k 0-21 total is greater than combines 0-14 and 15-21 total because six states could only provide combined 0-21

affecting children with disabilities.)

Nationwide, the average annual per person costs of Medicaid-financed residential programs in 1996, including the SSI benefit for Medicaid Home and Community Based Services (waiver) recipients, was $50,750 (Prouty & Lakin, 1997). The average federal SSI benefit in 1996 for children and youth with mental retardation was an estimated $5,600. If the 90,942 children and youth with mental retardation in out-of-home residential services had not been affected by the social interventions of family and community support that began with SSI in 1974, it might be assumed that the number of children and youth living in out-of-home MR/DD settings in 1997 would have grown proportionally to the growth of children and youth in the society as a whole (+3.5%) and today might number about 94,125 children and youth. Expenditures for these individuals based on the 1996 average Medicaid long-term care expenditures for persons with mental retardation would have been an estimated $4.8 billion.

But, instead of the projected scenario, in 1997 the number of children and youth living out-of-home in MR/DD settings were an estimated 25,842 individuals. Based on 1996 Medicaid reimbursements, expenditures for these individuals was an estimated $1.3 billion, or about $3.5 billion less than the estimated expenditures had out-of-home placement rates for children and youth with mental retardation remained at their 1977 levels. If the SSI alone were sufficient to produce such a result, the $2.25 billion spent on federal SSI benefits for the estimated 407,000 children with mental retardation on SSI rolls in mid-1997 would have yielded a substantial cost-benefit of about $1.25 billion per year. But, of course, SSI was only one of a number of significant commitments made in the mid-1970s and early 1980s to value families and communities as the preferred option for nurturing children and youth with mental retardation (and other disabilities). Other programs providing support for such ideals included the Education for All Handicapped Children Act of 1976 (now IDEA as amended), the Medicaid Home and Community Based Services ("waiver") authority in 1981, the Adoption Assistance and Child Welfare Act of 1980 and the emergence of state family subsidy and support programs which began in the 1970s and by 1996 had reached $500 million in annual expenditures (Braddock, Hemp, Parish & Westrich, 1998).

Although the savings projected for PL 104-193 do not reflect other costs that will be incurred as a result, costs that will be much more heavily borne by state and local governments, it appears unlikely that there is an absolute federal "cost benefit" that can be attributed to the support programs that have dramatically reduced out-of-home placements of children and youth with mental retardation over the past 20 years. But the benefits of keeping children and youth in families and communities have not always been viewed in terms of cost benefit. In establishing SSI and IDEA entitlements, the Congress of a generation ago wanted to provide as many children as possible the opportunity, if not the right, to benefit from typical developmental experiences of childhood, growing up in a family and going to a community school. By the standards of this previous generation of Congress, remarkable, albeit fragile, outcomes were attained. But the commitment to sustain these outcomes seems ever more in doubt.

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- *Family Needs Survey Results: Responses from Parents of Youth Children with Disabilities (Report #90-2)* (1990). Compiled by C.J. Gilman, S.D. Johnson, and K. McGrew. A summary of the results of a structured interview administered to 57 parents of children ages 3-10 with moderate to severe developmental disabilities. The survey gathered information about their current and future needs for information, sources of informal and formal service support, and involvement in school and non-school based activities, as well as perceived sources of stress and obstacles to adequate child care and other community services.

- *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1996 (Report #49)* (1997). Edited by K.C. Lakin and R.W. Prouty. A report providing statistics on persons with developmental disabilities in state, non-state, and Medicaid-funded residential programs in the United States for the fiscal year ending June 30, 1996.

- *Status and Changes in Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) Program: Results from Analysis of the Online Survey Certification and Reporting System (Report #47)* (1995). By K.C. Lakin and S.A. Larson. A report summarizing facility and resident information for the most recent surveys of Intermediate Care Facilities for Persons with Mental Retardation (ICFs-MR) in the OSCAR database as of January 1994. It also compares the characteristics of ICFs-MR in the OSCAR databases with the findings of a 1982 survey of all ICFs-MR.

- *Summary of National and State Databases on Residential Services for Persons with Developmental Disabilities (Report #44)* (1994). By K.C. Lakin and T. Morgan. A report on the current status of national and state information systems on residential services for persons with developmental disabilities. The report gives summaries of the types of information collected, how this information can be accessed, and suggests supports that would assist states in improving, utilizing, and sharing their data collection systems.

- *IMPACT: Feature Issue on Institution Closures.* This newsletter focuses on a critically important step in honoring the full citizenship of persons with developmental disabilities: the closing of institutions. Includes articles by self-advocates, policymakers, service providers, parents, and researchers.

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