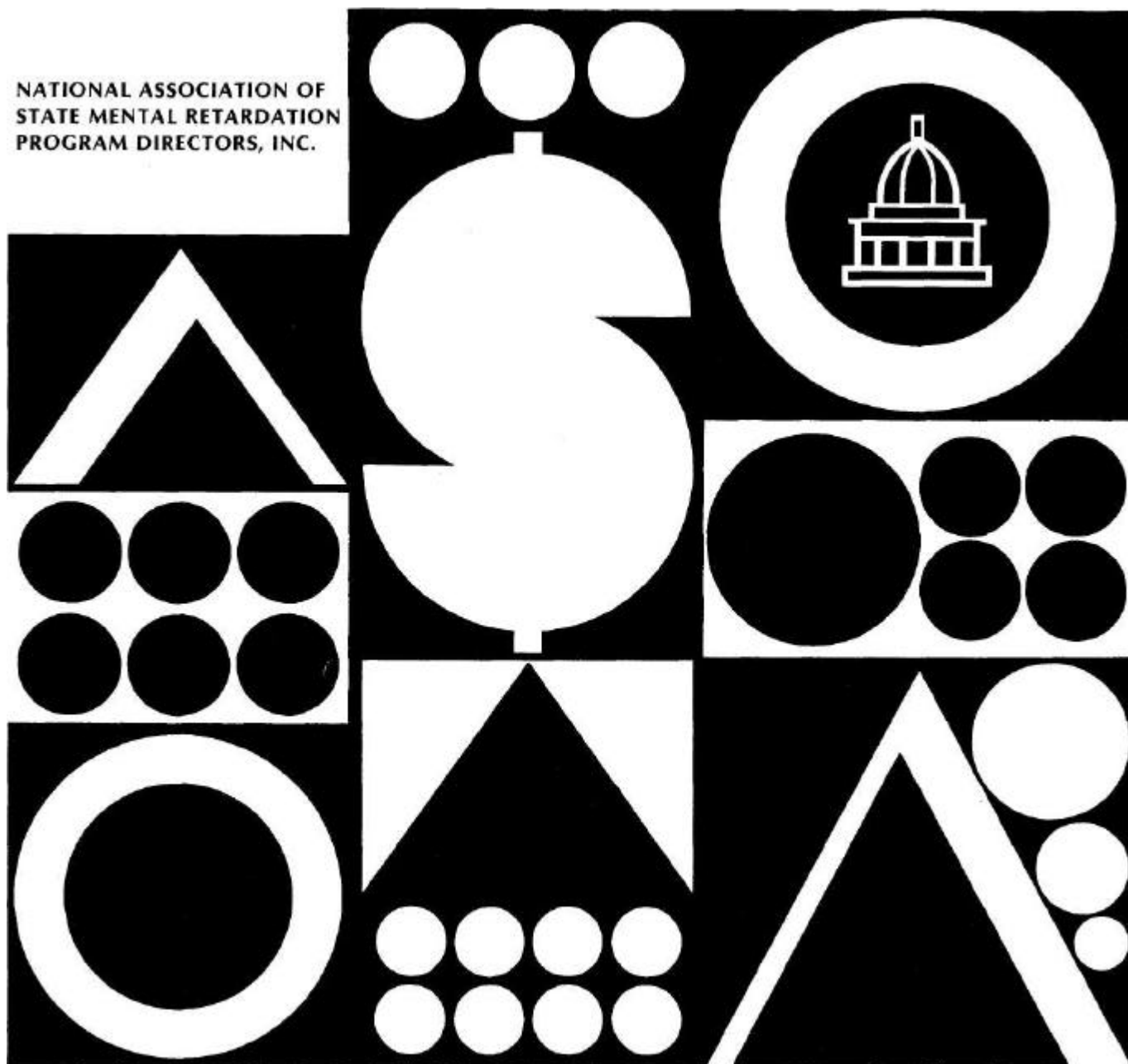


NATIONAL ASSOCIATION OF  
STATE MENTAL RETARDATION  
PROGRAM DIRECTORS, INC.



# FEDERAL FUNDING INQUIRY

THE HCB WAIVER PROGRAM AND  
SERVICES FOR PEOPLE WITH  
DEVELOPMENTAL DISABILITIES:  
AN UPDATE

This is the fourteenth in a periodic series of special reports on federal policies governing the financing and provision of services for persons with developmental disabilities. The general aim of these Federal Funding Inquiry reports is to explore, in detail, the implications of new and emerging federal assistance programs and policies as they affect citizens with developmental disabilities.

**THE HCB WAIVER PROGRAM AND SERVICES  
FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES:  
AN UPDATE**

by

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## PREFACE

This year, the Medicaid home and community-based (HCB) waiver program will mark its tenth anniversary. Following the enactment of Section 1915(c) of the Social Security Act as part of the Omnibus Budget Reconciliation Act of 1981 (Section 2176, P.L. 97-35), Montana and Oregon initiated HCB waiver programs on behalf of persons with developmental disabilities in December, 1981. And so began what has become an increasingly important relationship between this unique federal Medicaid program authority and the state efforts to meet the needs of Americans with developmental disabilities.

The National Association of State Mental Retardation Program Directors (NASMRPD) has had a particularly strong, abiding interest in the fortunes of this program since its inception. Over the past several years, the Association has advocated for changes in the program to make it a more effective tool to assist states in enhancing and expanding community developmental disabilities services. NASMRPD's staff have furnished advice to dozens of states regarding potential uses of the waiver authority to assist them in providing enhanced program options for people with developmental disabilities. On an ongoing basis, the Association attempts to keep member state MR/DD agencies as up-to-date as possible on federal HCB waiver policy developments as well as the steps particular states are taking to initiate new or modified HCB waiver programs.

The Association's ongoing interest in this program stems from the fact that it remains the most useful tool available to the states in order to meet the needs of persons with severe, life-long disabilities in settings other than ICF/MRs. The vigor with which the substantial majority of states have employed this Medicaid financing option over the past five years in particular has been remarkable. This year, about 55,000 people with developmental disabilities will be served through HCB waiver programs in operation in 46 jurisdictions. Despite basic problems in federal policies governing this program, it has emerged as the principle means that the states collectively have employed to expand the number of persons with developmental disabilities receiving Medicaid reimbursable long-term care services. And, as best as we can tell, the program will continue to expand at a brisk pace over the next few years.

Due to some of the HCB waiver authority's peculiar features, many observers have been quick to dismiss the program as having limited utility in assisting states to create improved, broader-based systems of community developmental disabilities services. After all, the HCB waiver program is limited in scope and afflicted by many of the myriad shortcomings in federal Medicaid policies affecting services to persons with developmental disabilities. The HCB waiver program, by its very nature, cannot be regarded as broad-scale "Medicaid reform" of these federal policies.

Yet, there is little doubt that the states' collective experiences with the HCB waiver program have contributed enormously to reshaping thinking about how federal policies might be modified to bring them into better

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alignment with contemporary values regarding "best practice" in serving people with developmental disabilities. Due to the HCB waiver program, people with developmental disabilities in many states today have access to a wider range of services than would otherwise be the case. The HCB waiver program has amply demonstrated that creating a "level playing field" between federal support for institutional services and more individualized, integrated opportunities for community living and participation has beneficial outcomes for consumers, their families, the states and the federal government.

The waiver program is by no means static. States continue to expand their programs, adding new services and program participants. Aided by the HCB waiver authority, several states have launched innovative supported living and family support programs that are assisting people with particularly severe disabilities to enjoy community living and exercise greater personal control over their day-to-day lives. The HCB waiver program has given states increased opportunities to expand the range of individuals who are supported in the community.

The HCB waiver program has become an important cog in state strategies to improve community developmental disabilities services and is likely to remain so for the foreseeable future. Hence, it remains important that policymakers, state officials, consumers and their families, advocates, service providers and others have access to comprehensive, systematic information regarding the effects this program is having nationwide.

This Federal Funding Inquiry report is the Association's fourth such report on the HCB waiver program. This report updates our last major report on the waiver program, which was published in September, 1989. Hopefully, this report will assist in achieving a better understanding of the role that the HCB waiver program is playing in meeting the needs of our citizens with developmental disabilities.

As with all Association reports, we owe enormous gratitude to the staff of NASMRPD member agencies who regularly share information and insights into the strategic and practical ramifications of federal policies affecting services to persons with developmental disabilities. A special note of thanks is due to the HCB waiver coordinators in more than forty states who took time from their busy schedules to respond to the survey questionnaire which furnished much of the basic information needed to complete this report.

Gary A. Smith Robert  
M. Gettings January,  
1991

# **CHAPTER I**

## **INTRODUCTION**

# **THE HCB WAIVER PROGRAM AND SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES: AN UPDATE**

## **I. INTRODUCTION**

In September 1989, NASMRPD issued a Federal Funding Inquiry report (Medicaid Home and Community-Based Services for Persons with Developmental Disabilities: The Home and Community-Based Waiver Experience) that was intended to take a fresh look at how states were employing Medicaid's home and community-based waiver authority to foster improved and expanded services to persons with mental retardation and other developmental disabilities. That report revealed that the HCB waiver program had become an increasingly important source of federal assistance in supporting community developmental disabilities services. The news that the HCB waiver program was expanding at a vigorous pace stood in contrast to the view expressed by many observers that the program had at best a minor impact on redirecting federal assistance from the ICF/MR program to other community developmental disabilities service options.

The 1989 report also furnished extensive information regarding the HCB waiver program's statutory underpinnings, federal administrative policies and the mechanics of managing this particularly unique Medicaid program. The aim of this report is not to replot all the ground that was covered in the 1989 report. Rather, the purposes here are to:

- Update the basic statistical information concerning nationwide trends in the numbers of individuals participating in the program and federal state Medicaid spending on their behalf as well as to furnish state-by-state statistics on the range and scope of program services;

- Highlight recent developments in how states are employing the program as well as federal statutory and administrative policies that affect state programs;

- Explore in greater depth some dimensions of this program that warrant more discussion than was possible in the 1989 report; and,

- Reassess the implications that the states' experiences with the HCB waiver program might have for constructively altering federal Medicaid policies affecting services to persons with developmental disabilities.

Since this report is an update of the Association's 1989 report, it necessarily assumes a certain degree of familiarity with the basic policy framework under which the program is managed. Readers who may not be familiar with that framework may wish to consult the 1989 report. [N.B., Copies of the 1989 report may be ordered from the Association.]

## I. Introduction

The remainder of this report is organized as follows:

Chapter II provides updated information on state-federal spending and the number of persons being served in developmental disabilities HCB waiver programs on a nationwide and state-by-state basis, including estimates for FY 1990-91. Parallel trends in the ICF/MR program also are discussed. In addition, information is provided on interstate variations in the utilization of the waiver program.

Chapter III examines developments in state utilization of the HCB waiver program on behalf of persons with developmental disabilities over the eighteen month period from July 1989 to December 1990, including: (a) the actual or prospective entry of additional states into the program; (b) the advent of special HCB waiver programs targeted specifically to nursing facility residents with developmental disabilities; and, (c) other major changes in state programs. Special attention is given to Arizona's unique program, which is furnishing HCB services to persons with developmental disabilities under an alternative federal statutory authority.

Chapter IV focuses on the types of services that states are offering under their HCB waiver programs, including some that appear to be particularly exemplary models.

Chapter V explores many of the administrative challenges that states face in managing their HCB waiver programs, including state interagency relationships, federal-state relations, and other dimensions of program operations.

Chapter VI looks at federal policy changes affecting the HCB waiver program that have occurred since 1989, as well as the ebb and flow of state-federal administrative issues that affect the program.

Chapter VII assess the present status and future prospects of the program, particularly in light of the lack of consensus regarding more extensive restructuring of federal Medicaid policies affecting services to persons with developmental disabilities. Potential changes in the HCB waiver program that might make it an even more effective means of meeting the needs of persons with developmental disabilities also are explored.

The Appendix to this report contains an updated and somewhat more detailed listing of the state developmental disabilities HCB waiver programs presently in operation, including listings of the services furnished under each state's program(s) and the state officials responsible for managing these programs.

A good deal of the information contained in this report was obtained via a three-part survey questionnaire which NASMRPD sent to state HCB waiver

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program coordinators in July 1990. Nearly all states completed this questionnaire. The survey instrument asked each coordinator to review and update information that had been provided to the Association in the spring of 1989 regarding the scope of the state's developmental disabilities HCB waiver program(s). In addition, all coordinators were asked to complete a brief questionnaire concerning any near-term plans the state might have for initiating additional waiver programs or modifying current programs as well as several more specific aspects of their programs. Finally, an open-ended, optional questionnaire also was included that asked each program coordinators express their views regarding certain features of the HCB waiver program as well as practices employed in managing their state's HCB waiver program(s).

Between the time that responses were received to this survey and the publication of this report, additional updates were obtained regarding HCB waiver requests which were in the Health Care Financing Administration's waiver review "pipeline" in order to assure that the information contained in this report would be as current as possible.