

Financing services for developmentally disabled people: Directions for reform

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The Secretary of the Department of Health and Human Services established a working group to examine current Federal policies affecting the financing of services to persons with mental retardation and other developmental disabilities. This article summarizes the Working Group's Report to the Secretary. The working group concluded that Federal

policies can act as a barrier to community and family living opportunities. Policy alternatives were identified that emphasize flexibility in order to provide appropriate services in a variety of settings, targeting services to the most severely disabled and fixing Federal costs.

Introduction

Prior to the 1960's, children and adults with mental retardation and other developmental disabilities (MR/DD) lived in large institutions or with their families. In general, people with severe disabilities were isolated from society and not a part of the public consciousness. Few received any services other than routine or custodial care regardless of where they lived. The past two decades have witnessed extraordinary changes in our understanding of the needs and capabilities of disabled people. Parents and other advocates have lobbied hard for services promoting individual development. Numerous lawsuits have been filed to secure the rights of people with disabilities. Some large institutions have closed. Thousands of young people with developmental disabilities have moved through the public school system and are emerging with expectations for a meaningful adult life. A new system of developmental services in the community is evolving.

A number of critics have questioned whether public policies, particularly Federal financing policies, have kept pace with these dramatic changes. The major Federal program specifically designed to finance services, the Medicaid-funded intermediate care facility for the mentally retarded (ICF/MR) program, is institution-based; to be eligible for services, individuals must be placed outside their homes and in need of active treatment and 24-hour supervision. Three-quarters of the persons served in ICF's/MR are in large, costly State facilities with an average size of 155 beds (Lakin et al., 1985, 1987).

In contrast to the relatively generous Federal financing of institutions, Federal support for family care and community-based residential arrangements is much more limited. Responsibility for these services is fragmented across a diverse array of Federal, State, and local programs.

The Federal Government's role in financing services for people with developmental disabilities was recently the subject of a major policy review within the Department of Health and Human Services. An intradepartmental working group of senior policy

officials was authorized by the Secretary to examine Federal policy barriers that limit access to community-based services and to develop cost-effective policy reforms. This article summarizes the results of that review.

Population characteristics

People with developmental disabilities have severely handicapping conditions that occur prior to birth, in childhood or in adolescence, which limit functioning in several major life activities. Although there is limited data on the prevalence of developmental disabilities, it is generally agreed that approximately 2.4 million individuals, or 1 percent of the total population, could be considered developmentally disabled and potentially in need of long-term support (Abramowicz and Richardson, 1975; Tarjan et al., 1973). Of this population, about 250,000 live in residential facilities including 145,000 people in ICF's/MR. Another 40,000-60,000 are in nursing homes. The remainder live with their families, on their own, or in other residential arrangements such as personal care homes (Lakin et al., 1985).

The working group identified a subgroup of the population as most in need of specialized assistance in order to reach their developmental potential. This group is comprised of persons functioning within the severe or profound range of mental retardation or other developmentally disabling conditions with comparable levels of severity. There are an estimated 450,000 people in this subgroup including: 405,000 people (90 percent) with a diagnosis of mental retardation; 180,000 (40 percent) children, most of whom live at home and receive their primary services through the public school system; 270,000 (60 percent) adults; and 110,000 people (primarily adults) who are already being served in ICF's/MR (Lakin et al., 1985). The working group recommended that a limited entitlement to services to this particularly vulnerable population be considered.

The service system

The MR/DD service system is comprised of several public agencies at multiple levels of Government and a mix of public and private service providers.

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Although Federal involvement is important, States continue to play the major role in shaping system characteristics, particularly the relative emphasis given to community and institutional services. Some States have moved aggressively toward a community-based service system and others rely heavily on large facilities. States also use Federal Medicaid dollars differently. For example, Minnesota has developed many small-scale ICF's/MR; Nebraska does not use Medicaid for its 174 group homes but does for its single large State facility (Jaskulski and Weader, 1987; Lakin et al., 1987).

The MR/DD services system can be categorized in terms of three types of living arrangements: large facilities (16 beds or more); community facilities (fewer than 16 beds); and family settings. Although living arrangement does not always determine the type of services an individual receives, it can be a major factor in shaping access to services. Regardless of living arrangements, developmentally disabled people require an array of services and supports including income maintenance, habilitation (e.g., training in self care), education, and vocational training. It is important to note that these developmental services are quite distinct from traditional long-term care that is largely custodial.

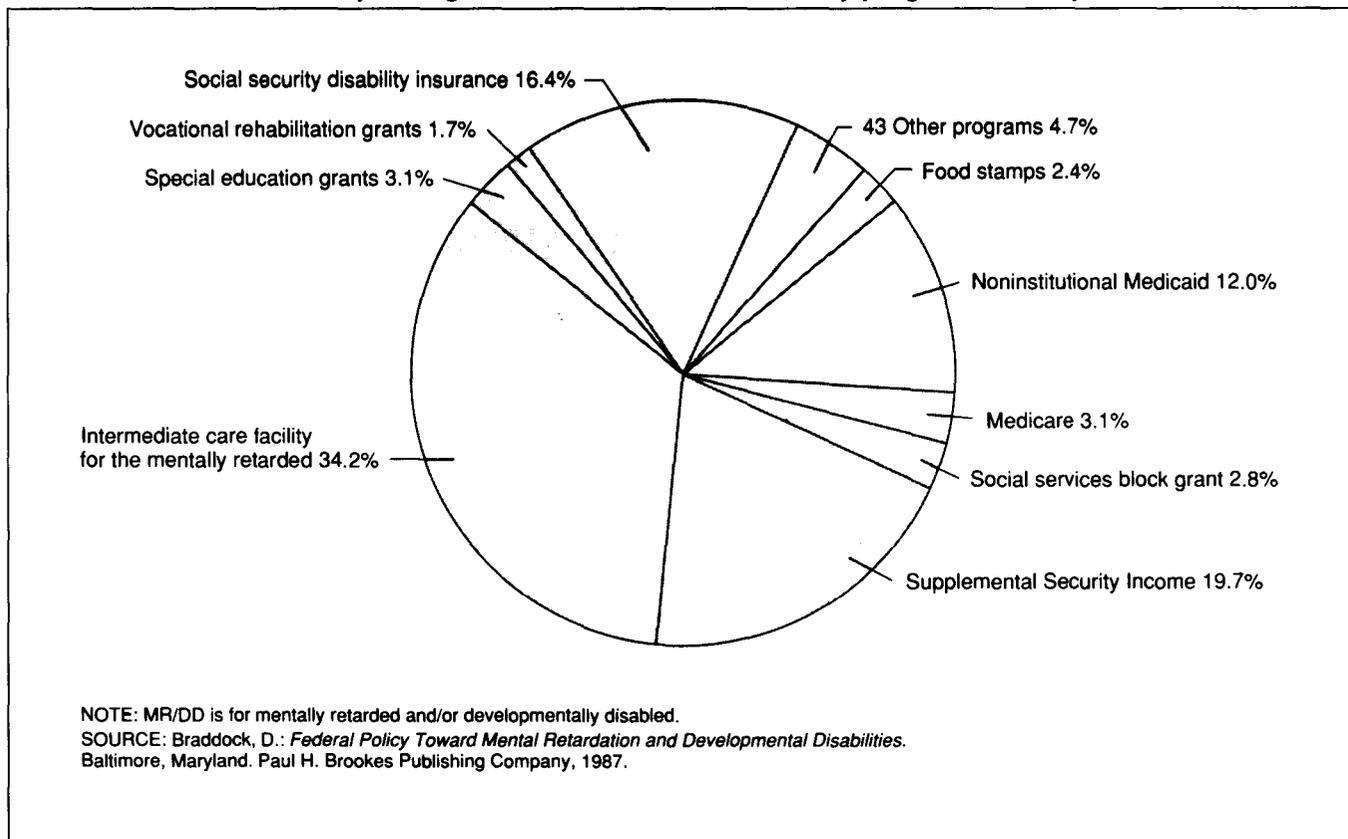
The research evidence

Research evidence indicates that advances in adaptive behavior and independent living skills are strongly associated with community living arrangements and learning experiences that promote independence and opportunities for interaction with nondisabled people. Research also demonstrates that innovations in training techniques and adaptive devices can enable those with severe disabilities to work productively and live successful, increasingly independent lives. (Close, 1977; Kushlick, 1975; Conroy, et al., 1982; Rosen, 1985; Noble and Conley, 1987).

The Federal role

The primary roles of the Federal Government are financing of services in partnership with State governments and providing leadership, particularly in establishing and articulating priorities and quality assurance. In fiscal year 1985, Federal expenditures were estimated at \$7.7 billion or more than 50 percent of total public financing for the MR/DD population.

Figure 1
Total Federal spending of \$7.773 billion for MR/DD, by program: Fiscal year 1985



A variety of Federal sources fund benefits and services as illustrated in Figure 1.

Two landmark pieces of Federal legislation have profoundly influenced the MR/DD services system. The Education for All Handicapped Children Act of 1975 mandates that States provide handicapped children with a free and appropriate education in the least restrictive setting. Guaranteeing access to education for even the most severely disabled has served as a significant disincentive to institutionalize children.

The other important legislative initiative is the Social Security Act amendments establishing the Medicaid ICF/MR program. Since its establishment in 1971, this program has become the largest single source of financing for MR/DD services. Originally created to provide health or rehabilitative services to mentally retarded people in State institutions, it has been a significant force in upgrading the quality of institutional care. Several features of the ICF/MR program are particularly noteworthy:

- expenditures accounted for almost 13 percent of the total Medicaid budget in fiscal year 1986 or \$5.2 billion.
- relatively few people participate; there were about 145,000 people served in 1986 at an average annual cost per person of \$35,000.
- nearly 90 percent of all State mental retardation institutions participate in the ICF/MR program (20 years ago, the same institutions were all State funded), and
- nearly 90 percent of ICF/MR expenditures go to large facilities (Burwell, 1987).

Supplemental Security Income (SSI) is the major source of cash assistance for developmentally disabled people living in the community. More than \$1.5 billion was paid in 1985 to more than 600,000 persons with mental retardation with the average Federal payment about \$250 per month. Social security disability insurance (SSDI) is the other significant cash benefit program for this population.

The Medicaid Home and Community-Based (HCB) Waiver program is used increasingly by States to support community care alternatives and to prevent inappropriate placement in institutions. In 1986, the Federal share of MR/DD waived services was \$110 million with 24,000 participants (Burwell, 1987).

There are a number of other relevant Federal programs including vocational rehabilitation and various programs administered by Housing and Urban Development, Department of Labor, and the Department of Agriculture that serve persons with developmental disabilities.

Working group findings and alternatives

Based on its review of Federal policies affecting persons with mental retardation and other developmental disabilities, the working group concluded the following:

- The primary Federal funding source for MR/DD services, the ICF/MR program, has not kept pace with significant changes in the field of developmental disabilities.
- The most important Federal support for the non-institutionalized population, the SSI and SSDI programs, are not designed to pay for a full range of MR/DD services.
- Lack of Federal participation in the financing of community services is widely perceived as a barrier to independence, productivity and community integration of developmentally disabled individuals.
- Medicaid, the primary funding source for MR/DD services does not appear to be a promising vehicle for Federal policy reform.

The working group identified two policy alternatives. The first would significantly restructure Federal financing and eliminate the ICF/MR program. The second outlines incremental changes within Medicaid. A third alternative, the Medicaid Home and Community Quality Services Act (S. 1673), was considered but rejected because of its cost implications.

Comprehensive reform proposal

This option would establish a new Federal program outside Medicaid by pooling dollars spent on the MR/DD population from (at a minimum) the ICF/MR Program, the Home and Community-Based Care waivers, and the personal care option under Medicaid. The new program would finance a range of residential, habilitative, vocational, and supportive services to persons with developmental disabilities.

Major features are:

Organization and Administration—A single Federal agency would administer the new program with authority to establish State allocation formulae, mandatory eligibility and service coverage requirements, and quality review and assurance mechanisms.

Eligibility—A mandatory population, limited to persons with severe or profound mental retardation or an equivalent developmental status, would be entitled by statute to receive a core set of services regardless of age or income. States would also be able to claim Federal financial participation (FFP) up to a specified ceiling for any other DD group they chose to designate.

Services—The mandatory population would have access to a core set of services including case management, residential services, respite and vocational/developmental services. Beyond these, States would have broad flexibility in the use of Federal matching funds and could choose the mix of institutional and community services most suited to their situation. Health care would continue to be provided through Medicaid.

Cost sharing—Cost sharing would be mandatory. Parents of dependent children under age 22 would be required to share costs based on ability to pay. Adults

with income from employment or public benefits would also contribute to the costs of services.

Financing—States could claim Federal financial participation (FFP), for eligible expenditures up to a pre-determined ceiling established by the Department for each fiscal year. The aggregate ceiling for the first year of implementation would equal projected Federal expenditures for that year, based on the Medicaid Forecasting System, for the ICF/MR, Medicaid waiver, and other long-term services for the MR/DD population as well as SSI payments for this population. After the first year, each State's ceiling will be adjusted for population growth and inflation using the Average Wage Index for social security-covered employment. Through 1993, each State spending less than the national per capita mean for MR/DD services will have greater increases in their ceiling than States which spend above the mean. This is intended to achieve greater equity in State per capita MR/DD spending.

Quality—The Federal administering agency would establish core requirements for States including: clients' rights and protections; access to individual case management; comprehensive functional assessments; individual program plans; uniform performance accounting systems; client monitoring programs, and minimum health and safety standards.

Projected program participation—An estimated 450,000 persons with severe or profound mental retardation or comparable developmental deficits would be entitled to services under the reform proposal, about 345,000 of whom already receive Medicaid-funded services. Approximately 179,000 persons in this mandatory population will be under 21 years of age and living at home with minimal service needs beyond special education. States would be able to serve, at their discretion, any other developmentally disabled individuals as resources permit.

Selected Medicaid changes

A second option developed by the working group proposes modifications to Medicaid, particularly the ICF/MR program. The intent is to make the Medicaid program more responsive to individual needs and to increase opportunities for services in community settings.

Strategies include:

Limiting ICF/MR eligibility—Objective criteria for ICF/MR placement could be established to restrict admission to individuals whose functional impairments are such that they require active treatment. A 6-month transition period for those in ICF's/MR not needing that level of care would be provided. New admissions to large ICF's/MR would be restricted and admissions of children under 21 years of age would be limited to family-like environments.

Reforming reimbursement—Payments for ICF/MR services vary dramatically among the States, from \$22,000 annually to almost \$65,000. A comprehensive study of the cost of providing ICF/MR services could

be conducted to provide a data base for defensible payment reforms. Experimentation with prospective client-centered payment systems would be pursued.

Improving quality assurance mechanisms—In response to the apparent conflict of interest resulting from States surveying and certifying their own facilities, ICF's/MR could have the option to choose an approved accrediting body to conduct the necessary surveys for certification. Federal surveyors would survey and certify public facilities with more than 15 beds, or at a minimum, impose Federal certification on public facilities.

Resident earnings—Currently only a small amount of earnings of ICF/MR residents may be retained for their personal use. This reform would allow residents to retain a larger portion of their earnings while contributing toward their room and board. Eligibility for ICF/MR services would continue until a resident's earnings were adequate to support living arrangements outside the ICF/MR.

Summary and conclusions

The working group found that current Federal policies can act as a barrier to community and family living opportunities. Future Federal reform efforts should focus on maximizing program flexibility at the State and local levels to allow a range of residential and developmental services. Federal resources should be targeted to those with the most severe disabilities. Finally, Federal program costs should be controlled rather than open-ended in order to provide a range of community services without enormous increases in public cost. The working group further concluded that the Medicaid program, with its health and welfare orientation, is an inappropriate vehicle for future reform.

With these conclusions in mind, the Department has developed a legislative proposal based on the working group's comprehensive reform proposal. Although no major legislation may be passed during this Congressional session which would reform the financing of services to persons with mental retardation and other developmental disabilities, the continued high level of interest in this policy area seems to indicate that it is only a matter of time before some type of reform is enacted.

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