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National Health Policy Forum
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**IMPROVING LIVES AND REDUCING EXPENDITURES:
MEDICAID'S AGENDA FOR DEVELOPMENTALLY DISABLED PEOPLE**

an overview with

Colleen Wieck, Ph.D.
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Minnesota Developmental
Disabilities Council

Valerie J. Bradley
President
Human Services Research
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and a panel discussion featuring

Ben Censoni
Department of Mental Health
State of Michigan

Jaylon Fincannon Department
of Mental Health
and Retardation
State of Texas

Howard Gold
Office of Mental Retardation
and Developmental Disabilities
State of New York

Edward Skarnulis, Ph.D.
Department of Human Services
State of Minnesota

and moderated by

Donald N. Muse, Ph.D.
Congressional Budget Office

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1:45 p.m. - 4:45 p.m.

Quality Inn Capitol Hill
415 New Jersey Ave., N.W.
Congressional Room

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fill quickly, so call early to avoid being placed
on the waiting list.

The last 15 to 20 years have seen striking changes in the
philosophy and practice of care for persons with mental retardation
and developmental disabilities (MR/DD). The field has moved from a
general belief that large institutions were an acceptable way to
care for this population to a consensus that such facilities are

more likely to hinder the full development of the MR/DD individual's potential. Medicaid funding for intermediate care facilities for the mentally retarded (ICFs-MR) has allowed states to improve their large institutions and to move part of their MR/DD population into smaller facilities located in community settings. Yet, some observers feel that even small ICFs-MR are too restrictive and too medically orientated to adequately meet the needs of many individuals with MR/DD, believing instead that large numbers of the population could be better served in a more home-like setting supported by a network of community services.

States wishing to move in this direction are often stymied by a number of obstacles, including federal reimbursement policies, the fears of some parents about the long term stability and quality of community placements, and the economic impacts of institutional closures on surrounding communities. For many states, Medicaid reimbursement policies are of the greatest concern because of the major role that the program has come to assume in financing long term care to the MR/DD population. Many state policymakers feel that current Medicaid policies deny them the flexibility needed to develop community alternatives. However, such policies reflect significant federal concern over the present high level of Medicaid expenditures for this population (\$3.59 billion in FY 1985) and continuing worries over using a medical assistance program to fund what might be viewed essentially as housing and social services.

In recent years, such federal and state concerns have surfaced in debates over several legislative initiatives in both the House and Senate that would alter the Medicaid program to further stimulate the growth of community-based services. Several approaches have been represented within these initiatives: some make additional federal funds available for small community facilities while phasing out federal funding for large institutions (The Community and Family Living Amendments of 1985); others either require or make optional the inclusion of home and community services in state Medicaid plans. While legislation embodying these approaches has yet to make significant progress in either chamber, some are expected to undergo further modification and re-surface in legislative action later in this Congress.

Defining Terms

The terms "mental retardation" and "developmental disability" have only vague meanings to many not directly involved with these fields. A diagnosis of mental retardation rests on two factors: a significantly below-average measured intelligence ("I.Q.") and a significantly limited ability to adapt in age-appropriate ways to the surrounding environment. In addition, four subclassifications of retardation are widely used at present. These subclassifications -- mild, moderate, severe, and profound retardation -- are based on I.Q. scores and assessments of functional abilities.

Over the last ten years the term "developmental disability" has begun to replace "mental retardation" in many program titles and descriptions. As set forth in the Developmental Disabilities Act of 1984 "developmental disability" refers to severe, chronic, physical or mental disability that occurs prior to young adulthood and that results in substantial functional limitations in at least three of the following major life activities: self-care, language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. The most frequently occurring conditions resulting in developmental disabilities are mental retardation, cerebral palsy, severe and uncontrolled epilepsy, autism, and other neurological and sensory impairments. The thinking behind the language in the act was that the programs it authorized should focus attention on those with more severe levels of disability (who traditionally had been underserved). Thus, individuals with mild forms of mental retardation are not typically considered to be developmentally disabled under this legislation.

While the more general definition of developmental disability could include some forms of mental illness, mental illness is usually considered a separate condition. This distinction often precludes mentally ill individuals from being served by developmental disabilities programs unless they are identified as being developmentally disabled as well.

Researchers report that the change in terminology from mental retardation to developmental disability has had little impact to date on the type of population receiving services under Medicaid and other public programs: mentally retarded people are still the overwhelming majority of program clients.

Medicaid stipulates that federal support be available both to mentally retarded individuals and to "persons with related conditions." The definition of "related conditions" has two major components: (a) an individual's disability must be the result of certain specified conditions - cerebral palsy, epilepsy, or conditions closely related to mental retardation - and (b) the person must have substantial functional limitations in at least three areas of major life activity. (Medicaid defines major life activities as including all of those listed in the Developmental Disabilities Act, with the exception of the capacity for economic self-sufficiency.) Mental illness is specifically excluded from the Medicaid definition of "related conditions."

The Mentally Retarded/Developmentally Disabled Population

The size of the MR/DD population is thought to be approximately 3.9 million, or 1.6 percent of the population. Approximately 2 million of these individuals are over the age of 18. The relatively large number of MR/DD individuals under 18 years of age in large part reflects the great number of children identified during their school years as deficient in "age-appropriate adaptation," many of whom go on to function at "normal" levels in adulthood. Sometimes

overlooked in policy discussions on the MR/DD population is the large number of people with MR/DD now surviving into old age, thanks in large part to new medical techniques that prolong life for many previously vulnerable individuals. Such people often require increasing amounts of care as they age.

The great majority of individuals with MR/DD have only mild to moderate degrees of disability. Most live on their own or with relatives and require minimal assistance from public programs. However, an estimated 377,000 people have severe or profound retardation, according to Dr. Charles Lakin at the University of Minnesota. Although many of these individuals live in various kinds of institutions and other residential facilities, many are living successfully in the community.

The percentage of people with mental retardation residing in various types of licensed care facilities has declined over the past two decades, with the less severely impaired, particularly children, increasingly served in the community. Nevertheless, a 1982 survey conducted by Dr. Lakin found that approximately 250,000 mentally retarded people were still served in licensed care facilities. (The number served in unlicensed residential facilities is difficult to monitor.) Despite a growing trend away from large institutions and toward the use of small community facilities, almost 180,000 of the individuals in the 1982 survey were in facilities of more than 15 beds, while nearly 110,000 were in facilities with more than 300 beds.

Significantly, those still residing in these large state institutions tend to be the most severely impaired: 57.2 percent had profound retardation and 23.8 percent severe retardation. Forty-three percent of residents suffered from multiple handicaps (including epilepsy, cerebral palsy, emotional handicaps, blindness, and deafness), up from 34.4 percent in 1967. The placement of those with severe disability levels in institutions has caused considerable debate. Some argue that the severely disabled are being discriminated against by being denied access to care in community settings. Others maintain that the severity of these individuals' disabilities requires continuing care in closely supervised institutional settings featuring medical support.

Changing Concepts of Care

From the 19th century until the 1960s, care for mentally retarded individuals who could not afford private care was delivered in large public institutions. Because mental retardation was thought both incurable and untreatable, individuals with more severe forms of retardation were often sent at birth to such institutions and remained there until they died. While in the institution, these individuals were typically given little treatment, had few social or recreational opportunities and, in general, were subjected to harsh living conditions.

As described in a comprehensive background paper prepared by the Congressional Research Service in September 1986, this situation began to change during the 1950s when parents of retarded children organized and began advocating for increased community-based treatment options and improved conditions within the large institutions. In 1963 a panel appointed by President Kennedy presented a national plan calling for increased use of community-based care and a reduction in the number of people served in large institutions.

Throughout the 1960s and 1970s, reports of poor living conditions and mistreatment in large institutions increased public support for deinstitutionalization of mentally retarded people (in much the same way as support grew for deinstitutionalization of the mentally ill). In response, several pieces of legislation were enacted and a number of precedent-setting lawsuits were brought; these resulted in dramatic changes in the service system for the mentally retarded.

This was the environment in which the legal and philosophical concepts behind community-based care and the techniques and technologies needed to implement these concepts were developed. These concepts include the following:

- Normalization – a belief that developmentally disabled people should live under conditions that are as close as possible to those of the rest of society; that day-to-day activities, responsibilities, housing, privacy, education, work, and social interactions should be as close to "normal" as possible.
- The right to habilitation – a right established by the courts in the early 1970s, under which residents of large institutions must receive habilitative treatment, that is, "active" treatment that focuses on improving their overall condition and functioning.
- The least restrictive alternative – a legal concept related to the constitutional protection from undue restraint, which implies that mentally retarded people should have access to residential placements offering as few restrictions on personal freedom as possible, given each individual's need for protection and habilitation.
- Nondiscrimination based on severity of handicap – the principle that those with severe or profound retardation should not be discriminated against in their choice of placement; that such individuals should have ready access to community placements and not be relegated to large institutions solely on the basis of the severity of their impairments.

As the principles guiding community care policies and programs were established, researchers and service providers began making major strides in identifying effective treatment and habilitative techniques for the MR/DD population. Such techniques – behavioral

management, in particular - have allowed many severely and profoundly retarded persons to acquire and maintain vocational, social, communication, and self-care skills to an extent considered impossible only a few years ago.

Habilitation programs where these skills are learned are often aimed at improving the functional levels of individuals with developmental disabilities to give them the ability to live both more independently and more productively in the community. A number of supportive services have been developed to assist developmentally disabled people to better function in the community or remain at home and to augment the process of habilitation. These include a range of residential, educational, vocational, employment, and social support services.

- Residential programs include a variety of community-based group homes (some of which are certified as ICFs-MR), several kinds of semi-independent or supported living programs, and foster family arrangements.
- Educational services are provided increasingly in public school settings in special education classes and, for less impaired children, in regular classrooms; they are also provided in specialized schools.
- Vocational services are specifically tailored for individuals with developmental disabilities and focus on increasing individual skills and potential for productive work. (Those not ready for formal vocational programs may be placed in various types of "day activity" programs where they receive pre-vocational training or, for the most severely impaired, training in various self-help and social skills.)
- Employment services include a range of supported work programs integrated into normal work settings that provide developmentally disabled individuals access to special job "coaches," personalized training and supervision, and physically modified work stations. (Specialists in the field of habilitation of MR/DD individuals feel that such services have the potential to completely replace the more traditional concept of vocational services.)
- Other support services include direct services to clients, such as case management, advocacy, counseling, specialized transportation, and therapeutic services, as well as services for family caregivers, such as respite care, caregiver training, and family subsidies.

The consensus among habilitation experts is that services such as these, if fully developed, would allow even those with the most severe levels of disability to live in the community. There remain, however, many concerns over the mechanics of transforming a system that remains heavily dependent on institutional care in many

states and widespread fears that community care for the most severely disabled would be prohibitively expensive.

Federal Programs for Developmentally Disabled Individuals

The evolution of federal programs serving developmentally disabled individuals clearly reflects the significant changes in the concept of care that have occurred in the last two decades. The involvement of the federal government in funding services, training, research, and income maintenance for the developmentally disabled has been extensive, involving programs in the Departments of Health and Human Services, Education, Housing, Agriculture, Labor, and Defense. A 1987 analysis of federal expenditure trends in this area (David Braddock, Federal Policy Toward Mental Retardation and Developmental Disabilities) shows that 82.3 percent of the \$4.68 billion in federal funds for the developmentally disabled in FY 1985 was expended within the category of public health services, and 69 percent of this (or \$2.66 billion) was expended in Medicaid's ICF-MR Program.

The Medicaid ICF-MR Program

The tremendous growth and resulting importance of the ICF-MR program in providing services to developmentally disabled people was not anticipated when the program was first authorized under the Social Security Amendments of 1971. Prior to this legislation, states provided the bulk of the funds for institutional care. Public institutions could receive Medicaid funding only if they qualified as skilled nursing facilities; thus a strong incentive existed for states to convert institutions for mentally retarded people into medically oriented nursing homes.

The ICF-MR program, which created a new type of intermediate care facility designed to meet the needs of the mentally retarded population, was aimed at improving the quality and scope of care for mentally retarded people and at increasing their opportunities for personal development. The ICF-MR program allowed states to receive federal funding for their institutions, without requiring expensive nursing care. At the same time, the federal government required states to improve physical conditions in their facilities and (at the urging of groups such as the National Association of Retarded Citizens) required them to provide habilitative and other "active" treatments to residents of state institutions. The program was very popular with states from the onset: within four months, 28 states had amended their state plans and were participating in the new program.

The focus on delivery of care in large institutions was somewhat altered in 1974 when Medicaid reimbursements to small, community ICFs-MR (of 15 beds or less) were allowed. Again this represented an attempt to alter the existing program to fit better with the concept of providing service in a more normal, less restrictive environment.

Meanwhile, expenditures for the ICF-MR program were growing astronomically. In unadjusted terms, federal funding rose from \$92 million in FY 1973 to \$2.17 billion in FY 1982 (even in constant dollars, a ten-fold increase in expenditures over ten years). Utilization of ICF-MR services also increased rapidly during this period, with the number of people served rising from 12,200 in FY 1972 to a peak of 151,200 in FY 1981. Until the late 1970s the large increases in costs and utilization were driven primarily by the certification of many existing facilities as ICFs-MR. To a lesser extent, increases were also caused by the opening of new, smaller facilities in communities to accept individuals formerly placed in large institutions. By 1980 the continued increase in expenditures was largely attributable to higher costs of providing service. These higher costs were brought about by factors such as increased labor costs and Medicaid regulations governing areas such as physical structure and record-keeping.

It was against this background of explosive growth in spending on ICFs-MR that the next step toward community-based care occurred. In 1981, the Omnibus Budget Reconciliation Act authorized three-year waivers permitting states to provide alternative home and community-based care and related services, providing that these services were no more expensive in the aggregate than the cost of serving the specified target population in institutional settings. In addition, such services could be reimbursed only for individuals who would otherwise require care in ICFs-MR. Thus, the waiver program was thought to address the goals of both reducing Medicaid expenditures and increasing community care options.

Since FY 1982 the growth of federal support for ICFs-MR has slowed, primarily because fewer new facilities are being certified and greater numbers of people with mild to moderate retardation are receiving services - largely state-funded - in alternative community settings. It is significant that 87 percent of ICF-MR reimbursements continue to go toward care in large (more than 15-bed) facilities. Seventy-five percent of total ICF-MR funds continues to flow to large state institutions, even though the population of these institutions continues to decline.

Meanwhile, advocates of community care have grown increasingly frustrated with what they believe is the inability of the waiver program to provide significant increases in federal funding for community care programs. They feel that the process of applying for waivers, the necessity to renew waivers periodically, and the need to document cost savings create uncertainty about the reliability of continuing federal participation, thereby hampering wide use of the program as a means to develop new systems of community care.

In addition, states vary considerably in their ability to use waivers. Essentially, states that have had a higher proportion of people placed in ICFs-MR are able to benefit from waivers because they can more easily demonstrate new cost savings for their Medicaid programs, while those with more extensive state-funded systems

of community-based services already in place may be penalized because few new savings will revert to their Medicaid programs.

As a result of these constraints, federal expenditures have been relatively low for MR/DD waived programs compared to those for the ICF-MR program (in FY 1986, \$145 million and \$2.9 billion, respectively) . In addition, relatively few people are served by MR/DD waiver programs (21,100, according to a HCFA survey conducted in September 1985), whereas many more, approximately 146,000, are served in both public and private ICFs-MR.

While states also have the option of amending their regular Medicaid plans to offer some kinds of community services, such an approach offers less flexibility in the choice of services (with fewer habilitative and developmental services permitted), as well as in geographic areas and the types of individuals covered. Thus, states have been left to shoulder a large part of the financial burden for expanding community services on their own.

Other Medicaid Services

HCFA estimated that in FY 1985 approximately 140,000 individuals with mental retardation were receiving Medicaid-reimbursable care in skilled nursing facilities and in regular intermediate care facilities. HCFA continues to accept such placements in cases where MR/DD individuals have reached their capacity of intellectual and social development or require primarily skilled medical care. However, HCFA recently increased compliance monitoring of inappropriate nursing home placements.

Many developmentally disabled people living in the community qualify for Medicaid-reimbursed medical services because they are eligible for Supplemental Security Income and meet other state-specific requirements. The federal share of Medicaid going to provide noninstitutional medical services to the developmentally disabled in FY 1985 has been estimated to be approximately \$929 million.

Educational Services

The federal government, primarily through PL 94-142, the Education for All Handicapped Act of 1975, finances several types of educational services used by children and youth with MR/DD. These include special education services in a variety of settings, transportation services, and other support services. Special education services accounted for over 90 percent of the \$354 million spent by the federal government in this area in FY 1985, with approximately 98,000 children served in community school

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The availability of special education day classes in the community has played a major role in reducing the population of institutions as more youngsters remain at home rather than enter institutions. The availability of these community-based services

for children has led to increased expectations on the part of parents regarding both the potential of their children and the nature of services designed for them. This, in turn, has contributed to the demand for community-based adult habilitation and work programs to absorb young adults leaving special education programs.

Human Development Services

Federal expenditures for human development services both in and out of institutions totaled \$347 million in FY 1985. Human development funding has three major components: (a) Social Services Block Grant monies (accounting for 64 percent of federal human development funding), which support a wide range of social services to people with MR/DD living in the community; (b) state grants authorized under the Developmental Disabilities Act, which provide funds for various service programs (including community living programs, employment-related activities, and child development services), planning activities carried on by state councils, and protection and advocacy programs; and (c) the Foster Grandparent Program, which serves children with MR/DD both in institutions and in the community.

The extent to which Social Services Block Grant monies are available to fund services for the MR/DD population varies considerably among states, depending on where such services fall in a state's range of priorities.

Vocational Rehabilitation

In FY 1984 the federal government provided approximately \$125 million for vocational rehabilitation services for people with MR/DD both in the community and in institutions. Federal funds are allotted to state vocational rehabilitation agencies to provide services such as evaluation, physical and mental restoration, vocational training, special devices required for employment, and other services required by the handicapped for employment.

Vocational rehabilitation services are available to mentally disabled people whose disabilities act as a substantial handicap to their becoming employed. Approximately 26,000 individuals with mental retardation (most with mild to moderate retardation) were served by state vocational rehabilitation agencies in FY 1984 (12 percent of their total caseload). Because more severely disabled individuals with mental retardation require ongoing support in work settings, and since state vocational rehabilitation agencies have not been authorized to provide such services, most of these individuals have been rejected as candidates for vocational rehabilitation agency services. The Rehabilitation Amendments of 1986 give state rehabilitation agencies both a mandate and new funding to develop supported employment services for people with severe disabilities (including those with severe levels of MR/DD).

The Forum Session

In many cases, the same people who were once labeled "retarded" and warehoused in substandard institutions are now found living full and productive lives in their communities. The approaches and techniques that have led to this change have only been developed in the last two decades. While the full potential of these new approaches has yet to be realized, many states have moved substantially toward complete reliance on community-based living arrangements for their MR/DD populations. Yet, there continues to be controversy over the extent to which such settings are both appropriate and practical for individuals with more severe forms of disability and related controversy over the proper role of the large institutions still used in many states.

To facilitate an understanding of the nature of the diverse and changing MR/DD population and to help sort through the equally diverse and changing nature of the state Medicaid programs that serve them, we have invited two individuals with considerable experience in research and program design in this area.

Colleen Wieck, Ph.D., will lead off the program by providing an overview of the developmentally disabled population, a review of the extensive progress made in treatment and habilitation programs, and a brief discussion of issues yet to be resolved in program design.

Dr. Wieck has been the executive director of the Minnesota Developmental Disabilities Council for six years. Prior to this, she spent three years at the University of Minnesota conducting research on costs associated with group homes and state institutions. Dr. Wieck has published extensively on a variety of MR/DD-related topics, including papers on ICF-MR program costs, the establishment of day programs for people with MR/DD, and the economic impacts of institutional closure.

Valerie J. Bradley will present an overview of current Medicaid-related policy issues, including concerns about the costs and quality of services delivered in both institutional and community settings, the use of waivers to fund home and community-based care, and issues arising from attempts to alter the program's present focus on institutional care.

" Ms. Bradley has been the president of the Human Services Research Institute in Cambridge, Massachusetts, since its beginning in 1976, overseeing research projects in developmental disabilities, mental health, substance abuse, and other human service programs. She has also served as a consultant on developmental disabilities and mental health issues to federal agencies and numerous state governments and has authored many articles and policy papers relating to the developmentally disabled population.

Following these presentations, our two speakers will be joined by a panel of representatives from states that have employed a

variety of approaches and strategies in designing and financing programs to serve their citizens with MR/DD. **Donald N. Muse, Ph.D.**, principal analyst with the Congressional Budget Office, will serve as moderator for this panel discussion among representatives of programs in New York, Minnesota, Michigan, and Texas.

New York, a state accounting for a significant proportion of national Medicaid expenditures for MR services, has employed the ICF-MR program and its state Medicaid plan to make heavy use of both institutional and community-based services. **Minnesota** heavily utilized the ICF-MR program as part of an aggressive policy to reduce the population of its state institutions but finds that restrictions on the use of waivers largely prevent placement of more severely disabled people in alternative community settings. **Michigan** has used state funds to develop the most extensive community service system in the country while using its state Medicaid plan to develop many small community ICFs-MR; however, the state still finds an unacceptably large number of individuals residing in large, state-operated ICFs-MR and nursing homes. Finally, **Texas** continues to rely heavily on its large, state-operated ICFs-MR to provide care to MR/DD individuals while beginning to develop more community placements through use of both the ICF-MR program and state funds.

The speakers and panelists will explore a variety of pressing policy questions, including the following:

- What barriers have states faced in attempting to develop community-based services? What is the nature of state and federal impediments to the further development of community-based programs?
- What has been the experience of states with program costs? How are capital costs handled for ICFs-MR and for various alternative community homes?
- How can quality of care be monitored in ICFs-MR, in small group homes, in home care delivery and in other community-based services? How is quality assurance linked to federal and state requirements? What are appropriate measures of quality?
- What proposals exist for altering federal and state policies in these areas?

Susan Axleroad
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