MINUTES OF THE JOINT MEETING OF
THE SENATE FINANCE COMMITTEE AND
THE ASSEMBLY WAYS AND MEANS COMMITTEE
Carson City, Nevada
March 25, 1981

A joint meeting of the Senate Finance Committee and the Assembly Ways and Means Committee was called to order by Acting Chairman Roger Bremner at 8:30 a.m., on Wednesday, March 25, 1981, in Room 131, Legislative Building, Carson City, Nevada.

SENATE FINANCE COMMITTEE MEMBERS PRESENT:

Senator Gene Echols
Senator James I. Gibson
Senator Norman D. Glaser
Senator Lawrence E. Jacobsen
Senator Clifford E. McCorkle
Senator Thomas R. C. Wilson

ASSEMBLY WAYS AND MEANS COMMITTEE MEMBERS PRESENT:

Assemblyman Roger Bremner, Chairman
Assemblyman Louis W. Bergevin
Assemblyman Bill D. Brady
Assemblyman Steven A. Coulter
Assemblyman Alan Glover
Assemblyman Karen W. Hayes
Assemblyman Thomas J. Hickey
Assemblyman Nicholas J. Horn
Assemblyman John W. Marvel
Assemblyman Dean Rhoads
Assemblyman Robert E. Robinson
Assemblyman John M. Vergiels
Assemblyman Peggy Westall

LEGISLATIVE COUNSEL BUREAU STAFF PRESENT:

John R. Crossley, Legislative Auditor
Ronald W. Sparks, Senate Fiscal Analyst
Willaim A. Bible, Assembly Fiscal Analyst
Judy Matteucci, Deputy Fiscal Analyst
Dan Miles, Deputy Fiscal Analyst
Ed Schorr, Deputy Fiscal Analyst
Jane Dunne, Secretary

The National Conference of State Legislatures presented a Workshop on Medicaid for this joint meeting. A copy of the agenda indicating the speakers and the topics of discussion is attached as Exhibit A.

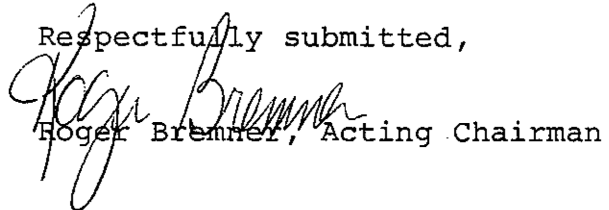
After the introduction by Mr. Hereford, a slide presentation was made by Mr. McDonough. A copy of the slides is attached as Exhibit B. Mr. Doug Storer introduced an article from the Wall Street Journal relating to Arizona's plan of health care, a copy of which is attached as Exhibit C.

Other exhibits include a letter regarding the Idaho Medicaid reimbursement system for hospital inpatient services (Exhibit D), a study on the Current and Future Development of Intermediate Care Facilities for the Mentally Retarded (Exhibit E), and a

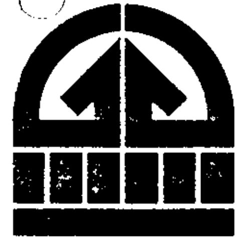
study by Mr. William C. Copeland and Mr. Iver A. Iversen entitled "An Optimization Approach to Reforming and Refinancing State Programs for the Mentally Retarded and Developmentally Disabled" (Exhibit F).

Tape recordings of the joint meeting are available for review in the Fiscal Analysis Division of the Legislative Counsel Bureau.

Respectfully submitted,



Roger Bremner, Acting Chairman



National Conference of State Legislatures

Workshop on Medicaid
National Conference of State Legislatures
&
Nevada Legislative Counsel Bureau

March 25, 1981

8:00	Welcome and Introduction Russ Hereford Program Manager, Human Resources National Conference of State Legislatures Denver, Colorado
8:15 - 9:00	An Overview of Medicaid Larry McDonough Regional Medicaid Director Health Care Financing Administration San Francisco, California *A brief history of Medicaid including a discussion of federal requirements in such areas as reimbursement, eligibility and services.*
9:00 - 10:00	Nevada and Medicaid Keith McDonald April Wilson Nevada Welfare Division *The Medicaid program as it operates in Nevada, including a brief history, services, costs and options for cost containment.*
10:00 - 11:00	A National Perspective Russ Hereford National Conference of State Legislatures *New initiatives of the Reagan Administration and an overview of action taken in other states.*
11:00 - 1:00	BREAK

Exhibit A

1:00 - 2:00	Hospital Reimbursement Pennie Bjornstad Chief, Bureau of Benefit Payments Idaho Department of Health and Welfare Boise, Idaho *An alternative to traditional Medicare hospital reimbursement principles.*
2:00 - 3:00	Long Term Care Tom Moore On-Lok Community Care Organization San Francisco, California *Nursing home reimbursement and feasible alternatives to institutional care.*
3:00 - 4:00	Care for the Mentally Retarded Bill Copeland DD/TA Project Humphrey Institute University of Minnesota Minneapolis, Minnesota *Funding care for the developmentally disabled along a continuum of care.*
4:00 - 4:30	Closing Session

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EXHIBIT B

HEALTH CARE FINANCING ADMINISTRATION
REGION IX
100 VAN NESS AVE 14TH FLOOR
SAN FRANCISCO, CALIFORNIA 94102

PHILIP NATHANSON
REGIONAL ADMINISTRATOR
GERALD MOSKOWITZ
DEPUTY REGIONAL ADMINISTRATOR
(415) 556-0254

BOYD SWARTZ
REGIONAL DIRECTOR
O.P.I.

HARRY BARBA
REGIONAL DIRECTOR
H.S.Q.B.

JOHN O'HARA
REGIONAL DIRECTOR
MEDICARE

LAWRENCE L. MCDONOUGH
REGIONAL DIRECTOR
MEDICAID

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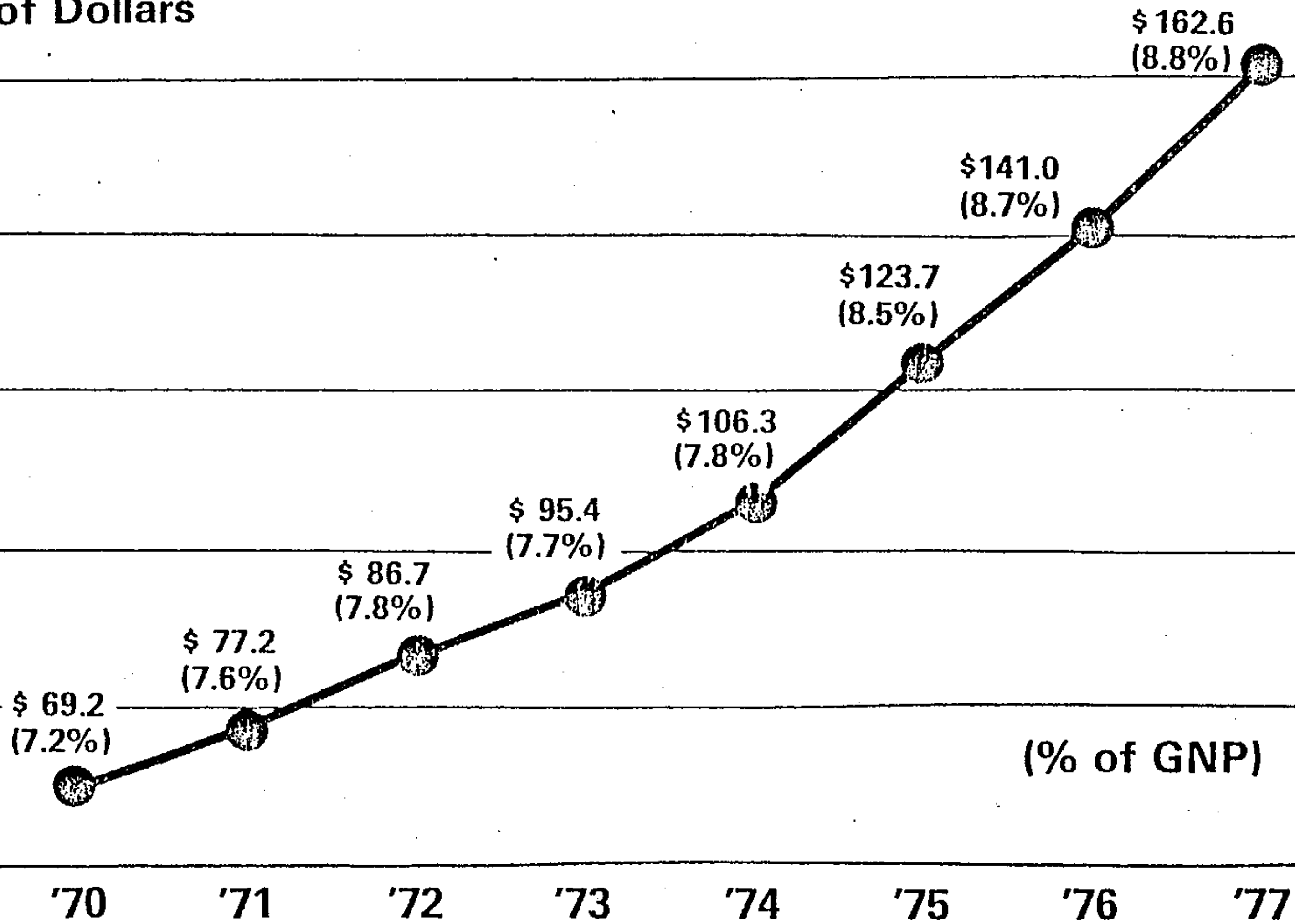
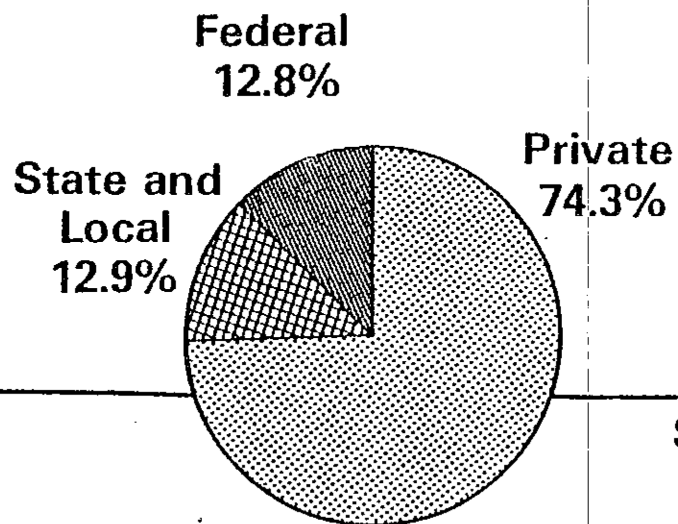
Medicaid's Goal:

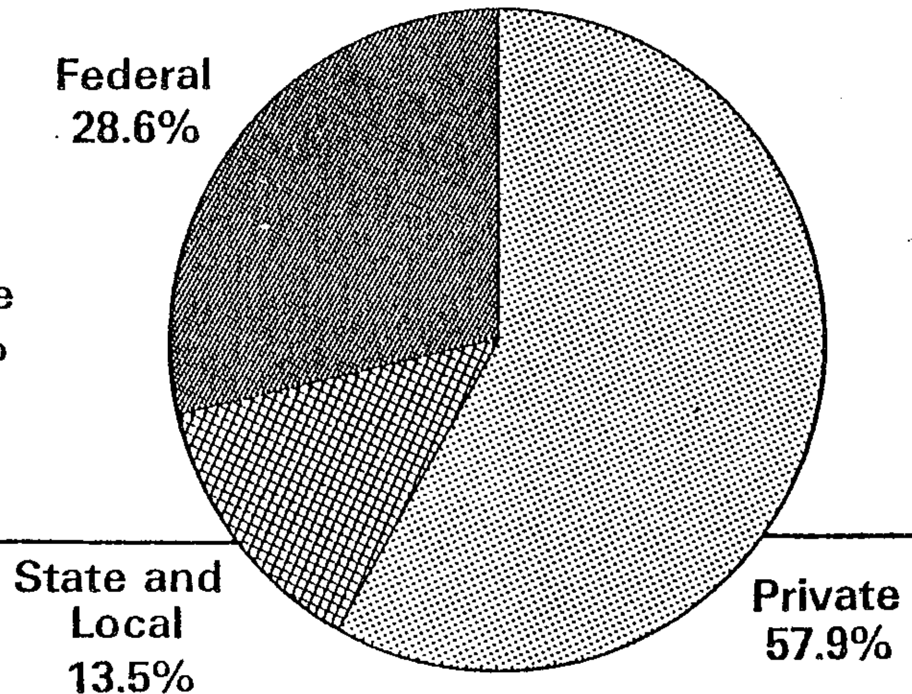
A health care delivery and financing system providing quality health care to low-income people in a cost-effective manner.

Total National Health Expenditures

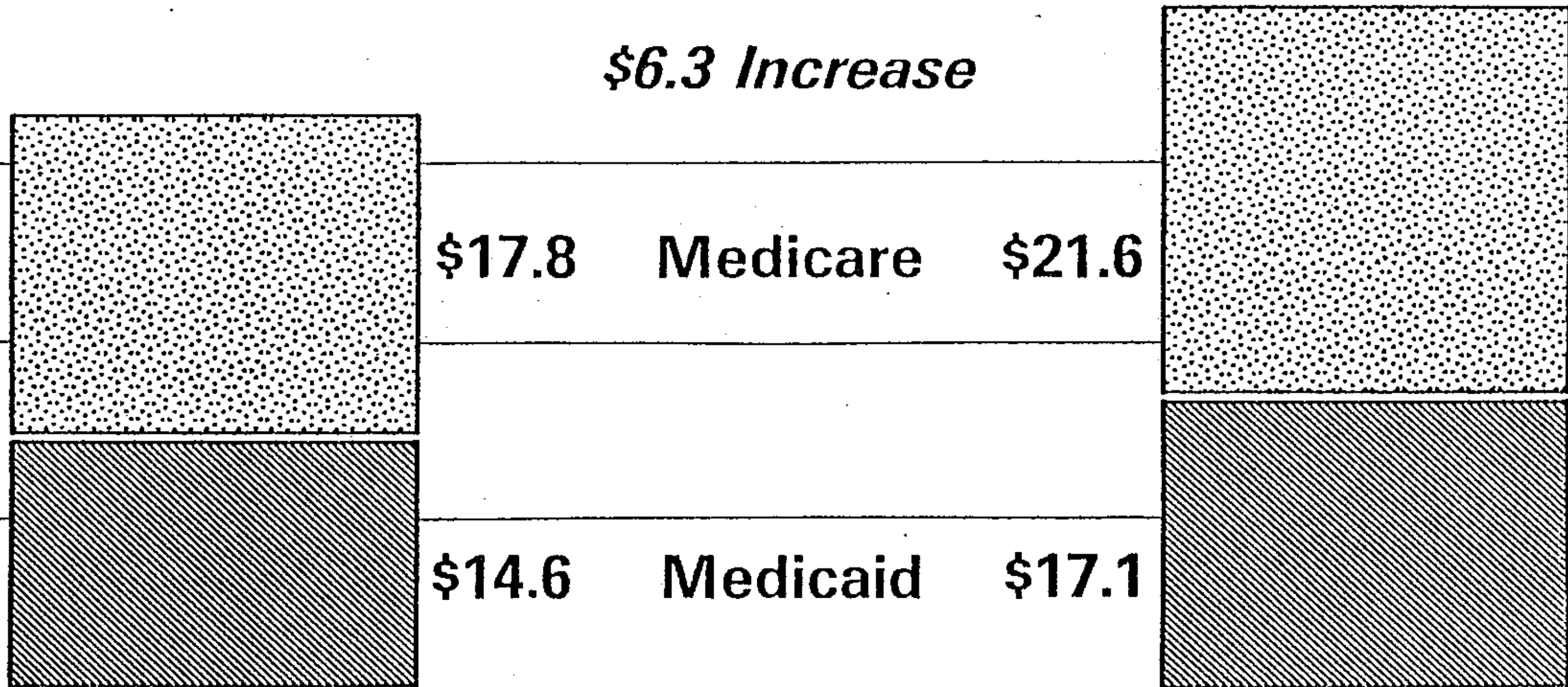


Distribution of National Health Expenditures, by Source of Funds





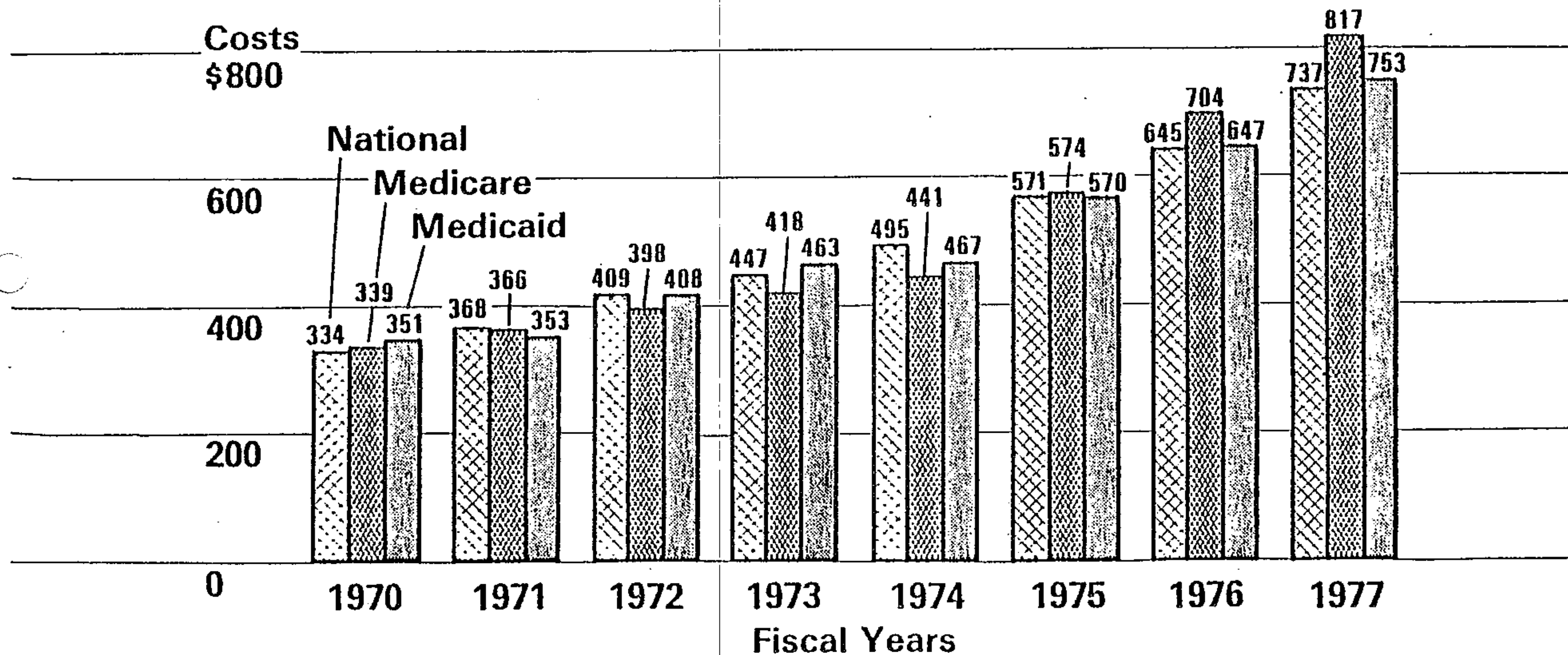
Medicaid and Medicare Program Costs* ($ in Billions)



*Includes Administrative Expenditures

Comparison of Health Care Expenditures; FY 1970-77

National Per Capita, Medicare Per Enrollee, Medicaid Per Beneficiary



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Medicaid:

Federal Direction and Support

- Legislation
- Regulations
- Guidelines
- Financial Matching
- Assessments/Evaluations
- Technical Assistance

Medicaid:

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State Administration and Operation

Within Federal Limits, States Decide:

- Eligibility
- Benefits Paid For
- Administrative Practices
- Reimbursement
- Operational Resource Requirements

Medicaid:

Eligibility

Who Is Eligible for Federally Assisted Medicaid?

1. Cash Recipients

All AFDC Families

Most SSI Beneficiaries

- Aged
- Blind
- Disabled

2. Medically Needy (Don't Get Cash)

AFDC-Type Families

SSI-Type Adults

The Medicaid Population

FY 1977

AFDC - 16.1 Million
23.1% Adults
47.7% Children

Aged - 3.7 Million
16.3%

Disabled - 2.8 Million
12.5%

Blind - 98,000
0.4%

Total 22.7 Million

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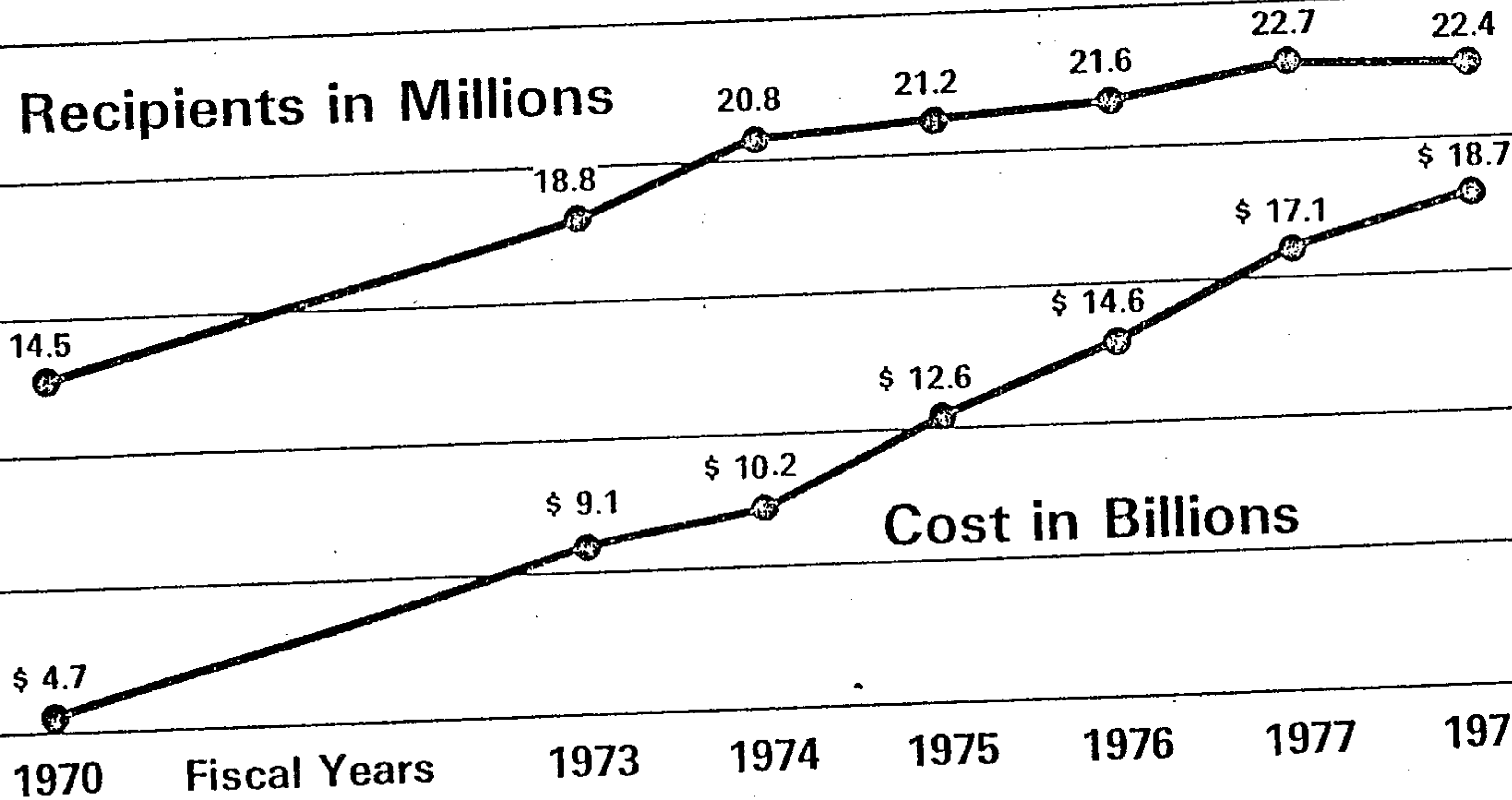
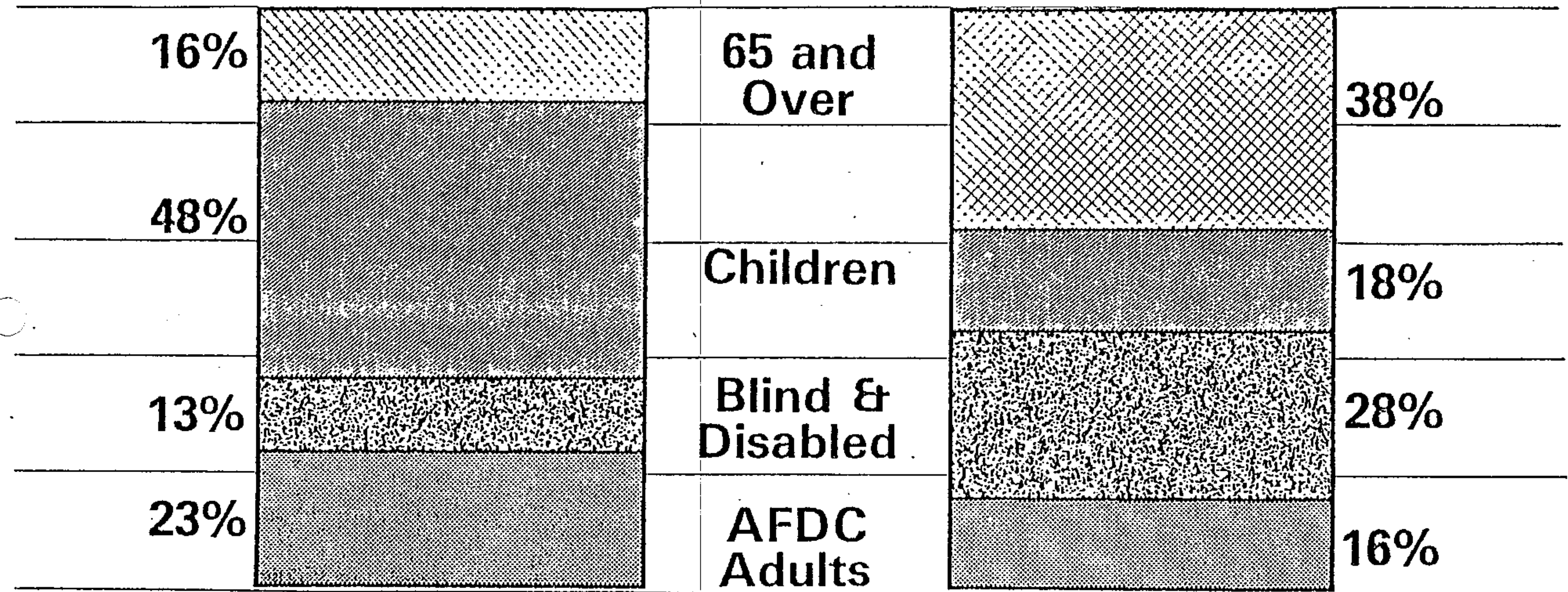
Comparison/Growth:
Medicaid Program Costs and Number of Recipients



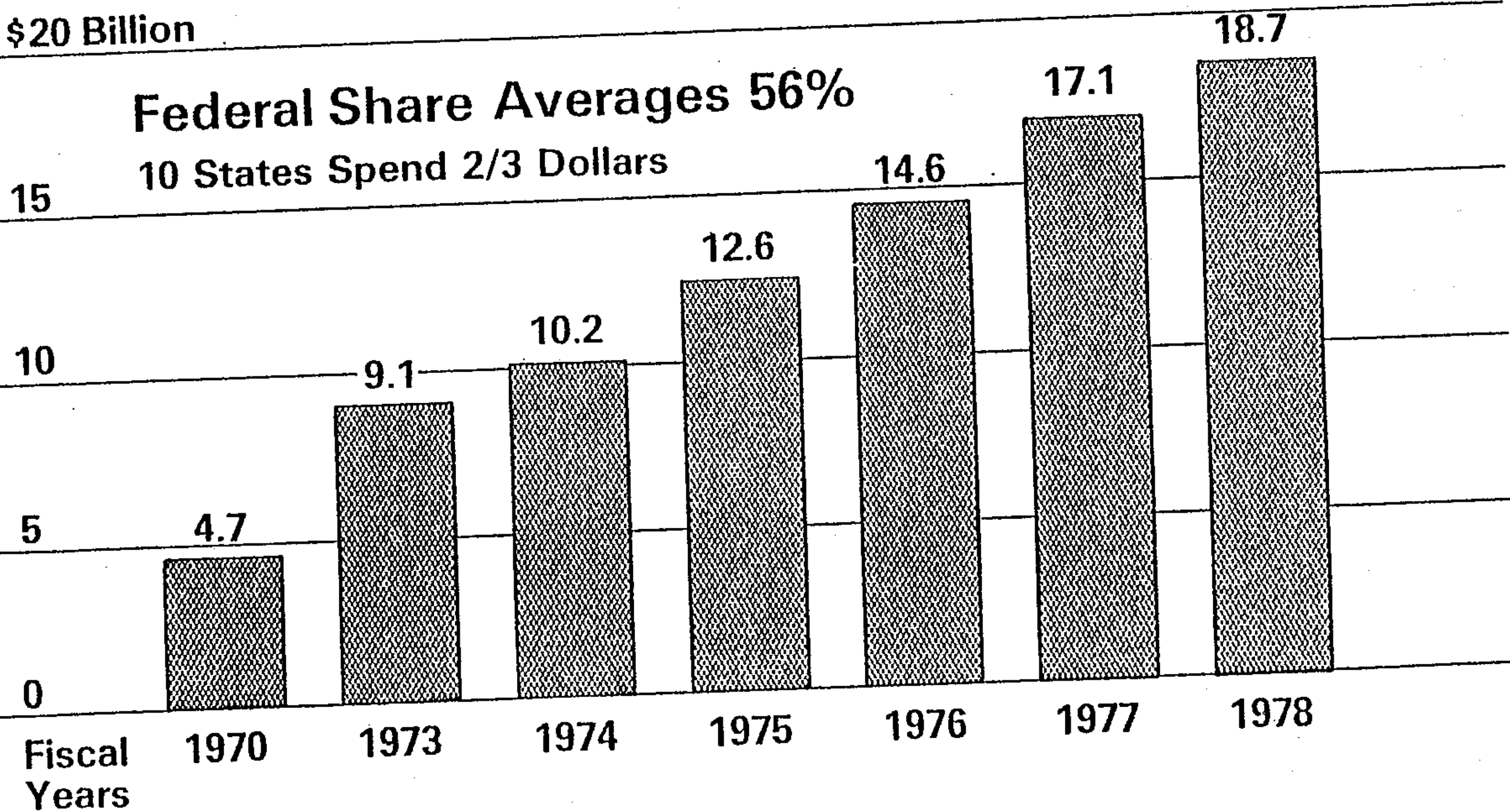
Medicaid Patients and Dollars

FY 1977



Expenditures

Federal, State, Local



Medicaid Services

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Required:

Inpatient - Outpatient Hospital

Physician

Laboratory and X-ray

Skilled Nursing Facility (Over 21's)

Home Health

Family Planning

EPSDT (Under 21's)

Rural Health Clinics

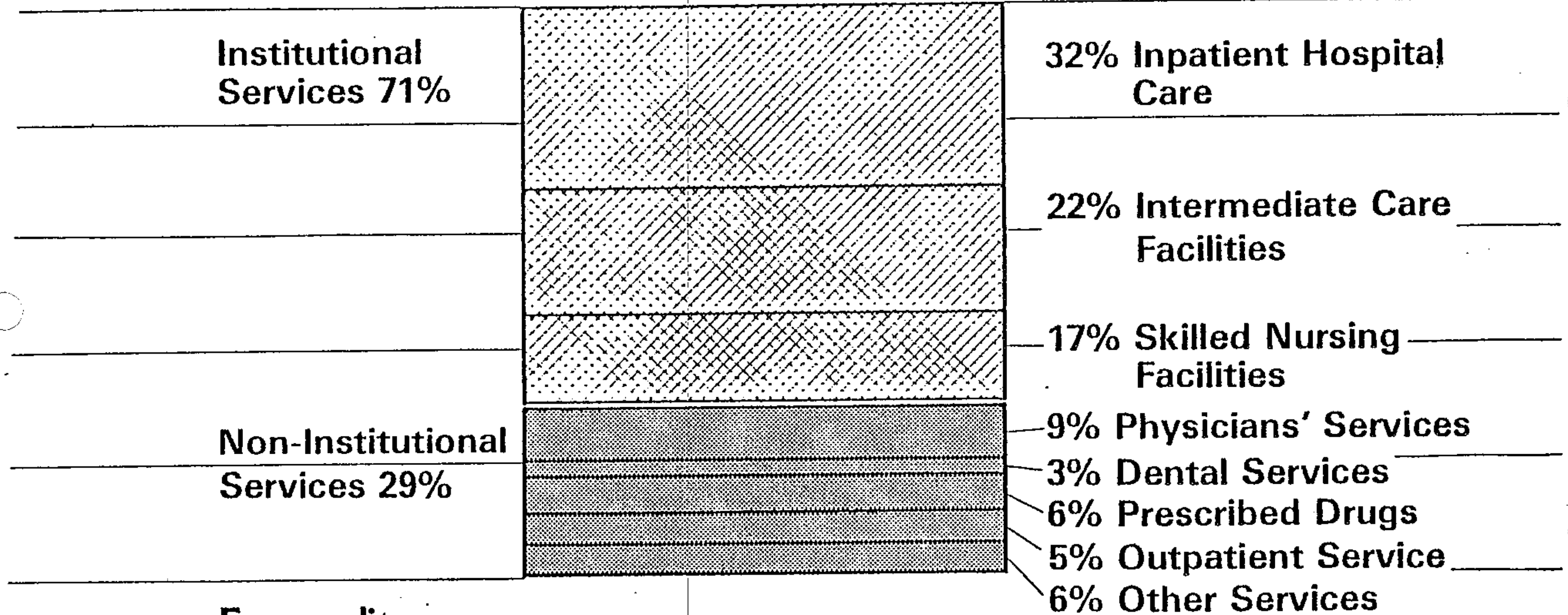
Medicaid Services

Optional:

- Rx Drugs
- Dental
- Physical Therapy
- Chiropractors
- Eyeglasses
- Optometrists
- Prosthetic Devices
- Podiatrists
- Emergency Hospitals
- SNF's for Under 21's
- Mental Hospitals for Over 65's
- Mental Hospitals for Under 21's
- TB Hospitals for Over 65's
- Private Duty Nursing
- Intermediate Care Facilities
- Other Miscellaneous

Medicaid Services and Funds

(FY 1977)



Expenditures—
by Services

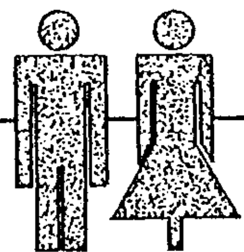
Summary of Medicaid Services and Coverage

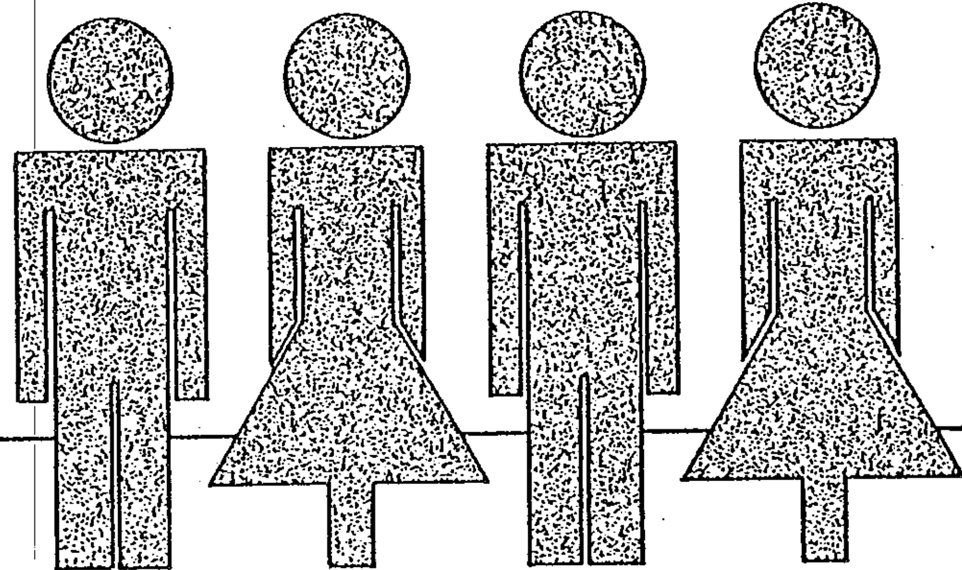
December 1977

Types of Services	Number of States Providing Services Only to Categorically Needy Eligibles	Number of States Also Providing Service to Medically Needy Eligibles	Total Number of States Providing Service Under Title XIX
Basic Required Medicaid Services	20	33	53
Optional Services:			
Clinic	13	29	42
Prescribed Drugs	19	32	51
Dental	12	22	34
Eyeglasses	10	25	35
Emergency Hospital	17	26	43
Institutional Services in Intermediate Care Facilities	26	24	50

Number of Staff Administering Medicaid

FY 1978





FEDERAL 708
(Central and Regional Offices)

STATE 22,000*

*Estimate

Impact of Medicaid

Indicators	(Pre-Medicaid) 1964	1976
No. Physician Visits per Person:		
By Poor	4.3	5.6
By Non-Poor	4.6	4.8
% Population with No Physician Visits in Prior 2 Years:		
Poor	27.7	15.1
Non-Poor	17.7	12.9

- 1976 Bureau of Census Estimate: 25 Million in Poverty
- Approximately 70% of Medicaid Population, or 15.1 Million, in Poverty
- 9.9 Million, or 40% Poverty Population, did not receive Medicaid

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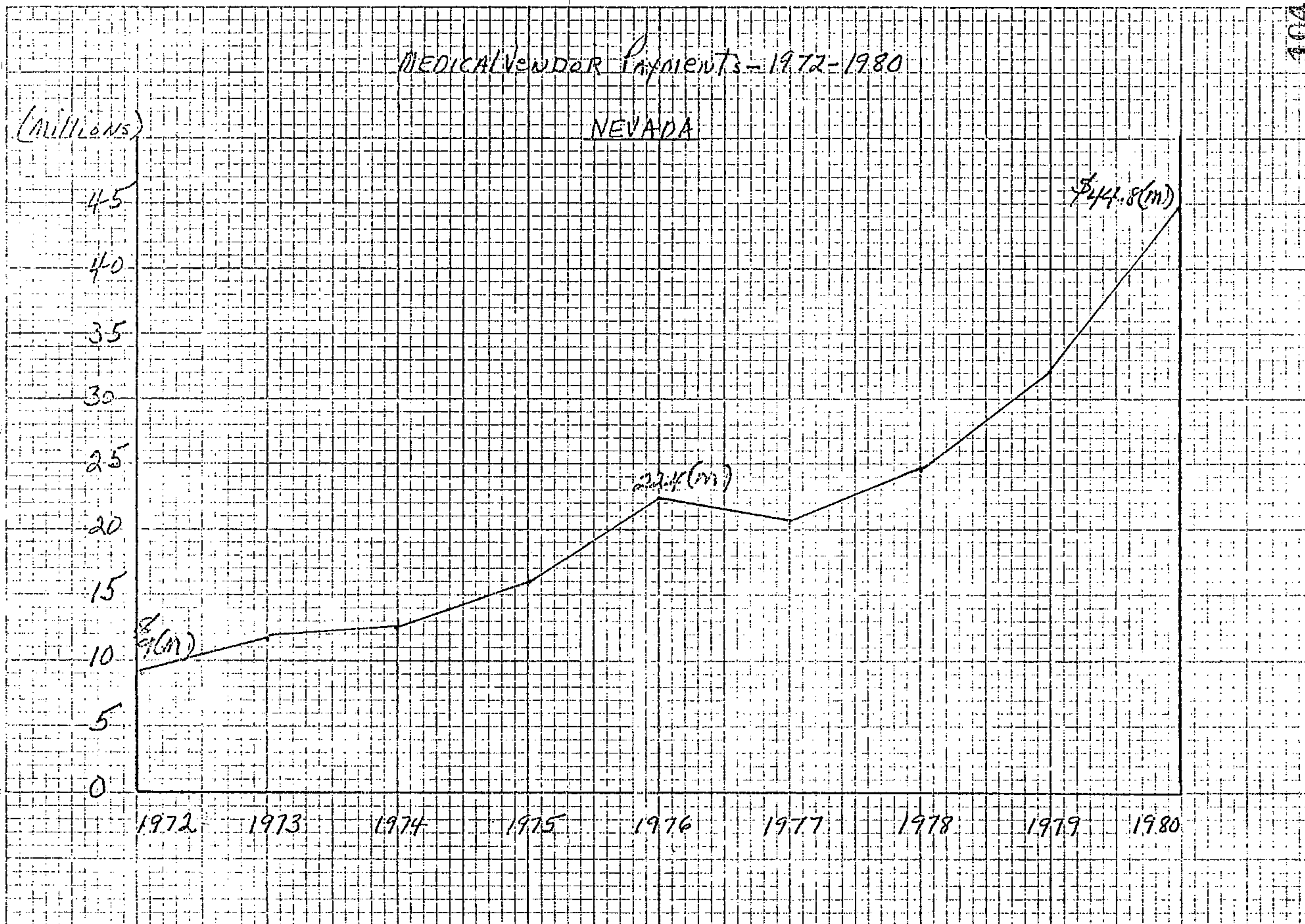

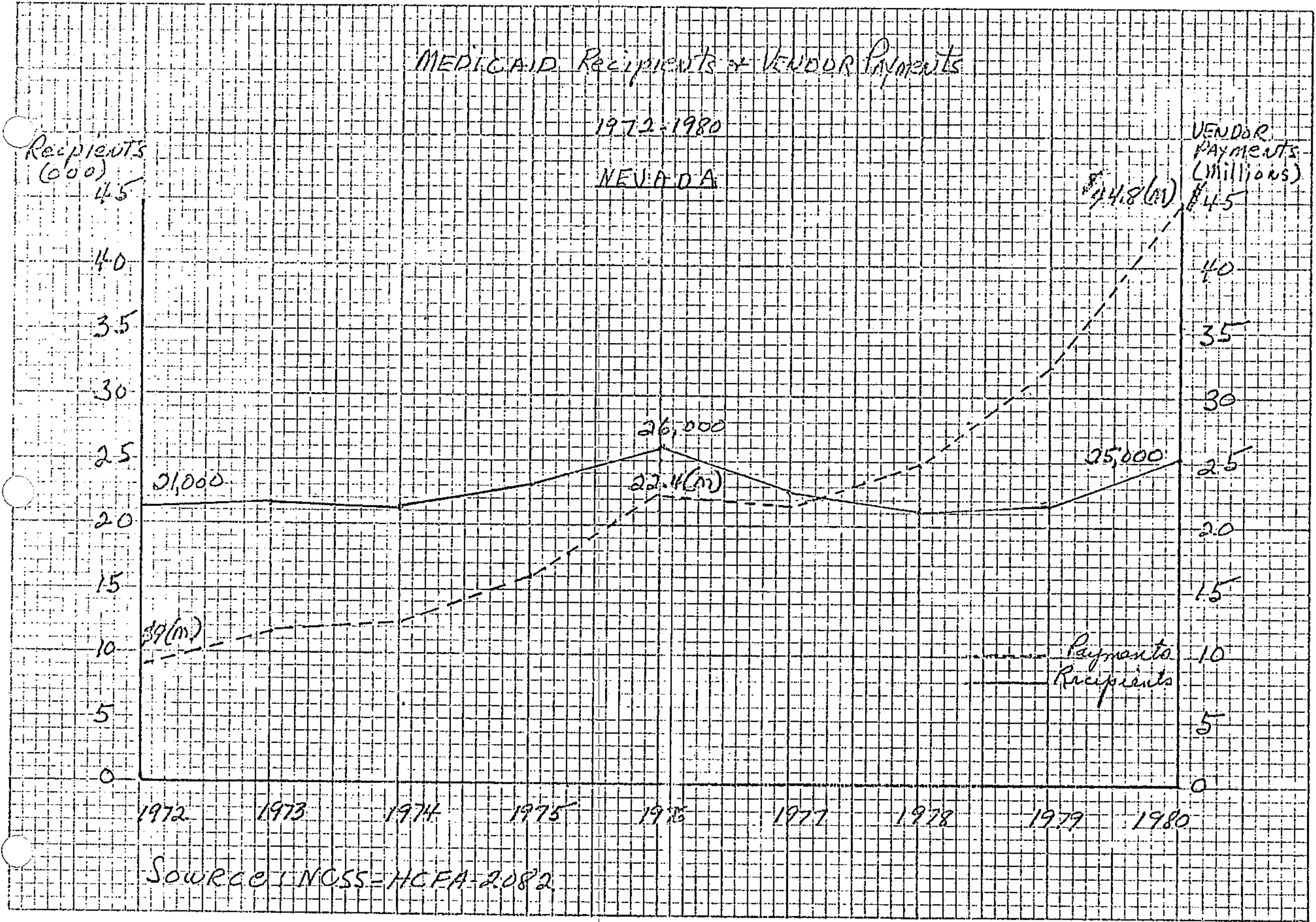

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THE MEDICAID POPULATION
NEVADA FISCAL YEAR 1980

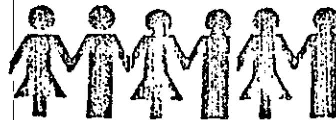
1C44

AFDC 14,949

22% ADULTS
37% CHILDREN

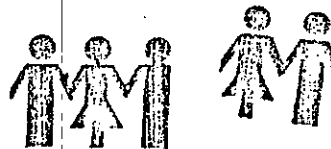
AGED 6,004

24%



DISABLED 4,067

16%

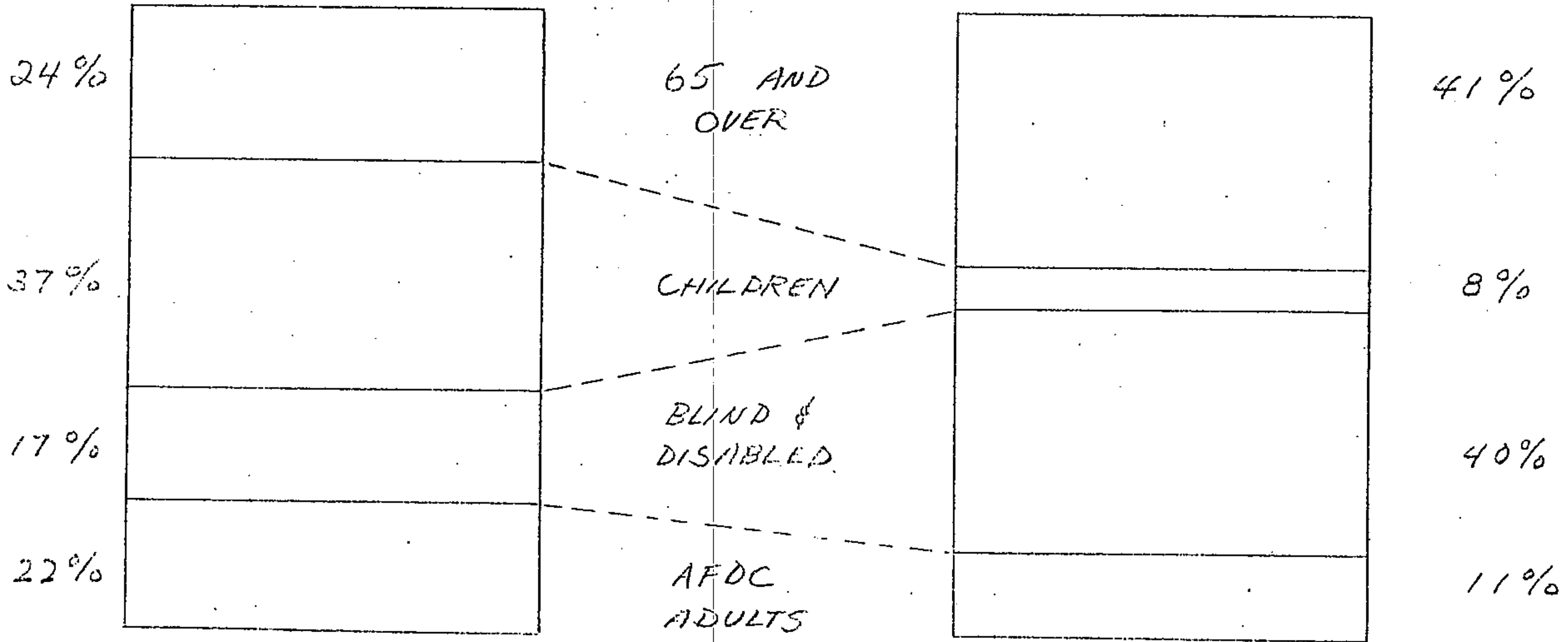


BLIND 371

2%

TOTAL 26,639

MEDICAID PATIENTS AND DOLLARS
NEVADA - FISCAL YEAR 1980



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AQUABEL

MADE IN USA

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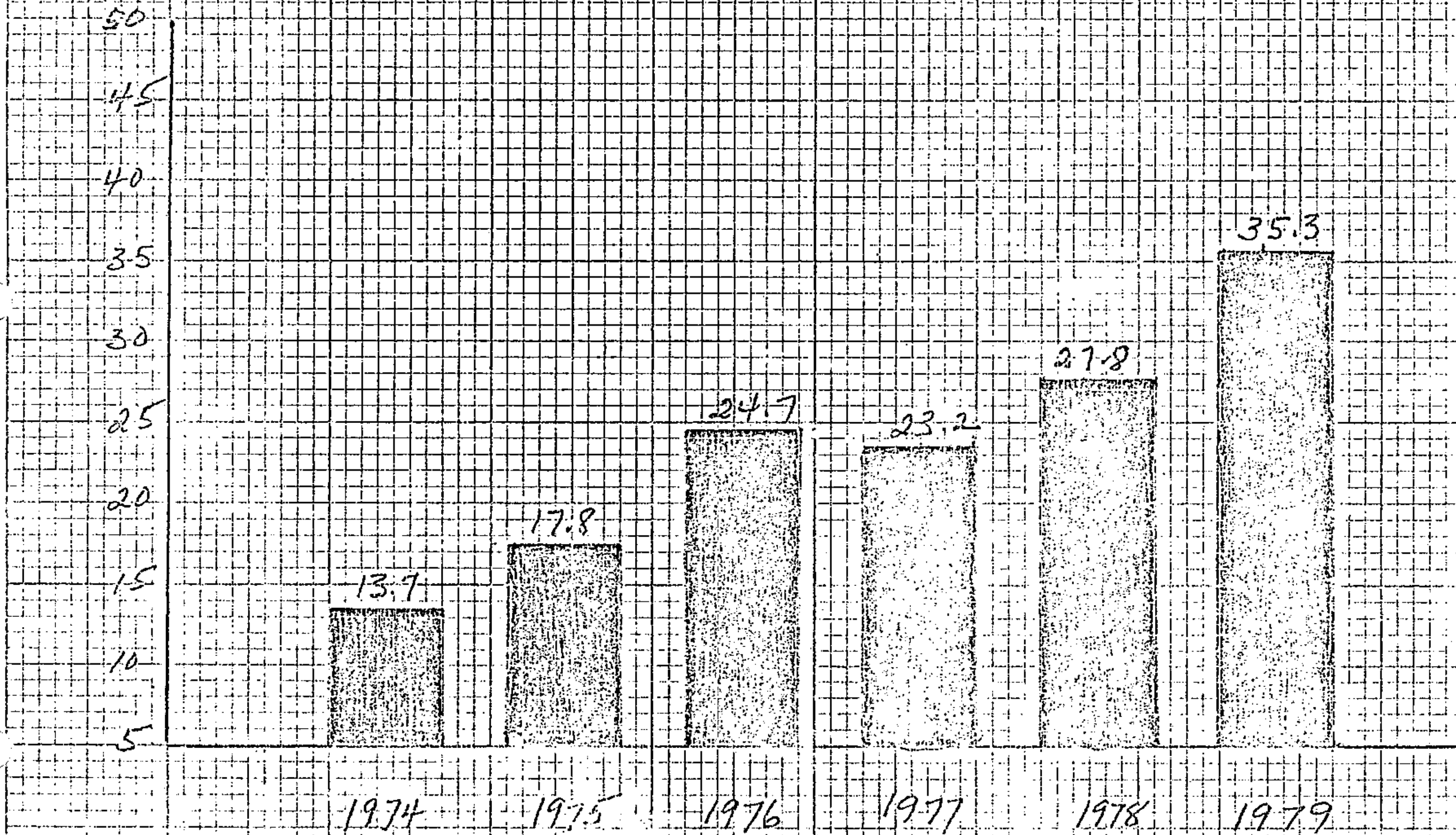
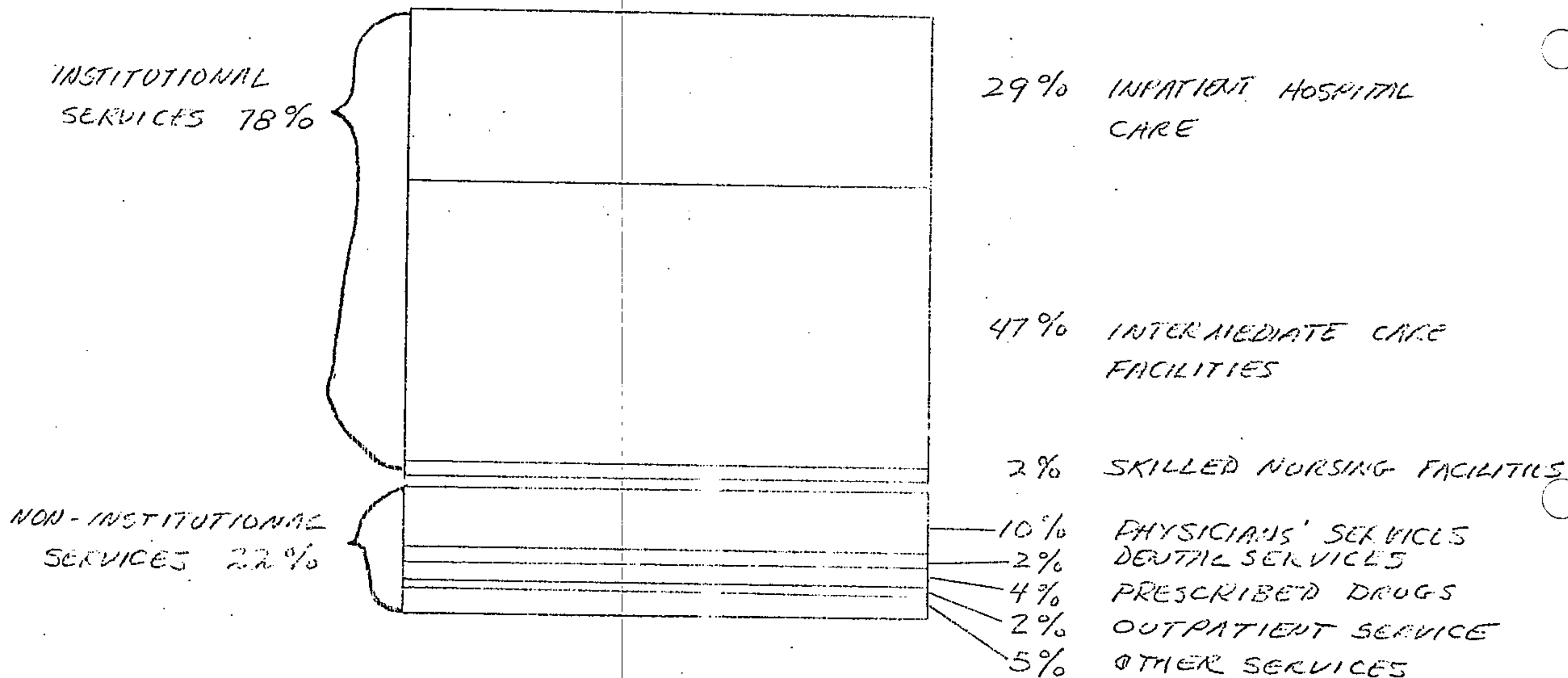


MEDICAID SERVICES AND FUNDS
NEVADA FISCAL YEAR 1980



Fringe benefits of executives may be taxed, back page.

Arizona's Plan Of Health Care In Critical State

By WILLIAM E. BLUNDELL
Staff Reporter of THE WALL STREET JOURNAL

Medicaid, the joint federal-state health care program for the poor, is a mess.

Huge increases in medical-care costs have pushed total Medicaid outlays to well over $20 billion, with no relief in sight. State budgets, which absorb almost half the expense, are starting to crack under the strain. And the public passion for taking a machete to state taxes, as well as spending, is starving some states for needed revenue when they need them most.

This ought to breed a certain smugness in Arizona, the only state that elected not to get stuck to the Medicaid tar baby. But there is no smugness now; Arizona's homegrown, county-financed indigent health care program is a mess, too. Costs are spiraling, and county budgets are cracking under the strain. Meanwhile, stringent limits on county and city spending, passed last June, mean less potential money for county health plans. The crisis has created a political uproar, and some legislators are crying out for . . . Medicaid.

Hitting Budget Ceilings

Santa Cruz County has already spent all the money it had budgeted for indigent medical care this fiscal year and recently had to stop its program. Most other counties are expected to bang their heads on budget ceilings within weeks. Total Arizona spending on medical care for the poor this year is expected to reach $141 million, almost double the amount spent four years ago. The counties, says Gov. Bruce Babbitt, are "moving inexorably toward bankruptcy."

The Arizona experience shows that going it alone is, by itself, no panacea for the problems of delivering both adequate and economical health care to the poor. But it also illustrates, in small scale, the enormous difficulty of doing that under any system.

Most of Arizona's county plans don't match Medicaid's liberal benefits—preventive health measures, eyeglasses, hearing aids, psychiatric care. But these goodies aren't what's breaking the counties' health budgets; rather it's the basic business of caring for the physically ill, coupled with new and costly methods of diagnosis and treatment.

Says a county health official: "A man comes in with frequent headaches and blurred vision. Nothing works. Do you send him for a brain scan? You bet you do; ethically you're practically obliged to. But that equipment didn't even exist years ago."

Billed for $105,000

The costs of treating catastrophic illness have become catastrophes themselves for the counties that pay for them. In little Santa Cruz County, population 18,000, which has already spent its indigent-care budget of $950,000 this year, a single case of stroke with coma has run up $105,000 in bills. The cost of special care for a "newborn transport" baby, one born very prematurely and often suffering severe functional problems, can exceed $100,000.

Counties also have little or no control over hospital rates or costs for long-term

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expertise to financial futures, too. Es... Inc., for e...ple, whose Swift & Co... liary hedges in corn and soybeans to ...f its turkey costs, has started to hedge ...ncial futures to offset potential losses ...g-term lending agreements, commer...aper and the like, says Chance Ba..., Esmark's assistant treasurer.

...all financial futures the market in ...ury bonds has become the largest in ...er of contracts, although the total face ... of outstanding contracts in Treasury ...s larger. (Treasury bill contracts trade ...its of $1 million, Treasury bond con...in units of $100,000.) On a recent trad...ay, with more than 225,000 contracts ...nding on $22.5 billion of bonds, that ...ek exceeded outstanding corn con... by 9% and soybean contracts by more ...100%. Corn and soybeans make two of ...ggest nonfinancial futures markets.

...for Business

...'s significant, and I'd suggest that per...we've only seen the beginning of the ...h," Marvin Duncan, economist for the ...al Reserve Bank of Kansas City, says ...ncial futures.

...e growth has created new business for ...rage firms. "The pie is getting big...a spokesman for the Futures Industry ...iation, a trade group, says. "Only real ...firms and those out in the hinterlands ...in financial futures these days."

...he competition in the business is tre...ous," says Mark Lahey, Chicago, who ...a 17-month-old financial futures bro...e firm that bears his name. "When ...ll Lynch whips up the troops, all of a ...r you've got 1,200 brokers selling fi...l-instrument futures."

...changes as well as brokerage houses ...ngaged in some self-interested promo...f financial futures. Increased commis...and big gains in the sale or lease value ...change memberships provide incen...In the past year, the value of a mem...p on the International Monetary Mar...s nearly doubled to $215,000.

...Finance Tilt

..., Walowitz and some other younger ...s lease their seats, a practice made ...le by recent changes in exchange ..."The younger generation is all going ...nancial futures," a clerk in currency ...cts says. "It's faster. There's more to ...," It also has a hint of high finance ...g in, say, pork bellies. "You don't ...a three-piece suit if you're just watch...e hog market," the clerk says.

...t uncommonly, sons of commodities ...s become traders themselves. Some ...ave gone into financial futures. Martin ...er, 62, of Chicago, a well-known trader ...rofesses to be the "oldest guy in the ...l," has a son, Leon, who trades in cur...s. Mr. Shender pere, after a discour... venture in Treasury bills, is sticking ...ommodities that have four legs. Of the ...ial futures pits, he says, "The pace is ...nd the bedlam is tremendous. Maybe ...s a lot younger. . . ."

...easing Field ...e Cautious

...w the lessors are much more conser...," says Michael R. Nadurak, a com... manager for Avco Corp., Greenwich, ... "Instead of assuming a 20% residual after seven years, they might assume

EXHIBIT C

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Counties also have little or no control over hospital rates or costs for long-term care for the aging, a particularly acute problem in a Sun Belt retirement haven—and one that can only get worse here and in other Sun Belt states as an increasingly large slice of the population is made up of retirees migrating to warmer climates. Cost problems have been further compounded by loose administration of county plans. Their backs to the wall, counties are trying to tighten up.

Cochise County, for example, now picks doctors who give primary care to the poor through competitive bidding and has opened a pharmacy as well. It has cut referrals in half by stipulating that specialists in the county who are also under contract with the health department be used first; after that another specialist group in Tucson, again under contract, can be used. This has almost ended what county health administrator Ron Maxwell calls "the old-buddy hand-off." He explains: "A doctor would say, 'Gee, old Jack in gastroenterology in Phoenix might be able to get a little out of this,' and he'd send a patient there."

Expansive Ruling

But suits over eligibility for indigent care by legal aid groups threaten to more than offset the counties' cost-control measures. In

Please Turn to Page 41, Column 5

THE WEEK AHEAD

Here's a list of major events and economic reports scheduled for the coming week (some dates are tentative):

TODAY

Supreme Court meets to hand down orders.

Common Market summit meeting convenes in Maastricht, the Netherlands.

TUESDAY

Consumer prices report for February.

WEDNESDAY

Burroughs holds annual meeting.

THURSDAY

Alcan Aluminium, General Tire annual meetings.

FRIDAY

Foreign trade report for February.

SATURDAY

Iowa Beef Processors annual meeting.

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...asing Field ...e Cautious

...w the lessors are much more conser... " says Michael R. Nadurak, a com... manager for Avco Corp., Greenwich. "Instead of assuming a 20% residual after seven years, they might assume ...dual value or little more than scrap which might be 1% or less of the re... cost."

...I. not long ago arranged a 36-month ... three IBM computers for Travel... ...ich estimates the leases save $40,000 ... on each computer. Mr. Cherney of ... says the lease guarantees the recov... at least 85% of the computers' cost ... it allows no early escape. "It's what the industry call a hell-or-high-water" he says. "Even if they never use the ...es, they'll have to pay the rental ... to the banks."

...ors more often are dealing as bro... middlemen, to avoid risking much ... own capital. They're laying off more ...isk on outside lenders and investors, ... high-income seekers of tax shelter. ...s ordinarily get deductions for de... ...ion and interest charges and some... ...et an investment tax credit, too, to ... big tax savings in the early years of ...

...I. eventually may have at risk less ... 15% residual value of the machines ... Travelers. The company is trying ... capital from outside investors who ...urchase an interest in the machines. ... Mr. Cherney says, he thinks the ... transaction is "one of our worst" deals because most others, he says, residual values of 10% or lower.

...ain Prospects

...g their business on a sounder foot... most leasing-company executives confidence in their long-term growth ...tability. But for the short run, at ... prospect is uncertain.

...ers and computer users are skittish. ... traditional lenders are temporarily ... market," says Kenneth Pontikes, ... of Comdisco Inc., Rosemont, Ill., dealer and lessor. "Their loan com... are reviewing their procedures."

... test will come when we bring an... ...al to our finance committee," says ...e, a senior vice president of Bank... Co., Des Moines, a lender with po... ...sses in O.P.M. leases.

...mers may become "overly cau... ... leasing executive fears. They may ... do business only with the biggest, ...wn lessors with public balance ...ut a computer manager at a big oil ... takes a philosophical view. He ...hing has really changed much. "It's ... other business," he says. "There ... good people to deal with and some ...ople to deal with."

UGI Plans to Purchase California Supply Stores

By a WALL STREET JOURNAL *Staff Reporter*

VALLEY FORGE, Pa.—UGI Corp. said it tentatively agreed to buy a California chain of retail industrial gas and welding supply stores for $20 million, and to assume some of the chain's liabilities.

Under the agreement in principle, UGI's AmeriGas unit would buy "substantially all" the operating and real estate assets of Victor California, a division of Pacific Lumber Co. of San Francisco.

The agreement is subject to a final agreement, and approval by government agencies and the boards of UGI and Pacific.

UGI is a diversified energy company; Pacific Lumber produces California redwood lumber.

Federal Reserve Data

KEY ASSETS AND LIABILITIES OF 10 WEEKLY REPORTING MEMBER BANKS IN NEW YORK CITY (in millions of dollars).

ASSETS:	Level Mar. 11, 1981	Change from Mar. 4, 1981
Total assets	[illegible]	+ 1,292
Total loans and investments	127,577	− 2,224
Including:		
Commercial and industrial loans	48,428	− 187
Domestic	45,961	− 144
Foreign	2,466	− 43
Acceptances, comm'l paper	789	+ 57
Finance company loans	4,088	+ 92
Personal loans	9,453	+ 47
Loan loss reserve	1,903	+ 11
U.S. Treasury securities	8,245	− 171
Federal agency securities	2,345	− 8
Municipal issues	10,646	− 25
Due in one year or less	1,409	+ 9
Longer term	9,237	− 34
LIABILITIES:		
Demand deposits	124,219	+ 799
Demand deposits adjusted (a)	24,353	+ 1,464
Time and savings deposits	56,228	+ 254
Negotiable CDs ($100,000 and up)	26,952	+ 237
Borrowings	44,062	+ 1,046

a-Excludes government and bank deposits, and cash items being collected.

MEMBER BANK RESERVE CHANGES

Changes in weekly averages of member bank reserves and related items during the week and year ended March 18, 1981 were as follows (in millions of dollars)-b

	March 18 1981	Chg from wk and March 11 1981	March 19 1980
Reserve bank credit:			
U.S. Gov't securities:			
Bought outright	118,711	+1,961	+ 3,488
Held under repurch agreem't	....	....	....
Federal agency issues:			
Bought outright	8,733	− 3	+ 522
Held under repurch agreem't	....	....	....
Acceptances—bought outright			
Held under repurch agreem't	....	....	....
Borrowings from Fed	774	+ 6	− 2,228
Seasonal borrowings	193	+ 8	+ 37
Float	3,343	+ 148	− 2,456
Other Federal Reserve Assets	10,077	+ 158	+ 5,378
Total Reserve Bank credit	141,436	+2,254	+ 4,273
Gold stock	11,156	....	− 16
SDR certificates	2,647	+ 129	− 321
Treasury currency outstanding	13,489	+ 5	+ 362
Total	168,729	+2,387	+ 4,299
Currency in circulation	132,772	+ 384	+ 9,989
Treasury cash holdings	465	+ 10	− 67
Treasury dpts with F.R. Bnks	3,131	+ 109	+ 617
Foreign deposits with F.R. Bnks	391	+ 115	+ 46
Other deposits with F.R. Bnks	352	+ 41	− 183
Other F.R. liabilities & capital	4,774	+ 78	− 56
Total	141,885	+ 750	+10,335
Reserves			
With F.R. Banks	26,844	+1,428	− 4,035
Total inc. cash	39,715	+ 628	− 1,738
Required reserves	39,491	+ 623	− 1,774
Excess reserves	224	+ 5	+ 44
Free reserves	−357	+ 7	....

b-The figures reflect adjustment for new Federal Reserve rules that impose reserve requirements on most deposit-taking institutions, including non-member commercial banks, mutual savings banks and savings and loan associations.

MONETARY AND RESERVE AGGREGATES (daily average in billions)

	One week ended: Mar. 11	Mar. 4
Money supply (M1-A) sa	365.7	365.7
Money supply (M1-B) sa	421.8	419.7
	Mar. 18	Mar. 11
Monetary base	161.31	160.41
Total Reserves	39.87	39.42
Nonborrowed Reserves	39.10	38.85
Required Reserves	39.65	39.40
	Four weeks ended: Mar. 11	Feb. 11

Arizona's Own Health-Care Plan Finds Itself in Critical Condition

Continued From Page 25

one case involving Cochise, the state appeals court issued a ruling so expansive that Mr. Maxwell says it amounts to saying, "If you lost your job yesterday, you're eligible."

So Mr. Maxwell, along with every other county official, is looking to the state capitol for a reworking of fuzzy, confusing laws and regulations on eligibility, and most of all for money. Some lawmakers from Pima County, which includes Tucson, are pressing for Medicaid. But Burton Barr, house majority leader for 16 years and one of the most powerful figures in the state, says cheerfully, "Arizona's not going to get Medicaid." And what Mr. Barr says usually goes.

In 1974, he backed legislation to set up Medicaid, and it passed. But alarmed by tales of waste, fraud and elephantine bureaucracy, he changed his mind and led the fight to kill funding for it. "I began to see that all we'd have would be a vast empire that would produce more paper than health care. Well, the hell with that," says Mr. Barr.

It's generally agreed that cows will fly before a standard Medicaid measure ever gets through the GOP-dominated Arizona house. Instead Mr. Barr and others want a $5 million emergency bailout for the rural counties, which are hardest hit, plus a new, prepaid health-care system relying on private insurers and other entities that would provide health care at fixed per capita rates—an idea also contained in a proposed health-care package of Gov. Babbitt's.

It is one of the few ideas Mr. Barr and the governor, a Democrat, share. The majority leader calls the governor "Brucie" and pokes fun at what he sees as a gubernatorial swerve to the right after the last elections. "He's Reagan's son. It's remarkable," quips Mr. Barr. The governor, in turn, accuses the Republican leadership of ideological tub-thumping over health care. "You would have thought the ghost of John C. Calhoun was stalking the halls," he says.

GOP leaders last week went to Washington to lobby for federal money for a new insurance plan. Gov. Babbitt, meanwhile, vows a special legislative session to solve the crisis. But tax-cut fever may make it hard for the state to pay its share of any plan. The Arizona Republic, Phoenix's morning newspaper, found that more than $76 million of tax-cut proposals were floating around the legislature, enough to devour Arizona's expected surplus three times over.

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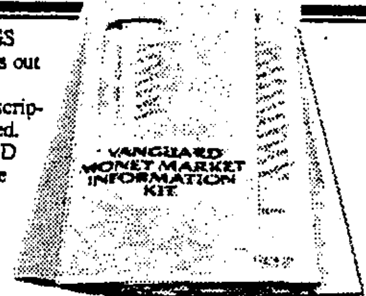

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ADDRESS

1050

February 5, 1981

Mr. Scott Call, Administrator
Fremont General Hospital
125 N. 8th West
St. Anthony, Idaho 83445

Dear Mr. Call:

Under the Idaho Medicaid reimbursement system for hospital inpatient services, a cost index will be applied to each hospital's operating costs for the prior year in determining the maximum reimbursement for the operating costs of a current cost reporting year. This letter is to inform you that the cost index for your facility for your fiscal year beginning January 1, 1981, has been computed to be 111.6. This index is made up of components as follows:

	Salaries	Dietary	Malpractice Insurance	Other Variable
Index Components	.1011	.1340	.1008	.1305
% of the Total	x .486	x .022	x .019	x .472
	.0491346	.002948	.0019152	.061596

The sum of the above products equals .1155938 for a resultant index of 111.6.

If you have any questions regarding this, please contact my office.

Sincerely,

Mark A. Christensen, C.P.A.
Medicaid Reimbursement Policy Specialist
Medical Assistance Section

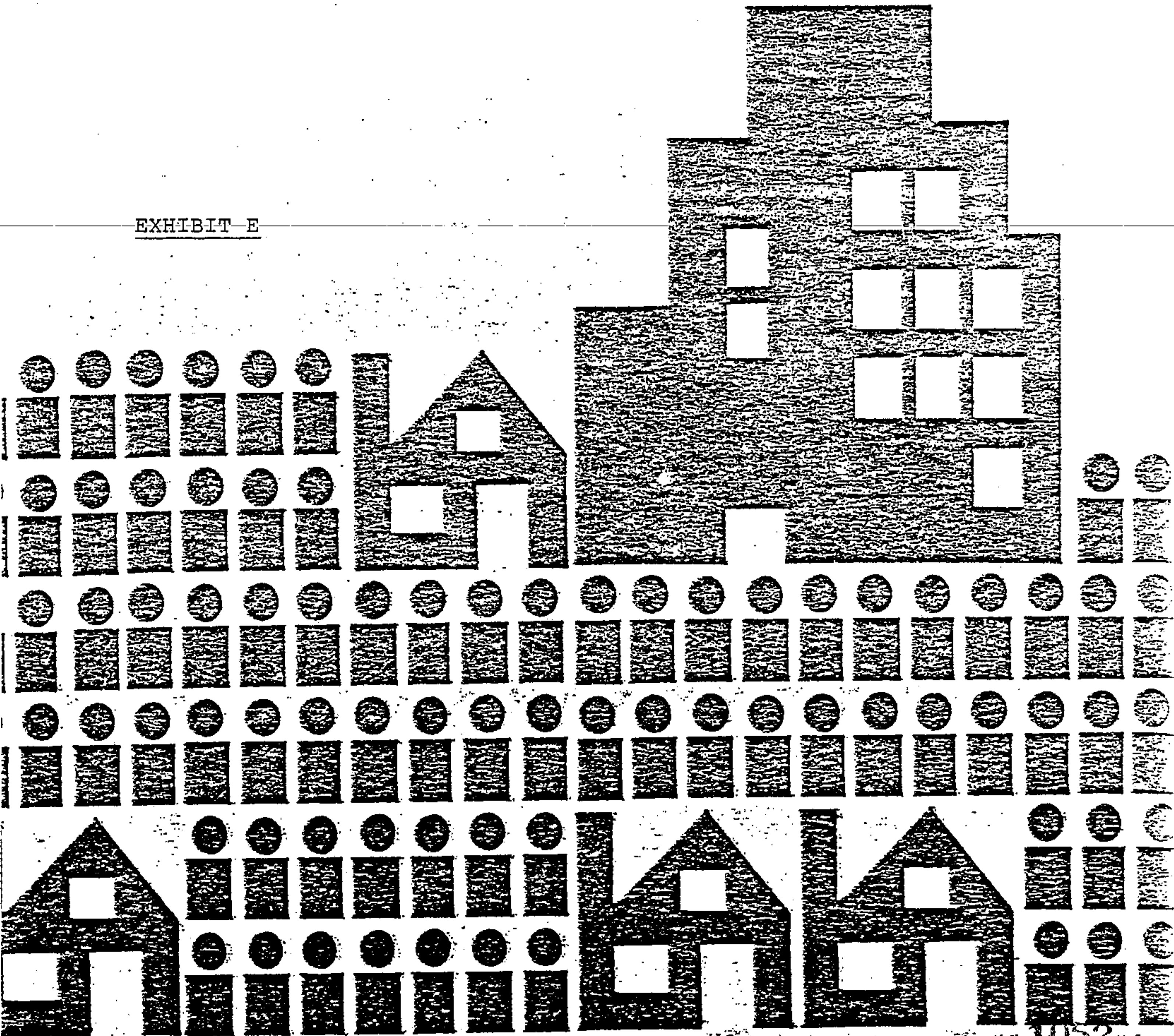
MAC/dzb/H-6

EXHIBIT D

A SURVEY OF STATE OFFICIALS

CURRENT AND FUTURE DEVELOPMENT OF INTERMEDIATE CARE FACILITIES FOR THE MENTALLY RETARDED

EXHIBIT E



A SURVEY OF STATE OFFICIALS

CURRENT AND FUTURE DEVELOPMENT OF INTERMEDIATE CARE FACILITIES FOR THE MENTALLY RETARDED

August, 1980

by

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Human Services Research Institute
Washington, D.C.

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Acknowledgements

We wish to extend our gratitude to the many individuals who contributed to the ICF/MR study. In particular, we wish to thank the survey respondents who so generously gave their time for the interviews, and responded to the sometimes lengthly data requests.

Special commendation is due to Gary Clarke, John Ashbaugh, and Valerie Bradley for their constructive suggestions during the review of the report. Recognition is due to Robert Gettings for his review and critique of the survey questionnaire, as well as to Emily Cravedi for her skillful preparation of the charts. Finally, our special thanks to Ellen Dowd, who so patiently retyped the many revisions and drafts of this report.

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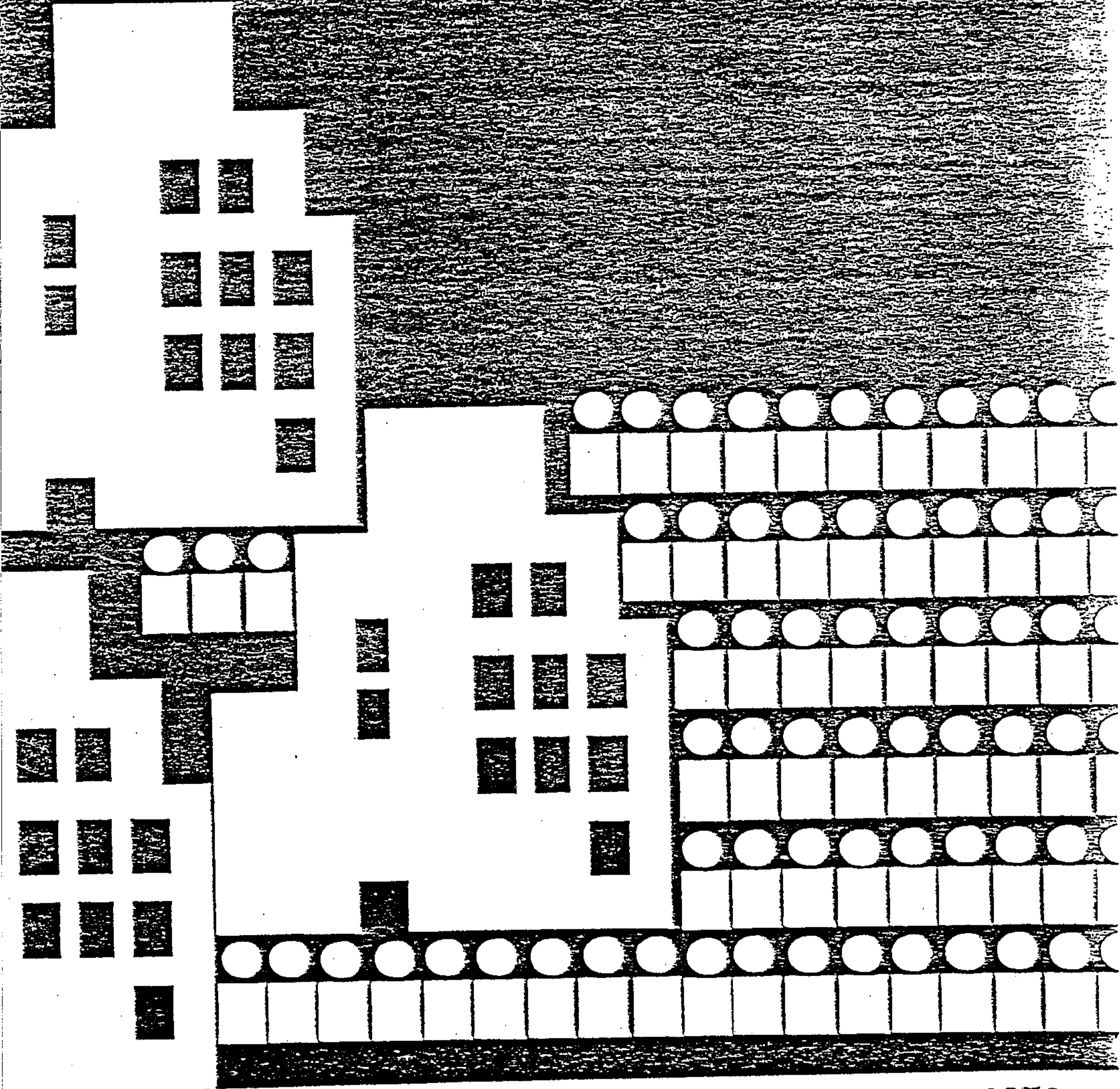
I. BACKGROUND



A. A Brief Overview of the ICF/MR Program

1. Background

The Intermediate Care Facility Program for the Mentally Retarded (ICF/MR) was added to the Medicaid (Title XIX) program as part of the 1971 amendments (P.L. 92-223) to the Social Security Act. In that year, the ICF/MR program became another optional service that states could offer under their Medicaid program.

The initiation of the ICF/MR concept is important to review since there have been many interpretations of the legislative intent behind the program. Some believe this to be a strictly medical program, while others feel it should be a habilitative program due to the client population it serves. Still others are unclear how the program should be operationalized, i.e., are small ICF/MRs appropriate given the current federal standards?

Prior to the 1971 authorization of the ICF/MR program, federal Medicaid funds were available for states to provide care to disabled adults in private (non-profit and proprietary) facilities, but not for those persons residing in public institutions. Public institutions, however, also were eligible for Medicaid funding, if they qualified as skilled nursing facilities (SNFs).

As a result of these incentives, some states were converting their public institutions to highly medical facilities in the late 1960s (e.g. **California, Pennsylvania, Wisconsin**). Others, however, were moving eligible retarded residents from public facilities into private facilities — either nursing homes or proprietary board and care homes. During this same time, the General Accounting Office (GAO) completed a study examining the level and extent of reimbursements for retarded institutional residents, specifically focusing on hospitals operated by the State of California. The review concluded that Medicaid reimbursement to public institutions was illegal under existing federal law, and recommended that HEW recover payments from all states pursuing practices similar to those in **California.**

In response to the GAO recommendations, officials from several states sought a statutory change in Title XIX to authorize Medicaid payments for residents of publicly-operated institutions for the mentally retarded. In order to strengthen their position, these states, most notably **Oklahoma** and **Wisconsin,** sought the assistance of other organizations to help them develop legislative support for the plan. One of these organizations, the National Association of Retarded Citizens (NARC), was critical to the success of the legislative initiative. The price for their involvement, however, was a guarantee that facilities receiving Medicaid funds be designed to meet the habilitative goals of their residents and

provide active programming. In other words, NARC wanted to diminish the influence of the medical model which was predominant in Medicaid statutes up to that time.

The merging of the two primary interest groups (i.e., state mental retardation officials and consumer representatives) led to several major amendments that specified conditions necessary for certification as an ICF/MR provider. Some of these conditions are detailed below. At the time the 1971 Medicaid amendments were drafted, however, the focus of the debate was on large, publicly-operated institutions for the mentally retarded. As a result, the issue of how to fund small public and private community residences was not discussed in the Congress' statements of legislative intent when enacting the law. Moreover, although the 15-or-less concept was eventually worked into the regulations promulgated in 1974, even today there is no clear statement of federal policy concerning Medicaid reimbursement of small community-based ICF/MRs.

2. What is an ICF/MR?

An ICF/MR program must meet the following generic definition of an intermediate care facility. The institution or community facility must:

1. Be licensed under state law to provide, on a regular basis, health-related care and services to individuals who do not require the degree of care and treatment a hospital or skilled nursing home is designed to provide but who, because of their mental or physical condition require care and service (above the level of room and board) which can be made available to them only through institutional facilities;
2. Meet such standards prescribed by the Secretary for the proper provision of such care, and,
3. Meet such standards of safety and sanitation as are established under regulation by the Secretary..

P.L. 92-223 (Section 1905(a)) specifies that ICF/MR reimbursement is available for services provided in a public institution (or distinct parts thereof) only if:

1. The primary purpose of such institutions is to provide health or rehabilitative services for mentally retarded individuals and if the institution meets such standards as may be prescribed by the Secretary;
2. The mentally retarded individual is receiving active treatment; and,
3. The state or political subdivision responsible for the operations of such institutions has agreed that the non-federal expenditures with respect to services furnished patients in such institutions will not be reduced because of payments made under this title; (maintenance of effort provision).

When states exercise the ICF/MR option of Medicaid, however, they are required to cover not only mentally retarded persons, but also persons with "related

conditions." Related conditions were originally defined to include epilepsy, cerebral palsy, autism or other developmental disabilities as defined pursuant to Part C of the Developmental Disabilities Services and Facilities Construction Act. New amendments to this Act in 1978 and subsequent regulations further expanded the definition of developmental disability, changing its focus from categorical disabilities to more generic functional limitations. As a result, coverage now includes not only mental retardation, epilepsy, and cerebral palsy, but also chronic mental illness, spina bifida and any other physicial or mental condition which meets certain criteria specified in the amendments.

3. The Small ICF/MR (15 beds or less)

The January 17, 1974 regulations promulgating the ICF/MR program included the option that small facilities of 15 residents or fewer could qualify for Title XIX reimbursement. It should be noted that an "institution" as defined in Title XIX regulations means *"... an establishment which furnishes (a single or multiple facilities) food and shelter to four or more persons unrelated to the proprietor ..."* (45 C.F.R., Sec. 448.60(6)(1)). These small ICF/MR facilities may use the Life Safety Code standards for Lodging and Rooming House residences instead of the code for institutions. As a result of this new change, states were able to fund smaller, less institutional settings for the mentally retarded. These standards can be used under the following circumstances:[1]

1. For physical plant standards, (program and staffing standards may not be waived);
2. If residents were ambulatory, which must be certified by a physician or psychologist;
3. If residents are engaged in active treatment;
4. If residents are capable of following directions and taking appropriate action for self-preservation under emergency conditions; and,
5. If it will not adversely affect the health and safety of the residents.

At the time these statutory changes were made many states were already committed to a deinstitutionalization policy and believed that the ICF/MR option for small facilities would help them fulfill their deinstitutionalization goals. The 1974 regulations, however, provided very little guidance to the states pertaining to the conditions under which a small community residence could be certified as an ICF/MR provider. In fact, except for a few minor modifications in the 1977 regulations applicable to small ICF/MR facilities, and interpretive guidelines issued by HCFA in 1977 which provided some direction for states desiring to

[1] It should be noted that many states have placed mobile, non-ambulatory residents into small ICF/MRs using the Lodging or Rooming House Section of the Life Safety Code. A letter regarding the authorization of such placements was sent to Robert L. Okin, M.D., Massachusetts Department of Mental Health, from Hale Champion, DHEW, Washington, D.C. in March 1978.

develop small ICF/MRs,[2] DHHS has not addressed the question of certification of small community residences since 1974. As a result, states have had to utilize standards which were designed around the model of a large institutional facility and, as noted by many state officials, simply do not work when applied to the small 15 bed or less residence. Attempting to provide a small, family-like living environment in the context of the broad ICF/MR program has been a barrier for many states desiring to initiate small ICF/MRs. Furthermore, the vagueness of the regulations often slows many states' efforts to utilize Title XIX to encourage deinstitutionalization.

Although there have been attempts to establish and clarify HEW's policy regarding the use of Title XIX, ICF/MR program for small residences, there is still no overall federal policy guiding this program. Those states that ventured forth in the mid-1970s to develop community programs using the ICF/MR program, developed an ad-hoc approach to licensure and certification of small residential arrangements under ICF/MR. Although the program does permit the development of small residences that are not medically oriented but still "health related," the program itself is housed within a strictly medical program and must incorporate certain review procedures that are usually dominated by physicians and nurses.

[2] Health Care Financing Administration, *Interpretive Guidelines for the Application of the 1977 Standards for Institutions for the Mentally Retarded or Persons with Related Conditions.* (45 C.F.R. 249.13) 1977.

B. The Reason for the Study

The ICF/MR program for both institutional and community settings is becoming an important and critical force in shaping residential environments for mentally retarded and other developmentally disabled persons. In Fiscal Year 1978, an estimated $1.5 billion was spent in ICF/MRs (both federal and state funds) to support disabled residents. For the most part, these funds have been spent in large institutional settings, with less than 20 states using the ICF/MR funding stream for community settings.

Although the Health Care Financing Administration (HCFA) which is in charge of the Medicaid program, does collect some information describing ICF/MRs, this data is usually one or two years out-of-date and generally is limited in scope. Some studies have been conducted by various organizations describing certain aspects of the ICF/MR program.[3] For the most part, however, there has been very little information available at either the state or federal level regarding the nature and potential impact of ICF/MR funding. In addition, very little information has been available regarding the ways in which states use, and intend to use, this source of funds in the future. Federal policymakers have also had little data available to them describing the major constraints that limit the responsiveness of the program, and the many program variations among the states that have pursued the small ICF/MR concept.

Several agencies recently have expressed an interest in gathering more detailed information regarding the ICF/MR program, including the increasing need to assess the current and potential characteristics of facilities and residents in the program. As a result of this interest, the President's Committee on Mental Retardation (PCMR) awarded a contract to HSRI to develop an initial study which would be used to capture current information on the ICF/MR program. During the course of the project, HSRI joined forces with the George Washington University, Intergovernmental Health Policy Project (IHPP) which had been ask-

---

3 See, for example, Center for the Development of Community Alternative Service Systems, *Intermediate Care Facilities for the Mentally Retarded (ICF/MR): An Overview of the Intent, Development, Provisions for Services and Current Usage of Medicaid Funds in ICF/MR Settings*, 1978; Federal Program Information and Assistance Project, *Intermediate Care Facilities for the Mentally Retarded*, 1978; Thomas Gilhool, *Working Paper on the Uses of Title XIX Sustain Community Residential Services for Developmentally Disabled People*, (First Draft), June 10, 1979; National Association of State Mental Retardation Program Directors.

ed by HCFA to look into similar programmatic issues affecting the ICF/MR system. Through this collaboration, the scope of the two individual projects was broadened, making it possible to produce a more comprehensive report.

In addition to collecting statistical information, such as the number of facilities, beds and clients in both institutional and community settings, this study designed questions to gain insight into the following: how states have interpreted certain program components of the program; how they have operationalized their small ICF/MR programs; and, the nature of the problems they face in implementing the program.

C. Project Methodology and Limitations

The purpose of the overall study was to collect information regarding:

- The current status of the ICF/MR networks in the 50 states;
- The scope of planned ICF/MR networks projected for the future;
- The key factors — economic, administrative, social and political — facilitating or inhibiting these networks; and,
- The federal policy and regulatory changes necessary to facilitate the development of such networks.

Given these general goals, HSRI and the IHPP employed a methodology similar to that employed by the National Association of State Mental Retardation Program Directors (NASMRPD) in their numerous reports to PCMR. As in those efforts, this study relied on structured telephone interviews with state mental retardation/developmental disabilities officials and other knowledgeable state officials to retrieve the necessary information.

The methodology consisted of eight major tasks:

1. Designing interview schedules to obtain estimates for the fiscal year 1978-79 and projections for 1983-84; data was requested for both state/county and privately administered facilities, for both ICF/MRs less than and more than 16 beds, for facility and client characteristics, and for the relative share of cost among the local governing unit, the state, and the federal government (a copy of the survey instrument can be found in the Appendix);
2. Contacting state mental retardation program directors by mail, informing them of the purposes of the study and requesting them to supply names of persons with knowledge of the ICF/MR program;
3. Arranging and preparing telephone interviews;

4. Conducting extensive phone interviews with one or more officials in respondent states;
5. Making follow-up contacts, where required, to secure missing information;
6. Supplementing interview data, where appropriate, with document reviews pertinent to particular state plans;
7. Reviewing general policy materials relating to the ICF/MR program;
8. Synthesizing the results of the interviews in a 20-30 page report.

A total of 42 states responded to the initial request for information, and telephone interviews were conducted in 39 states. Based on the number of states currently providing ICF/MR services (44), the response rate was approximately 89 percent. Though the response rate was high, results of the telephone survey should be interpreted cautiously. Much of the data presented is based on "best guess" estimates and approximations by state officials. Specific costs, especially the projected costs for 1983-84, were difficult to ascertain and should also be treated as tentative and somewhat speculative. For instance, some states only plan on a two year basis and could give estimates for 1984 that were, at best, educated speculation. Further, because the level of development of ICF/MRs varies so greatly from state to state, it is difficult to generalize about the program. For instance, "average" reimbursement rates for ICF/MRs within a state may represent only one or two facilities.

It should also be noted that the bulk of information collected during the survey was derived from state mental retardation/developmental disabilities officials. Although staff responsible for Medicaid certification and facility licensing were interviewed in some states, the major data source was state MR/DD officials. Thus, as a general matter, the data presented herein are only as good as the information available to such individuals at the state level. In the future, a more comprehensive survey should be implemented which includes respondents from the health and Medicaid agencies in each state.

D. Organization of the Report

The remainder of the report is divided into two major sections: Descriptive Analysis, and Issues for Future Development. In the first section, a summary of the survey data for both the existing ICF/MR system and future trends is presented. The summary includes statistical tables illustrating highlights in the data. State specific examples drawn from the open-ended questions are also included in the discussion where appropriate. The last section provides a more in-depth examination of pertinent issues emanating from the survey questions and results. The areas selected for closer scrutiny include:

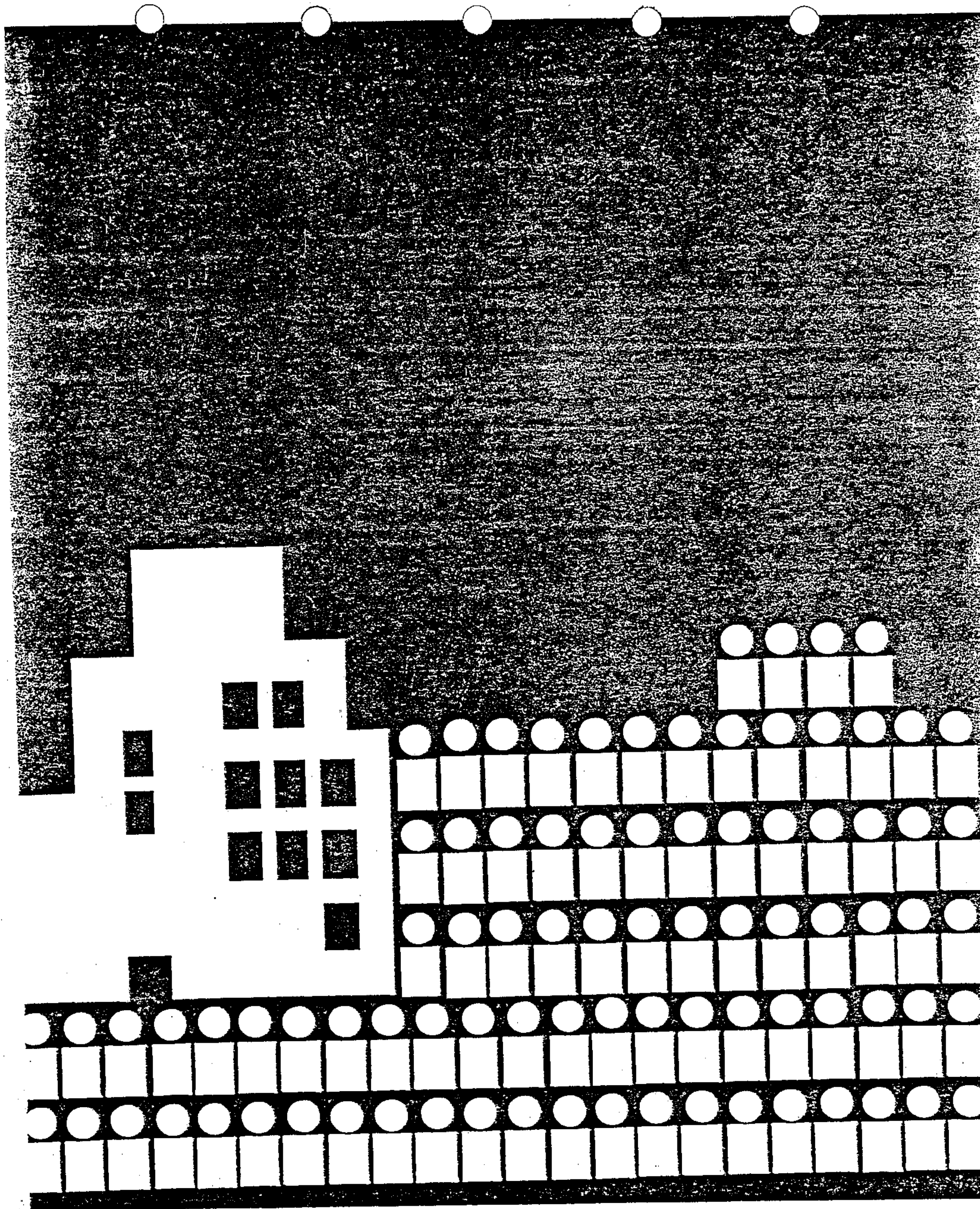
- **Quality Assurance** — state licensing and certification procedures for small ICF/MRs; and the use of Independent Professional Reviews and Utilization Reviews; role of the state mental retardation office in licensing, certification, and policy coordination; and, the administrative auspices of ICF/MRs;

- **Planning** — current exemplary state programs; future plans for ICF/MRs-state specific; certificate of need process as it relates to ICF/MRs, and the relationship between institutional compliance plans and the development of community alternatives through ICF/MR;

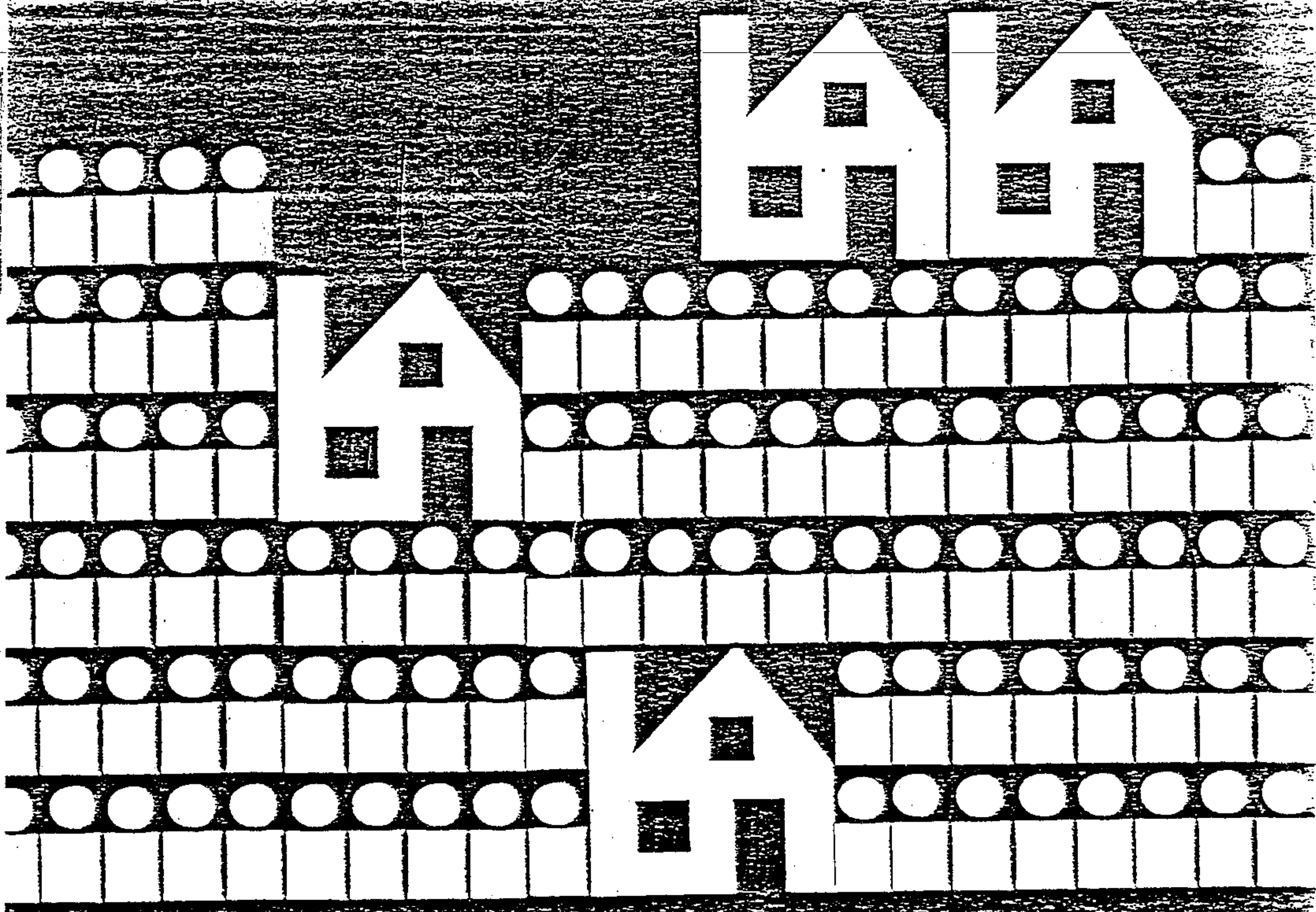
- **Program Obstacles** — start-up problems associated with small ICF/MRs, controversies regarding size and medical versus habilitative, problems entailed in meeting ANSI, 504 and Life Safety Code requirements in small ICF/MR facilities; and other issues relevant to standards for model, both large and small ICF/MR facilities;

- **Funding** — alternative financing for residential care of the mentally retarded; relative costs of the ICF/MR program and its relationship to other federal funding streams, and the nature of the reimbursement systems developed by the states — especially for small ICF/MR facilities;

- **Policy Coordination** — HCFA's role in assisting states to implement small ICF/MR programs, the ways in which federal policy affects state coordination, the potential impact of the new developmental disabilities definition on the ICF/MR program, and the effect of lawsuits and court decrees on the development of small ICF/MRs.



II. DESCRIPTIVE ANALYSIS OF THE ICF/MR PROGRAM



Section II—Descriptive Analysis of the ICF/MR Program

Since its inception in 1972, states have used the ICF/MR program to provide residential placements for mentally retarded persons and others with related conditions in both institutional and community settings. This section of the report will present information by type of ICF/MR: small privately-administered; small publicly-administered; large privately-administered; and large publicly-administered facilities. Within each type of ICF/MR, four principal components are described: 1) facility characteristics; 2) bed capacity; 3) client characteristics; and 4) costs.

This information is based on a survey of 39 state respondents (See Appendix I for a complete list of the data elements and definitions of each type of facility). State officials were asked to provide ICF/MR facility and client data, "current" as of June 30, 1979, and projected to June 30, 1984. "Current" cost information was requested for the fiscal year July 1978 -June 1979. "Projected" cost information was requested for the period July 1983 - June 1984.[1]

Survey respondents were asked to provide the total yearly operating budgets (excluding capital improvements or repair costs amounting to more than $25,000) for each ICF/MR category. Providing total operational costs, and federal, state and local shares, however, was difficult for many of the survey respondents. The most complete information was secured on publicly operated large ICF/MRs.

If survey respondents could not provide the total costs, the average per diem provided by the respondents was multiplied by the number of certified beds in that category in that state, and then multiplied again by 365 (days) to develop a rough approximation of annual operating expenditures. (This figure was based upon the average percent occupancy rate as identified by survey respondents.) If state respondents provided their federal matching percentage under Medicaid, that figure was used to calculate state and federal shares of the total. Where matching percentages were not provided, they were obtained from HCFA publications (*Data on the Medicaid Program*).

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1 Data are available upon request.

A. Small Privately-Administered ICF/MR Facilities

1. Facility Characteristics

Only 17 of the states responding to the survey (40 percent) have developed small private ICF/MRs. Together they reported a total of 256 privately administered small ICF/MRs (less than 16 beds) as of June 30, 1979.[3] Of these 17 respondents, only one — **Minnesota** — has more than 30 privately administered small ICF/MRs in operation. **Minnesota**, the first state to use the ICF/MR program as a major component of its community-based residential system, has approximately 174 small privately administered ICF/MRs in the state. Fourteen of the 17 states, however, have less than 10 small privately administered ICF/MRs in their respective states.

States are predicting significant increases in the number of small privately administered ICF/MRs by 1984. Twenty-one states project a combined total of 1,412 small, privately administered ICF/MR facilities by June 30, 1984—an increase of at least 552 percent over currently reported figures. Six new states plan to develop small ICF/MRs by 1984. These states are **California, Indiana, Louisiana, Maine, Tennessee,** and **Washington.** Moreover, certain states such as **Massachusetts** and **Michigan** plan a significant expansion of their small private ICF/MR network. **Massachusetts**, for example, had only two small private ICF/MRs as of June 30, 1979, but is planning to develop 93 by 1984. **Michigan** had 14 small ICF/MRs as of June 30, 1979, and anticipates having 225 in operation by 1984. Other states like **Nebraska** and **Kentucky** are in the midst of implementing a small ICF/MR program in their respective states, but could not estimate how many small ICF/MRs would be operational by 1984.

2. Bed Capacity

As of June 30, 1979, 16 of the 39 responding states reported approximately 3,898 private small ICF/MR beds currently in existence. Five states reported only eight beds (one facility) and one other state (**Minnesota**) reported 2500 beds (174 facilities). **Michigan** and **Virginia** indicated that not all of their small ICF/MRs were licensed. These uncertified beds were not included in the total. Fourteen of the 16 states reported having fewer than 250 small, private ICF/MR beds in the state. These facilities reportedly range in size from four to 15 beds.

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[3] Two additional states—**Connecticut** and **Hawaii**—are known to have small ICF/MRs, but did not respond to the survey.

Twenty-two of the 39 survey respondents anticipate a total of 13,604 licensed small ICF/MR private beds in operation by June 30, 1981. This figure includes several states such as **Nebraska** and **Kentucky** who could not estimate the number of facilities but projected the number of beds. This figure also does not include **New York** and **New Jersey.** Six states expect to have from 251-500 licensed beds, and six states anticipate at least 1000 licensed ICF/MR beds in small private facilities.

Minnesota, which currently has the largest number of small privately administered ICF/MRs in the country, is projecting an additional 350 community ICF/MR beds by 1981. According to the survey respondent, this could be the last wave of new small ICF/MR residences in that state. The future demand for small ICF/MRs in **Minnesota** is linked to the state's six year plan. As part of this long-range plan, **Minnesota** would like to develop 500 community placements for semi-independent living and move approximately 500-600 clients currently residing in small ICF/MRs into these independent settings. The 600 ICF/MR beds freed up by the move would enable another 600 clients to be deinstitutionalized. This residential plan is predicated on the receipt of additional funds for semi-independent living.

3. Client Characteristics

Not all of the respondents in the 17 states with a small ICF/MR program were able to roughly describe the characteristics of clients in those facilities. Thirteen states estimated that the average percent of clients referred to small privately administered ICF/MRs from public institutions was approximately 53 percent. Twelve respondents provided estimates of client retardation levels as of June 30,1979 for small privately administered ICF/MRs and 11 respondents predicted client levels of retardation as of June 30, 1984. The majority of clients in small private ICF/MRs are reported to be mildly or moderately retarded at present. In the future, the majority of small ICF/MR clients are projected to be severely and profoundly retarded. **Michigan** and **Massachusestts** could not provide an estimated percentage but did note that they are serving primarily severely and/or profoundly mentally retarded persons in their small private ICF/MRs. **Minnesota** indicated that they serve only a small percentage of severely disabled persons while **Alaska** noted that 20 percent of its ICF/MR clients are moderately retarded. Future predictions also include several states, such as **Idaho** and **Maine,** who could not provide estimated percentages of clients with mild/moderate retardation, but who did indicate that most of their small ICF/MR residences would be made up of more severely disabled persons.

Survey respondents were asked to provide estimates of the percentages of clients in each type of ICF/MR who are either non-ambulatory, mobile/non-ambulatory, or ambulatory.[3] Ten respondents estimated the percentage of non-

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[3] See definitons in Appendix I.

ambulatory clients residing in small privately administered ICF/MRs. Seven of the ten states responding to this question reported that *no* non-ambulatory clients were being served in their small private ICF/MRs. Thirteen respondents estimated the percentage of mobile/non-ambulatory clients residing in small privately administered ICF/MRs. Nine of the 13 states indicated that 10 percent or less of their clients in their small private ICF/MRs were mobile/non-ambulatory. No appreciable change was projected in the future.

4. Costs

Twelve respondents provided cost estimates for small facilities. These states spent approximately $67.5 million on small privately operated ICF/MRs from July 1978 through June 1979. The federal share was approximately $37.7 million, while the state share was $31.8 million. Only **Virginia** reported a local share. **New York** and **Texas**, two states with a large number of small private ICF/MRs are notably absent from this accounting. Thirteen state respondents were able to provide information on operating costs, or charges per client day, by ICF/MR category. The majority of per diems in these 13 states were between $20 and $60 for small private ICF/MRs. Three states (**Alaska, New York** and **Massachusetts**), however, reported average per diems of over $80. Per diem ranges varied from $52 to $100 in New York to $26.64 to $39.28 in South Dakota.

B. Small Publicly-Administered ICF/MRs

1. Facility Characteristics

A small number of survey respondents indicated that their states either are or will be developing publicly-operated small ICF/MRs. As of June 30, 1979, five of the 39 states responding to the survey operate a total of 66 small public ICF/MRs. The five states are: **South Carolina, Texas, Rhode Island, Ohio** and **North Carolina. Connecticut,** which does operate small ICF/MRs, did not respond to the survey.

Another three states — **Virginia, Oklahoma** and **Louisiana** — plan to operate small public ICF/MRs, bringing the total number of small public ICF/MRs projected to be built by 1984 to 378, a 572 percent increase. The percentage increase in the number of small, publicly operated ICF/MRs is dramatic, but the total number of states participating in this program is less than ten. **Rhode Island** stands out as one of the states estimating a substantial expansion in its small publicly-administered ICF/MR program: from 15 residences in 1979 to 200

by June 1984. **Rhode Island** plans on using institutional employees to staff its small publicly operated faclities. Other states like **Michigan** have considered using state institutional employees to staff their small ICF/MRs but were discouraged by the "above-market" public employee pay/benefit scales.

2. Bed Capacity

A total of 604 licensed beds in small public ICF/MRs were reported in five states. The number of beds in a state ranged from five in **North Carolina** to 319 in **Texas.** The size of facilities in these states ranges from four to 15 beds.

As of June 30, 1984, the number of publicly-operated small ICF/MR beds in these and three other states (**Louisiana, Oklahoma, Virginia**) is expected to increase to 2,582. The number of small public ICF/MR beds in a state is expected to range from 48 beds in **Louisiana** to 900 beds in **Rhode Island.**

3. Client Characteristics

Aside from one state (**Texas**), all of the survey respondents indicate that for both the present and the future, more than 80 percent of the clients in small public ICF/MRs will be referred from public institutions.

The number of respondents providing client characteristic information on small publicly operated ICF/MRs was quite small (four for 1979 and eight for 1984). Three state respondents (**Ohio, North Carolina, Virginia**), indicated they would serve less than 50 percent mildly and/or moderately retarded persons in their small residences.

Very little information was received from respondents concerning mobile and/or non-ambulatory clients in small public ICF/MRs. As of June 30, 1979, three state respondents (**Rhode Island, South Carolina, Texas**) indicated they had no non-ambulatory clients in their small ICF/MRs. **Rhode Island** did, however, note that all of their clients were mobile, non-ambulatory. By June 30, 1984, **Ohio** predicts that approximately 35 percent and 20 percent of their clients will be non-ambulatory and mobile non-ambulatory respectively. Both **Louisiana** and **North Carolina** estimate that approximately 15 percent of their clients will be mobile non-ambulatory by that date.

4. Costs

Only two state respondents provided costs for publicly operated small ICF/MRs. **Rhode Island** estimated that approximately $2,230,150 was spent on small ICF/MRs from July 1978 to June 1979. **Ohio** estimated that $804,825 was spent on public small ICF/MRs during that same time period.

C. Large Privately-Administered ICF/MRs

1. Facility Characteritics

Twenty-four of the 39 states responding to the survey reported 237 large private ICF/MRs (over 16 beds) currently in operation. Eighteen, or 46 percent of these states had from one to ten such facilities, including six states with only one such facility. **Minnesota** reported 51 large privately administered ICF/MRs within the state.

Only 16 of the 39 survey respondents projected the number of large privately administered ICF/MRs for 1984. Several respondents expect no growth in large privately administered ICF/MRs. **New York** did not attempt to estimate the future number of large private ICF/MRs. Other states like **Ohio**, however, expect new growth in this portion of their ICF/MR program — bringing to a total of 70 large private ICF/MRs expected to be operating in their states by 1984.

2. Bed Capacity

There are a substantial number of beds in large privately administered ICF/MRs. Twenty-four of the 39 states responding to the survey reported a total of 14,678 beds, ranging from 35 beds in **Tennessee** to 2,600 beds in **California.** Eighty percent of the responding states, however, reported no more than 750 beds were in this category.

The privately operated ICF/MRs tend to range in size from 20 to 50 beds at the lower end of the scale, but many are as large as 300-400 beds. Some states like **New York** report extremely large differences in their facilities. Facilities in this state range in size from 16 to 612 beds.

Eight of the 21 respondents reported that occupancy rates for their large private facilities ranged from 96 to 100 percent. All but one of the 21 state respondents (**Utah**) indicated occupancy rates of over 86 percent. **Utah** reported an 82 percent occupancy rate. Occupancy rates are expected to remain high in the future. Eight states projected occupancy rates of 90 percent and over.

3. Client Characteristics

The referral rate to large privately administered ICF/MRs from large public institutions is lower than the referral rates for small facilities, averaging approx-

imately 46 percent; the median, however, is only 33 percent (N=17). The mean percent of mildly and moderately retarded clients in large private ICF/MRs (38 percent) was higher than in the large publicly operated ICF/MRs.

Data on privately administered large ICF/MRs serving non-ambulatory and mobile, non-ambulatory clients is limited. Sixteen respondents provided information on the percentage of non-ambulatory clients and 12 provided information on mobile, non-ambulatory clients. The mean percentage of non-ambulatory clients reported in privately administered large ICF/MRs is 23 percent, while the mean percentage for mobile, non-ambulatory persons served in these same facilities is 16 percent.

4. Costs

Respondents in ten states provided cost estimates for privately administered large ICF/MRs. These states spent approximately $107.3 million in such facilities from July 1978 to June 1979. The federal share was approximately $60.3 million, while the state share amounted to $45.9 million. A local share was reported for only one state and amounted to $1.1 million. (Once again, several significant states, such as **New York, Minnesota, Texas** and **Ohio** are absent from this accounting.) For large private ICF/MRs, 11 of the 15 states responding to this question reported average per diems ranging from $30 to $50. Per diem ranges varied from $34.87 to $75 in Kentucky to $20 to $36 in Utah.

D. Large Publicly-Administered ICF/MRs

1. Facility Characteristics

Thirty-seven of the 39 survey respondents (95 percent) reported a total of 221 large public ICF/MRs (over 16 beds) in operation. The number of such facilities in these states ranges from one to 21. The median number of large publicly operated ICF/MRs in these states is four facilities. Twenty-two of the 37 states operate less than five large, publicly-administered ICF/MRs.

Only 27 of the 39 states provided projections for the numbers of large publicly administered ICF/MRs. Some states are projecting growth by 1984 in spite of the fact that many states (**Minnesota, Michigan, Nebraska, Montana, New Hampshire, Pennsylvania** and others) are planning reductions in the total number of state institutional ICF/MR beds. **New York** was not included in these figures, but according to its FY 81-82 plan, the state anticipates a decline in the number of large publicly operated ICF/MRs. It should be noted that for purposes of this survey, large ICF/MRs can mean any residence over 16 beds, but the term

does not necessarily imply huge, 500 bed or more facilities. **Florida**, for example, is limited by regulation to no more than 60 beds in any single ICF/MR facility. In addition, each living unit within a facility in that state must total no more than 15 beds.

2. Bed Capacity

Thirty-seven of the 39 states indicated that a total of 96,899 ICF/MR beds are currently certified/licensed in large public facilities in their states. The range of total certified beds among respondents was 120 beds in Alaska to 16,079 in New York. Nine states have from zero to 500 beds; seven from 500 to 1,00 beds; and 21 states reported having over 1,000 beds. Three states, **New York, Pennsylvania**, and **Texas**, have over 7,000 ICF/MR beds in large public facilities.

Publicly operated large ICF/MRs vary widely in size (e.g., from 21 beds to 1,206 beds in **Pennsylvania**, and from 200 to 2,240 beds in **Virginia**). Seven states have facilities ranging from 100 beds to 1900 beds. Another eight states have facilities ranging from 30 to 1,600 beds. Twenty of the 33 respondents indicated that occupancy ranged from 96 to 100 percent in their large publicly operated ICF/MRs. The other 13 state respondents reported that occupancy ranged from 86 to 95 percent.

A number of states, for example, **Oklahoma**, estimate that the same number of beds will be needed in 1984 as were needed in 1979. **Florida** is even projecting a large increase (from 481 to 2,744 licensed beds)[4], while **Ohio** expects to add 19 new public facilities, increasing the total number of licensed beds from 2,769 to approximately 4,000.

Although the number of state respondents willing to project the future of large public ICF/MRs was only 19 — too few to indicate a generalizable trend — a number of the respondents do forsee a decrease in the bed size of their largest institutions. The size of **New Jersey** facilities, for example, currently range from 282 to 1,302 beds. By 1984, the state official predicted, the largest facility would be 750 beds. Similarly, **Washington** anticipates decreasing the size of its largest facility to 584 beds (currently 898). **Rhode Island** hopes to decrease the size of its only publicly operated ICF/MR from 700 to 100 beds by 1984.

Occupancy rates for these facilities are projected to remain high. Fourteen of the 16 states responding to this survey question projected at least an 86 percent occupancy rate.

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4 Of these beds, 744 will be cluster arrangements consisting of small facilities (15 beds or less), that may or may nt be located on the campus of a larger facility.

3. Client Characteristics

The mean percent of the clients in large public ICF/MRs who are mildly and/or moderately retarded is reported to be 27.4 percent (N = 27). Only four out of the 27 states responding to this question (15 percent) indicated that their large public ICF/MRs serve a population comprised of 40 percent or more clients who are mildly/moderately retarded. Fifteen of the 27 respondents (56 percent) noted that 21 to 40 percent of their clients are mildly or moderately retarded.

In the 12 states venturing to make projections for 1984, the mean percent of mildly/moderately retarded clients in large public ICF/MRs is expected to drop to 13 percent, with a range from 2 to 24 percent. Only one of the twelve states projects that the large public ICF/MRs will have a population comprised of more than 20 percent moderately and mildly retarded clients.

The mean percentage of non-ambulatory clients in large public ICF/MRs was reported to be 17.3 percent (N = 27). Ten of the 27 states reported that between 21 and 40 percent of the clients were non-ambulatory and 17 states estimated that 0 to 20 percent were non-ambulatory.

Only nine respondents provided future estimates. Of those nine, all but one predicted that they will serve more than 30 percent clients who are non-ambulatory in large public ICF/MRs by June 30, 1984.

As of June 30, 1979, the majority of state respondents (20 of 25) reported serving from 0-20 percent clients classified as mobile, non-ambulatory. Few respondents (seven) provided future estimates for mobile, non-ambulatory clients.

4. Costs

Total cost figures for large publicly operated ICF/MRs were provided by respondents in 29 states. Of these 29 respondents, an estimated total of $1.9 billion was spent between June 1978 to June 1979 on public ICF/MRs with more than 16 beds. Roughly $1 billion of this amount was federal funds, and $969 million was state funds. Six states reported local contributions amounting to approximately $14 million. Seventy-five percent of the average per diems for publicly administered ICF/MRs of more than 16 beds fell between $41 and $70. Per diem ranges within some states were significant. For example, per diems in Louisiana ranged from $35.92 to $105.72 and per diems in Massachusetts ranged from $95 to $278.

E. Summary Tables

As evident in Table 1, many states are predicting a significant increase in the number of small privately-administered ICF/MRs by June 30, 1984. A similar pattern is also found in the small publicly-administered ICF/MRs. Some states are also predicting increases in both their large public and private ICF/MRs. These new facilities, however, do not necessarily represent large institutional settings (i.e., 1000 beds), but can include any facility over 16 beds as defined in the survey. Many of these new facilities, including small and large ICF/MRs, will be new construction and/or substantial rehabilitation, indicating a significant amount of capital investment by each state sponsoring such development in the next few years.

TABLE 1. Number of ICF/MR's By Type

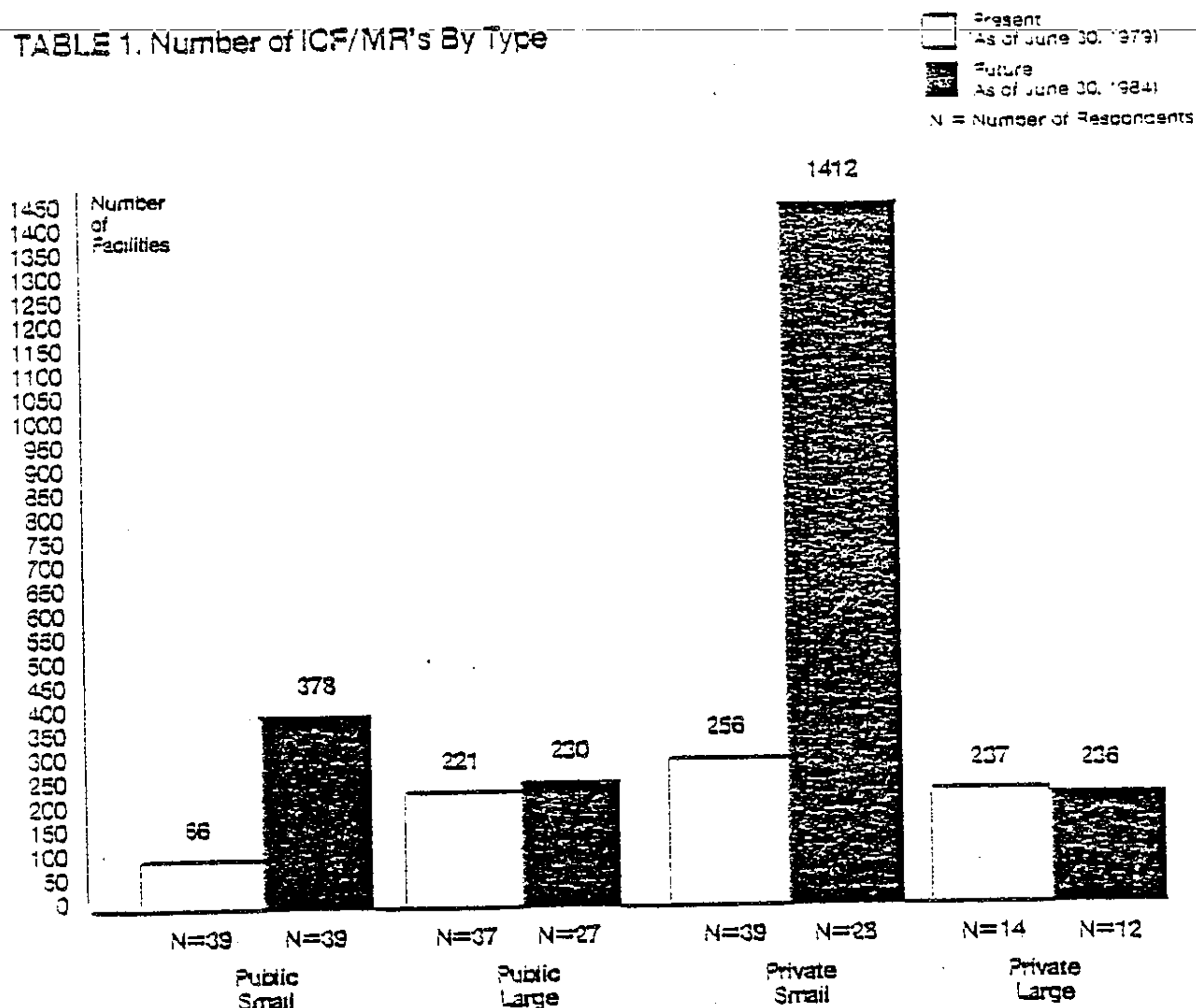


Table 2 provides the reader with the total amount of licensed/certified beds for each ICF/MR category. Although not displayed, the range of beds within each ICF/MR type should also be described. Whereas large public ICF/MRs range from 17 beds (**Maine**) to 2,240 beds (**Virginia**), large private facilities range from 16 beds (**Florida**) to 612 beds (**New York**), indicating that large private ICF/MRs are somewhat smaller as compared to large public ICF/MRs. For instance, at least nine states (**California, Maryland, New Jersey, New York, Oregon, Louisiana, Pennsylvania, South Carolina** and **Virginia**) have large public ICF/MRs of over 1000 beds.

Within small public and small privately-administered ICF/MRs, there is no discernable trend in terms of size of facility. However, by June 30, 1984, **Texas** expects to increase the minimum size of its small publicly operated ICF/MR from four beds to eight beds. Given the anticipated demand for small community residences during the next decade, many states may not be able to restrict the size of small ICF/MRs to six or eight beds as they would like to do. Further, because of the increasing costs of new ICF/MR development, states may be forced to utilize fewer facilities, thus increasing the number of beds in each facility.

TABLE 2. Number of ICF/MR Beds By Type

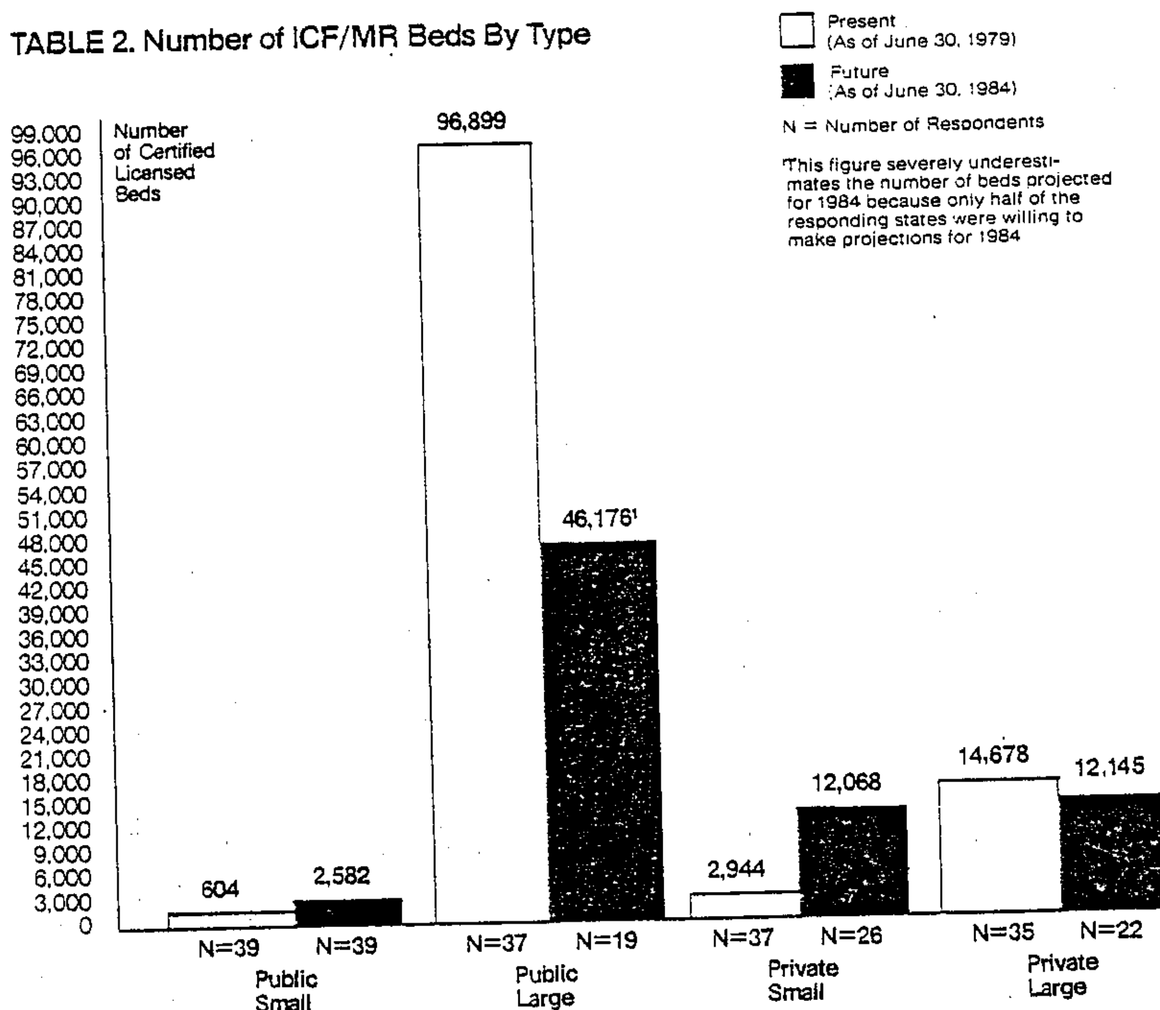
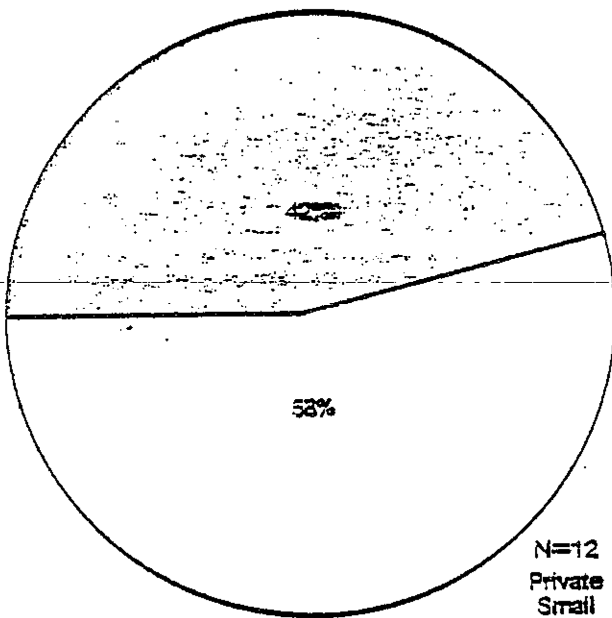


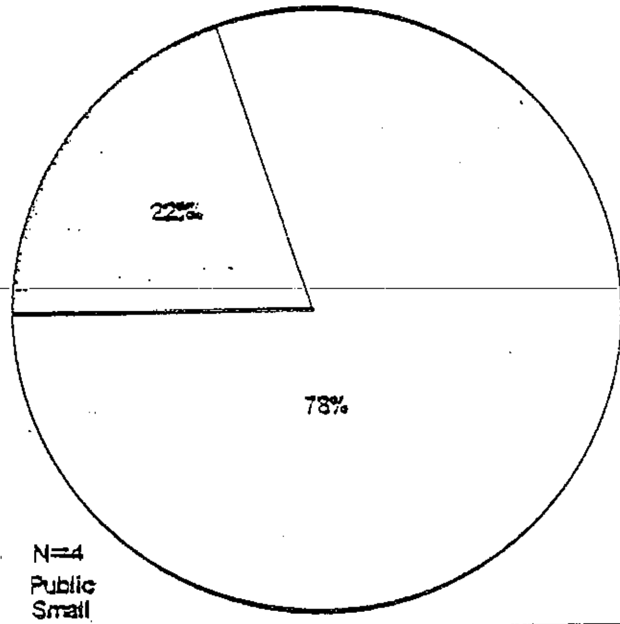
TABLE 3. Average Percent Mildly and Moderately Retarded vs. Severely and Profoundly Retarded By ICF/MR Type as of June 30, 1979*

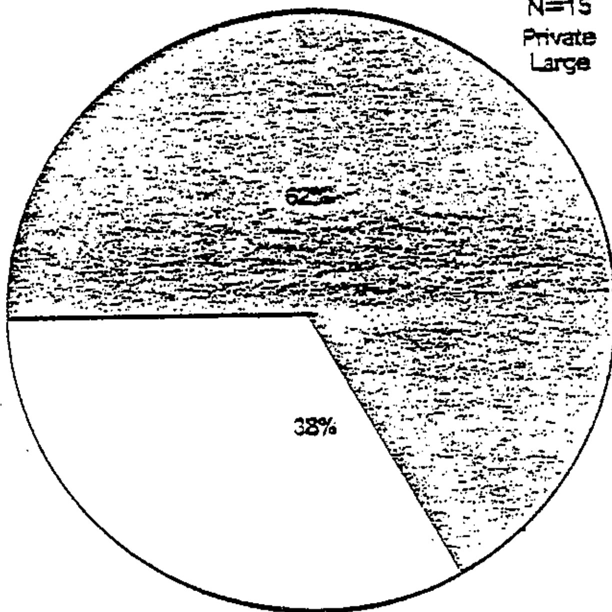
Mildly and Moderately Retarded

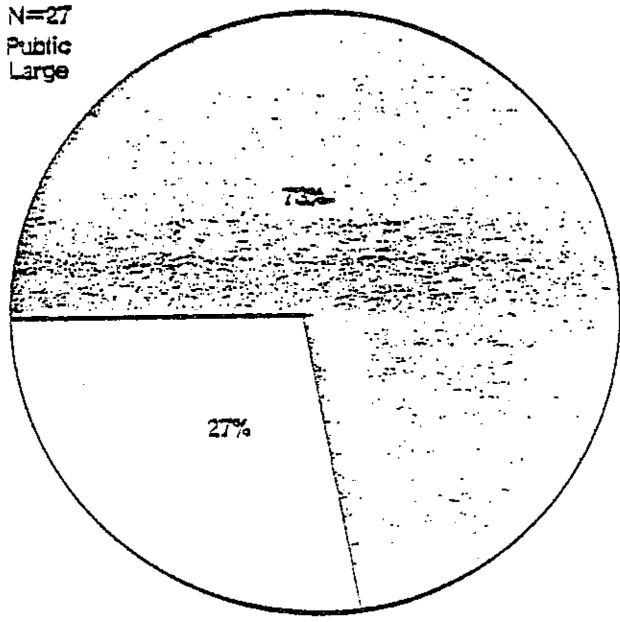
Severely and Profoundly Retarded

N = Number of Respondents Providing Percentage Estimates









*Non-weighted average of states responding.

Tables 3 and 4 describe the types of clients currently served in both small and large ICF/MRs. Interestingly, large public and private ICF/MRs are serving more disabled clients than small private and publicly administered ICF/MRs. Of the four states providing estimated percentages in small public ICF/MRs, the mean percentage of mild/moderately retarded clients is 78 percent. Twelve states indicate that 58 percent of the clients served in small privately-administered ICF/MRs are mildly and/or moderately retarded. Twenty-seven states noted that an average of 27 percent of the clients served in large public ICF/MRs are mildly/moderately retarded and 15 states noted that 38 percent of the clients in private ICF/MRs are mildly/moderately retarded.

Although very few states could predict with confidence the percentage of clients who would be mildly and/or moderately disabled by June 30, 1984, the trend appears to be that small private and public ICF/MRs will increasingly be serving more disabled clients as they receive more and more clients from large public institutions.

In terms of clients' mobility characteristics, large public and private ICF/MRs appear to be serving a few more non-ambulatory and mobile, non-ambulatory clients than small public or private ICF/MRs. For example, 17 percent of the clients in 27 states providing information for large public ICF/MRs are non-ambulatory and 17 percent are mobile, non-ambulatory. Ten states noted that 15 percent of their clients in small private ICF/MRs were non-ambulatory. The average percent is misleading, however, since there were so few states responding and the range of cases is extreme. For example, among the ten states providing information on small private ICF/MRs, seven noted that no (0 percent) clients were non-ambulatory, while 90 percent of the small private ICF/MR clients in one state (**Nevada**) are non-ambulatory. A similar pattern can be found among those states providing information on clients who are mobile, non-ambulatory in small publicly-administered ICF/MRs. It should be noted that the remaining clients not identified as non-ambulatory should be classified as ambulatory. This does not mean, however, that all of the ambulatory clients are capable of self-preservation.

* States were asked to provide the estimated percent of non-ambulatory and mobile non-ambulatory clients residing in ICF/MR facilities. For those states providing an estimated percent, an average percent was calculated for non-ambulatory and mobile non-ambulatory respectively. With the exception of small publicly-administered facilities, only those states providing estimated percent for both non-ambulatory and mobile non-ambulatory were included in the total. The average percent is equal to the sum of each states percent divided by the number of states responding.

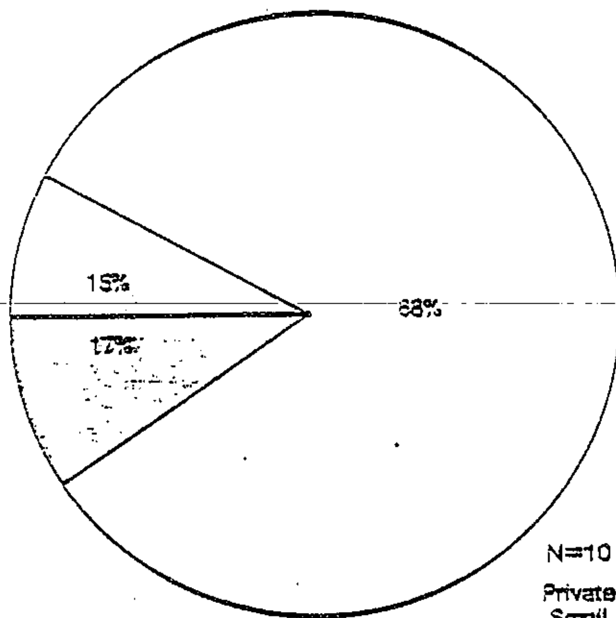
TABLE 4. Average Percent Non-Ambulatory, Mobile Non-Ambulatory, and Ambulatory Clients*

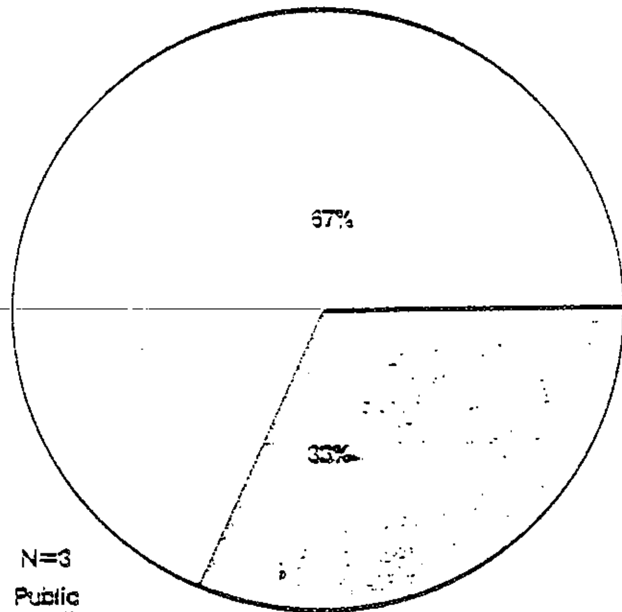
Non-Ambulatory

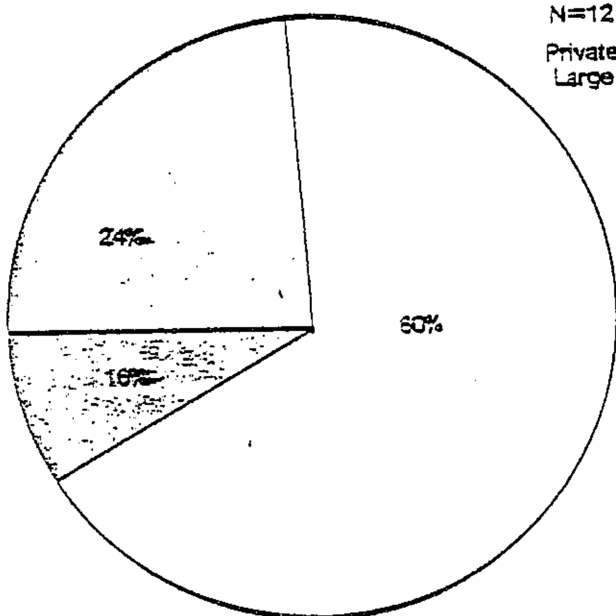
Mobile Non-Ambulatory

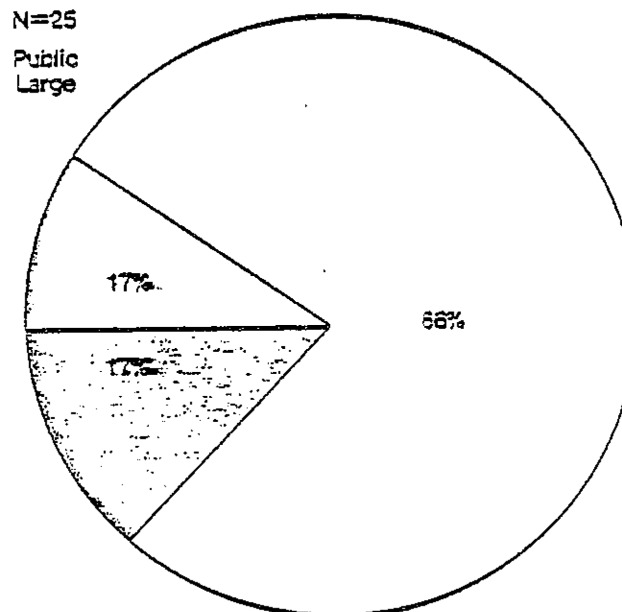
Ambulatory

N = Number of Respondents Providing Percentages









*Non-weighted average of states responding.

Tables 5 and 6 describe the average per diems and the range of per diems by ICF/MR type. Although there is not a wide range in the average per diems provided by type of ICF/MR ($55 for small public; $59 for small private and $44 for large private), large public ICF/MRs continue to receive higher average per diems than any other category of ICF/MR facility.

Twenty-four of the 32 states providing information on large public ICF/MRs indicated that their average per diems fall between $40 and $70 whereas ten of the 13 states providing information on small privately-administered ICF/MRs have per diems ranging from $20 to $55.

In terms of total operational costs requested from the states participating in the survey, total figures for each type of ICF/MR facility were presented in the previous sections. Since the same states did not respond to all questions, it is difficult to accurately compare the costs of one type of ICF/MR with another. However, nine states were able to provide rough estimates of their operational costs for both large public ICF/MRs and small privately-administered ICF/MRs (**Alaska, Florida, Idaho, Michigan, Montana, Ohio, Oregon, South Dakota** and **Virginia**). It should be noted that several of these states have only one small privately-administered ICF/MR. Nevertheless, for those states, in FY 1979, approximately $335,252,494 was spent in large public ICF/MRs whereas only $31,326,814 was spent in small privately-administered ICF/MRs.

By taking this estimate, it appears that the overwhelming majority of ICF/MR funds continue to be spent in large public institutions.

TABLE 5. Average Per Diems By ICF/MR Type as of June 30, 1979

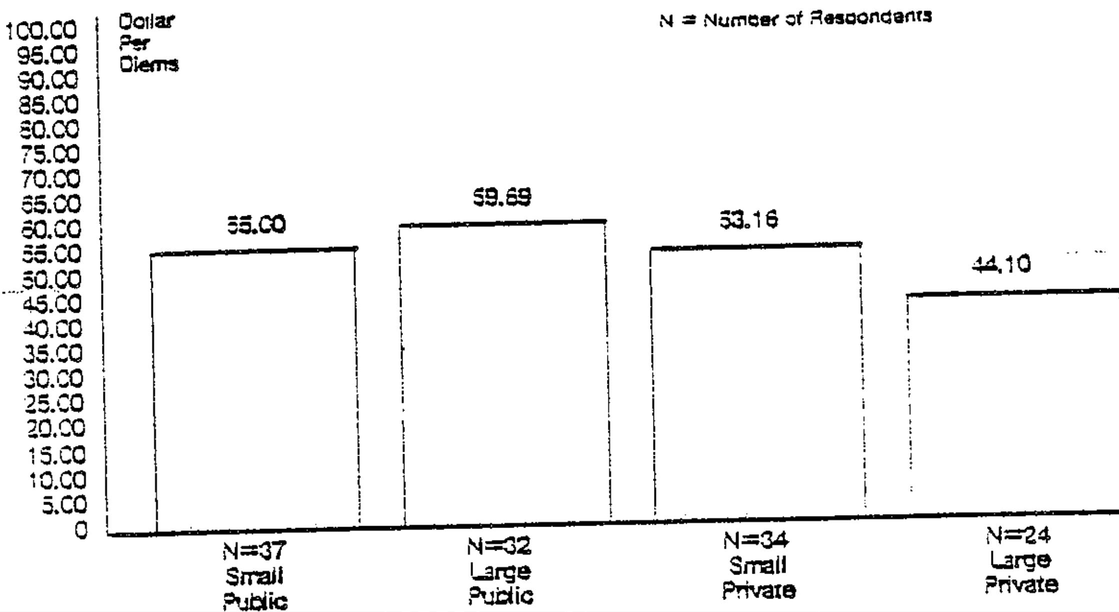
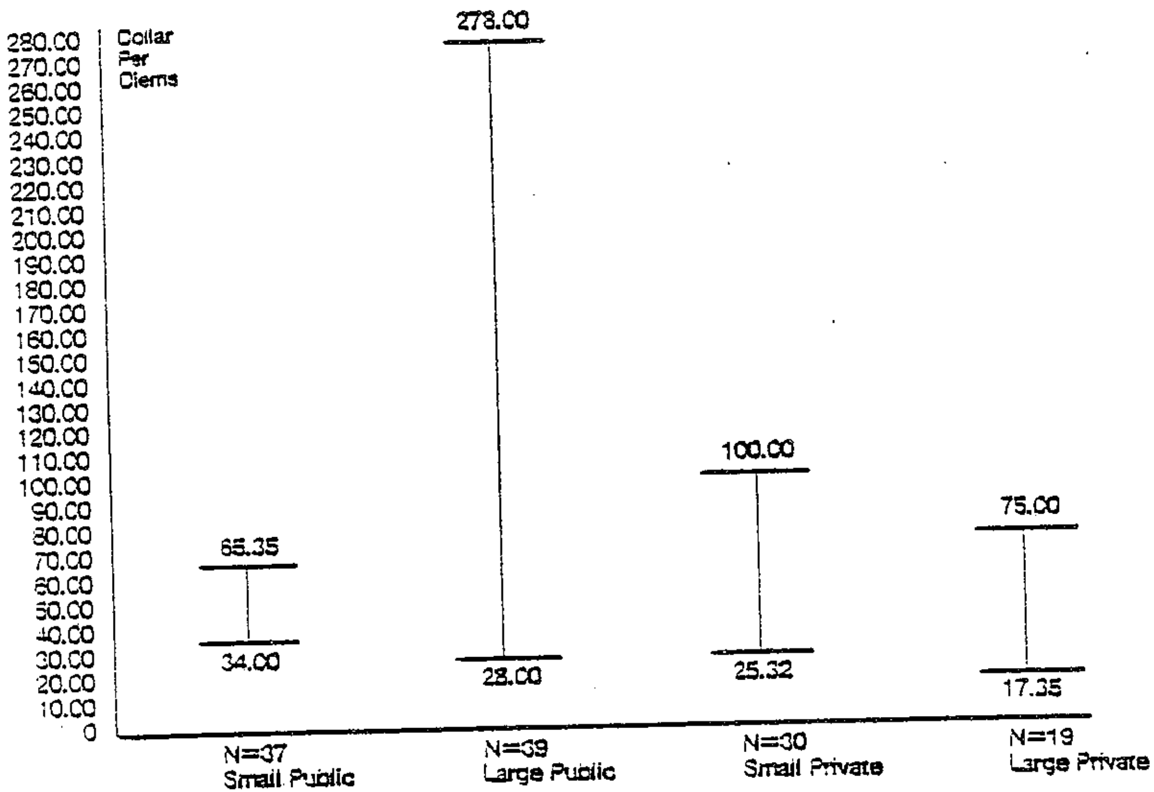
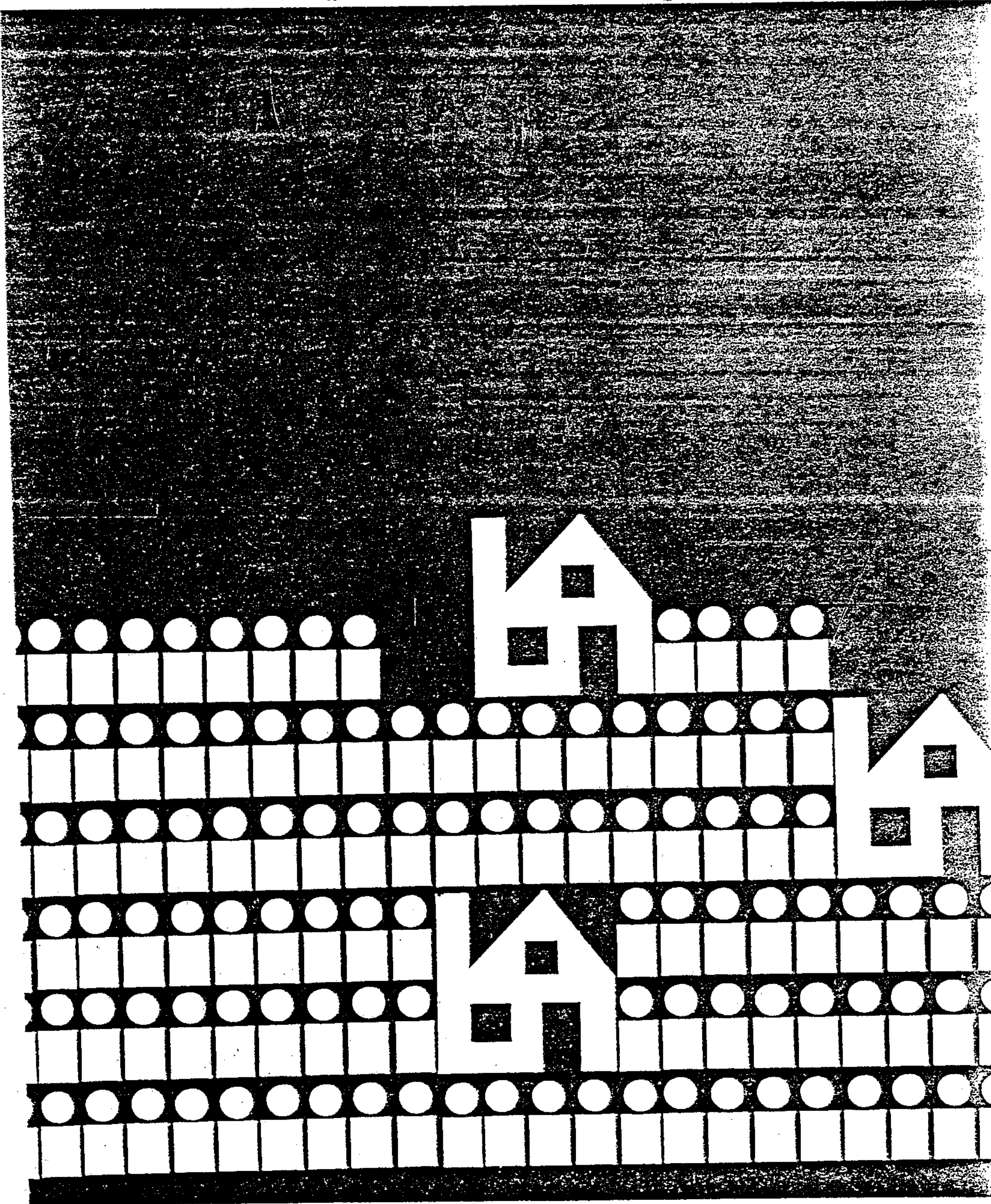
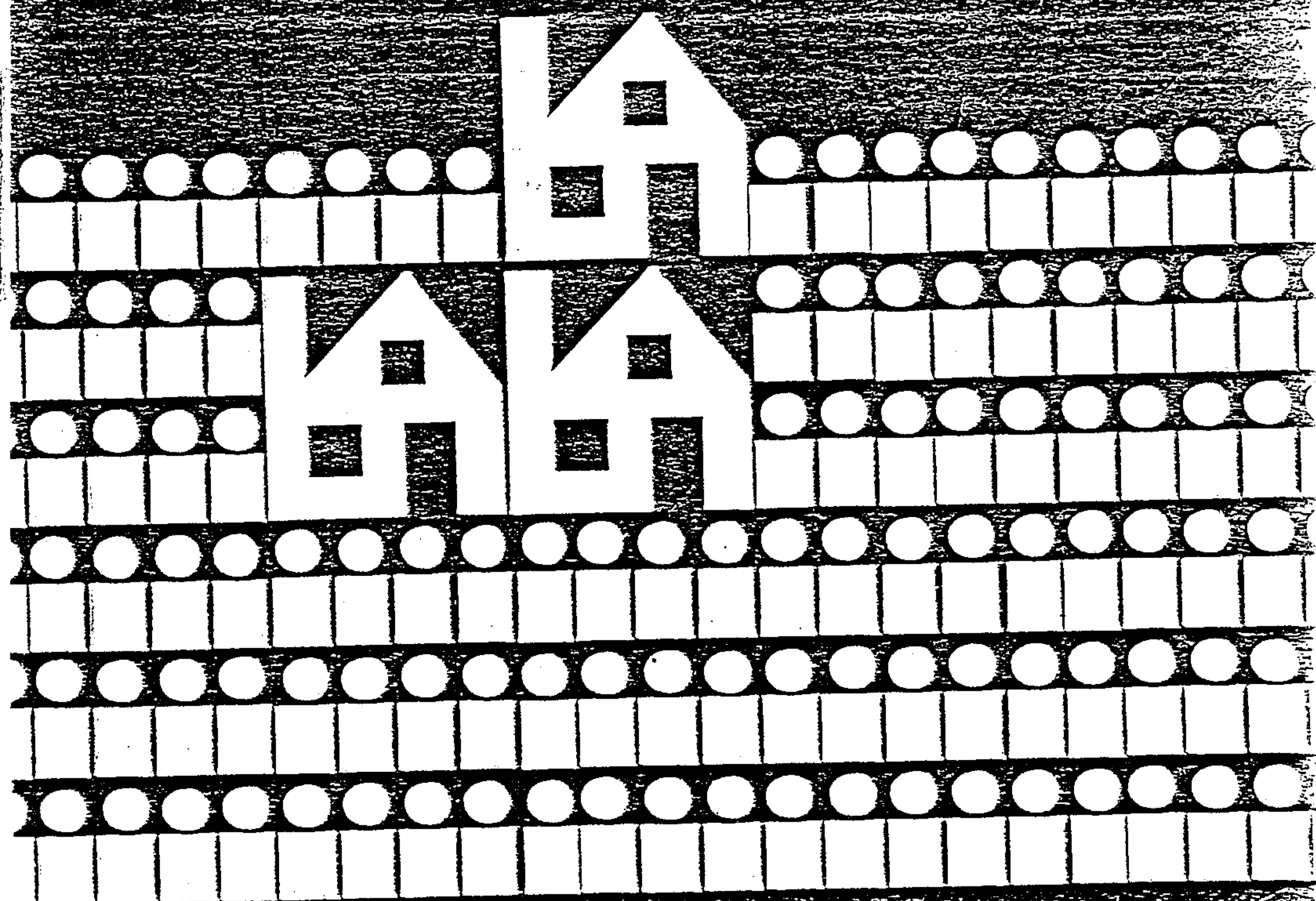


TABLE 6. Range in Per Diems By ICF/MR as of June 30, 1979





III. POLICY IMPLICATIONS FOR THE FUTURE DEVELOPMENT OF ICF/MRS



I. QUALITY ASSURANCE

A. Surveying, Licensing and Certification

Survey and certification procedures for large and small ICF/MRs varied from state to state. Most state officials indicated that their licensing and certification procedures generally follow federal guidelines for ICF/MRs. For these states, the MR/DD agency has either a limited role or "no role what-so-ever" in the survey and certification process. Other states report they have established additional standards and requirements for ICF/MRs. These requirements may or may not be more restrictive than the federal standards. When the MR/DD agency does participate in the survey and certification process, it is generally to assure that all facilities meet additional minimum state criteria established by the MR/DD agency. Consequently, the MR/DD agency has licensure responsibility prior to survey and certification by the health department (e.g., **Ohio, Rhode Island, Alabama**), or conducts additional review and approval procedures for small facilities (e.g., **Colorado, Minnesota, Michigan**).

In **Rhode Island**, for example, the Department of Mental Health, Retardation and Hospitals has developed licensure standards for ICF/MRs, that must be complied with before the Health Department can survey and certify. Officials in the MH/RH Department in Rhode Island, however, are trying to eliminate this latter process because their licensure standards are less stringent than the federal ICF/MR standards. Instead, the MR Division in Rhode Island is trying to establish responsibility for endorsing all ICF/MR programs. In addition to the MR Division's licensure responsibilities, officials in that department noted that they are trying to establish a monitoring and evaluation unit to develop program standards for small ICF/MRs that adhere to normalization principles. These standards will be related to program rather than licensing issues, and will emphasize quality of life issues. They will address such questions as, "Is it a place where you would want your son or daughter to live?"; "Does the bedroom reflect the individual's personality?"; etc.

Small ICF/MRs in **Minnesota** also must meet certain Division of Mental Retardation programmatic criteria/standards before the facility is licensed and certified by the State Department of Health. When a provider applies for

ICF/MR funding, this triggers action among three departments/divisions: Health, Mental Retardation and Finance. All three agencies work together in reviewing the application. The Division of Mental Retardation, however, has ultimate control over the approval of any potential ICF/MR provider. This action also applies to agencies desiring to establish residences over 16 beds.

Other states that will be developing small ICF/MR programs in the near future are also contemplating various roles for the MR/DD agency in the surveying, licensing and certification process concerning Title XIX facilities. State officials in **Maine** noted that responsibility for licensing and certification currently rests with the Department of Human Services, an overall cabinet post. The Bureau of Mental Retardation, however, must sign a statement documenting that the proposed ICF/MR residence is programmatically sound before the licensure and certification process for small ICF/MRs is completed.

Other states, including **New York, South Dakota, North Carolina,** and **Colorado,** have either established various responsibilities for the MR/DD agency, or adapted additional standards applicable to ICF/MRs. In **New York,** the Department of Health has delegated surveying responsibility for community-based ICF/MRs to the MR/DD agency. **South Dakota** has adopted the JCAH AC-MR/DD standards for small ICF/MR facilities—standards that are somewhat more stringent than the federal regulations. In **North Carolina,** all small community ICF/MRs must comply with state group home guidelines, in addition to federal regulations. Officials in **Colorado** noted that their procedures for surveying small and large facilities are somewhat different. For small facilities, Colorado has incorporated additional criteria into their survey which were adopted from models in Michigan and Minnesota (discussed at later point).

B. Client Eligibility Criteria for Small ICF/MRs

Several other states have established additional client eligibility criteria for small ICF/MRs. It appears that there is a wide diversity among the states as to whom they regard as eligible for ICF/MR services. **Texas** will qualify those clients who are in need of transitional living services. Although IQ is a factor in determining eligibility **Texas** also looks at the level of adaptive behavior and other physical and behavioral characteristics. Overall, however, the client must benefit from active treatment. Further, active treatment as defined in Texas regulations can include special education classes and pre-vocational training. As evident in Texas' response to the survey, most of their clients in small ICF/MRs fall into the mild/moderate range of retardation.

In **Vermont,** clients must have substantial programming needs in order to qualify for ICF/MRs. As noted by a Vermont staff person, these clients are more

likely to be in the severe to profound category.

Similarly, **Michigan**'s AIS/MR facilities will serve those residents who have multiple handicaps and/or a level of self-help skill development which requires continued intensive habilitative training and interdisciplinary program services support. Residents who are medically fragile or who have related medical problems that require intensive medical supervision will not be served in AIS/MR facilities.

New York also has developed additional client eligibility criteria for admission to their community-based ICF/MR program. For admission to either a state operated or privately administered small ICF/MR, an individual must evidence at least one of the following several characteristics:

1. A diagnosis of a developmental disability, a health care or other habilitative or rehabilitative need, which is evidenced by a severe or moderate deficit in at least one (1) area of adaptive behavior.

2. A diagnosis of a developmental disability and a severe behavior problem. Such clients shall not manifest a primary diagnosis of mental illness. In the case of an individual who has demonstrated a behavior or behaviors which resulted in injury to other persons, or had the potential for injuring other persons, the review and recommendation is required of an outside consultant committee consisting of at least a psychiatrist, one QMRP psychologist, and one other QMRP. The committee shall include as part of its membership a representative of the provider and a representative of the DDSO. This committee shall consider the following factors in determining the appropriateness of admission.

    a. The client is in need of the highly structured programming which can best be provided at the Intermediate Care Facility, and no less restrictive need-appropriate service exists.

    b. The lack of highly structured programming will result in a probable increase in the incidence of the severe behavior problem.

    c. The Intermediate Care Facility can provide such programming. (The fact that such programming does not currently exist at the facility shall not be the overriding reason for denying admission.)

    d. How frequently these incidents of antisocial behavior must occur in order for an individual to be judged appropriate for ICF level of care depends to some extent on the severity of the problem and its history, but generally, incidents which occurred more than two years ago should not be used to justify admission.

An Intermediate Care Facility may impose more restrictive admission policies with approval of the Commissioner, to allow it to focus its services on a specific

set of health, habilitative or rehabilitative needs of the developmentally disabled (e.g., agency wishes to deal primarily with developmentally disabled individuals evidencing severe behavior problems). However, admission may not be limited to a specific diagnostic population of the developmentally disabled.

Upon admission to the Intermediate Care Facility, a Level of Care Eligibility Determination shall be completed for each client in the form and format prescribed by OMRDD.

C. Administration/Management

At least five state MR officials noted that they have good working relationships with their state health departments (**Virginia, Ohio, South Carolina, Colorado, Illinois**) concerning their survey and licensing process.

Virginia, for example, has worked with its health department to train health department surveyors in the area of developmental disabilities.

In past years, the Ohio Department of Health contracted with the MR/DD agency to do program surveys. Although the health department severed this contract as of January 1, 1980, they have not yet been able to hire someone to complete the surveys. As a result, the MR division is still participating in these surveys, and anticipates that it will continue to do so in the role of consultant. In addition, the Ohio Department of MH/MR and the Ohio Department of Public Welfare have entered into an interagency agreement to provide the maximum amount of coordination in the delivery of medical care and services to mentally retarded individuals that are hospitalized or institutionalized under the Title XIX program.

In **Illinois,** certification is done by the Department of Public Health. The Department of Mental Health, however, is working with Public Health to establish an interagency agreement concerning utilization review and quality assurance. Under this agreement, the Mental Health Department will actively participate in the IPR and UR survey, and the Public Health Department will have the final sign-off.

In **Colorado,** the Division of Developmental Disabilities must first approve each ICF/MR application for less than 16 beds before it is forwarded to the Department of Health for certification. Further, the Division has its own survey team consisting of Central Office staff and representatives from around the state who survey small ICF/MR residences in addition to the Health Department. The two agencies have developed a close working relationship and Health will not issue a license without the Division of DDs prior approval. The Divison's survey team uses a checklist which has incorporated elements from the Program Analysis Service System (PASS) and criteria developed in **Michigan** and **California** to review each small ICF/MR. The Division's survey is completed in one day and

their findings are then sent to the provider with a timetable for making improvements.

States with limited participation in ICF/MR surveys and certification noted that their roles are usually in the form of technical assistance. For example, in **Wisconsin**, the Bureau of DD is only involved in reviewing the program statement for a facility. In **Florida** the Developmental Services Program Office does not participate in the survey or certification process except in technical assistance, monitoring, planning, and policy making for ICF/MR programs.

D. IPR and Utilization Review

Approximately 11 state officials indicated that IPRs and URs were generally ineffective and inefficient. This mainly stems from the review teams' lack of appropriate skills concerning developmentally disabled persons and their orientation toward the nursing home, medical model.

A recent report prepared by the MR/DD Division in **INDIANA** summed up the problem as follows:

"Nursing homes which have mentally retarded people and ICF/MRs are too frequently licensed and monitored by agencies and persons lacking necessary familiarity and expertise in the area of mental retardation. Typically, the surveyors are not trained in the developmental model nor oriented to the developmental process. Therefore, state surveyors and evaluators know little of current methodologies, technologies, or advancements in the field of mental retardation. They often know even less about how these processes might be implemented. In fact, their main training is in the medical aspects of human service."

Many state officials consistently expressed the sentiments noted above. One state official related a story to illustrate his point.

A physician on the review team did not want to classify a client for the highest level of care because he said the client was too dumb to have that amount of money spent on him. He rationalized that his own son at Harvard doesn't receive that much money!

Another state official referred to the IPRs as "cattle calls" — four unqualified people enter a facility, shake hands, round up the clients, ask their names, shake their hands, and leave. In essence, they said it is perfunctory and ineffective.

On the other hand, approximately 14 state officials noted that IPRs and URs were somewhat helpful, although at least seven states qualified their statements by emphasizing that they are often too concerned with documentation and the medical model. Where IPRs and URs were viewed positively, it was mainly due to the participation of persons trained in MR/DD on the review team. In **Virginia**, the health department has trained surveyors in developmental disabilities. In **Washington**, developmental disability specialists are a part of the utilization review team. In **North Carolina**, all ICF/MR certification team leaders have been employees of the mental retardation centers.

E Information

At this time, very few states have developed specialized management information systems specifically applicable to the ICF/MR program. The MMIS has not proved to be useful for gathering data on ICF/MRs. **Montana**, for instance, noted that the system is not applicable to the MR/DD population.

Several states, however, have developed a general system that tracks all MR/DD clients in the state. **Texas**, for example, utilizes a modified version of a behavioral characteristics progression which computerizes all MR/DD clients' progress. **Florida** utilizes a client information system which maintains complete data on every client in the state in such areas as client progress, and habilitaton plan information systems. **Oregon** also is looking to develop a computerized statewide client assessment and tracking system, as well as putting results of the IPRs on a computer. **Minnesota** has been able to generate client specific data, including clients in ICF/MRs, through its Minnesota Developmental Programming System.

II. PLANNING

A. Current Exemplary Programs

Michigan, Minnesota and a few other states have been recognized as developing "model" small ICF/MR programs. Implementation procedures for **Michigan**'s small ICF/MR program, known as the Alternative Intermediate Services for the Mentally Retarded (AIS/MR) were published in December, 1977 and are still operative. The AIS/MR program serves mentally retarded persons (or persons with related developmental disabilities) who are in need of intense habilitative training, 24 hour supervision, and active treatment in a community setting. The program is composed of residential facilities of less than 12 beds that provide ICF/MR services to clients in conjunction with **Michigan**'s Regional Centers for Developmenal Disabilities.

AIS/MR clients receive the same services as those provided to Regional Center clients, however, AIS/MR services are procured from community based generic providers primarily under the auspices of local community mental health boards.

Clients in AIS/MR residences are the responsibilities of the State Department of Mental Health and the local AIS/MR administrative unit. These units are attached to various Regional Centers for Developmental Disabilities and perform five basic functions: 1) residential alternatives development; 2) case management; 3) clinical supportive service and/or technical assistance 4) billing coordination; and, 5) internal coordination. The AIS/MR units are also responsible for site and program development. This includes contacting builders and potential investors who may want to invest in community residential development.

Private investment has spurred the development of small ICF/MRs in **Michigan**. The use of private investment is advantageous to both the state and to private investors. This arrangement enables the Department to hold ten year leases with each private investor and at the same time, allows the private sector to invest in property as a tax shelter. The Office of Management and Budget executes and oversees the lease arrangement with the private organizations.

AIS/MRs may be operated by Community Mental Health Services Board staff, non-profit specialized housing groups, or by proprietary organizations. AIS/MR providers are encouraged to contract for three to six facilities, and/or a total of 30 to 50 beds. Any contract that will cause a single corporation's total capacity to exceed 100 beds will require the approval of the ICF/MR project

manager. In addition, a single corporation may sign a maximum of eight contracts to operate AIS/MR facilities. These facilities are licensed under the Adult Foster Care License Act, or the Child Care Organization Licensing Act.

Colorado, like **Michigan** and **Texas**, has taken advantage of private investments to stimulate the new construction of small ICF/MRs. An arrangement was developed with a large west coast investment firm to sell certificates totaling approximately $17 million. Six investors purchased the certificates which will enable the Division of DD to build 32 small ICF/MRs in the next two years; each residence will be leased back to the state. These small residences will be satellites of the State's Regional Centers.

In **Colorado**, 22 private non-profit Community Services Boards (CSBs), are responsible for approving any program concerning developmentally disabled persons in the state. Prior approval by the CSB is mandatory for any provider interested in applying for ICF/MR funds. If an application is approved, the Division of Developmental Disabilities enters into a contract with each CSB which subsequently enters into a subcontract with the actual provider.

For several years, start-up funds were not available in **Colorado** to develop ICF/MRs in the community. During this past fiscal year, however, the State Legislature's Joint Budget Committee allocated start-up funds for 100 small ICF/MR beds. Approximately $1,500 is available for each ICF/MR bed. As a result, a new ICF/MR provider with up to eight beds may receive $12,000 for start-up expenses.

The Division of Developmental Disabilities monitors small ICF/MRs by employing one staff person full time to survey the small residences together with a team of interested persons from different regions in the state.

Minnesota, currently funds 174 small ICF/MRs. Beginnning its program in 1976, the Division of Mental Retardation, within the Department of Public Welfare, stimulated the development of small ICF/MRs by providing direct technical assistance to potential providers under a federally funded project. This project provided technical assistance to small ICF/MR providers at a time when no other state in the country had any experience developing small ICF/MRs. The technical assistance team acted as a resource on all issues concerning development, financing, certification and licensing of small ICF/MRs.

In **Minnesota**, all small ICF/MRs must be licensed under Rule 34, before the ICF/MR can be certified by the Department of Health. This rule is a program license developed by the Division in 1971 for any facility providing residential or domiciliary care services for mentally retarded persons. In addition, each individual client must be determined to be in need of the type of ICF/MR service to be delivered in a small group home.

Minnesota's small ICF/MR program is managed at the county level where county welfare workers perform case management functions. Final sign-off and approval of ICF/MR applications rests with the Division of Mental Retardation.

Several other states will utilize innovative procedures as they proceed to develop small ICF/MR programs. **Maine**, for example, will provide programmatic assistance to potential providers who desire to establish small ICF/MRs.

The Bureau of Mental Retardation will pay a portion of the development costs to get the residence underway. These pre-development costs will be paid through state grants and will help defray some of the costs for the certificate of need application, preliminary architectural plans, and lawyers' fees.

Rhode Island is currently operating a small ICF/MR program, however, state officials noted that this program will be expanding. For its 20 new small ICF/MRs, the Division will hire one person to administer 12 homes with four persons in each home. As a result, each administrator will be responsible for 48 persons. This administrator will be paid a higher salary because of the additional residences he or she will have to oversee. Live-in staff, houseparents, will continue to provide the day-to-day supervisory services for the clients in each home, while supportive services, i.e., social worker, physical therapist, occuational therapist, psychologist, will be shared among the 12 homes. Officials in **Rhode Island** have found this administrative system lowers costs. For example, officials noted that one provider operating one home for children charges $60 per diem, while another provider, who operates five homes, experiences per diems that are approximately $35. Both providers render services to similar client populations.

B. Future Plans for ICF/MRs—State Specific

With the exception of a few states, almost all states contacted were at some stage of development for small ICF/MRs. The stages of development varied considerably from state to state. This section will capsule where several states are today in terms of small ICF/MR development.

Illinois

The Governor's Rate Review Board has approved the development of small ICF/MRs (15 beds or less) in this state. Officials indicated that the facilities will probably average approximately eight beds. The rate that has been established is $36 a day, which includes capital costs, program costs and staffing costs. The Department of Public Health also has submitted draft rules for licensure and regulation of small ICF/MRs.

The executive branch in Illinois has not appropriated funds for capital construction of new ICF/MRs. As a result, the state is purchasing existing four bedroom homes.

Louisiana

Louisiana currently has sixteen privately administered, residential facilities for the mentally retarded that are solely state funded at a total annual cost of approximately $1,720,533. The state is now looking to expand its residential program, and at the same time save state dollars through use of the ICF/MR option.

As a result, state officials are now meeting with consultants from Michigan and New York to study those states' ICF/MR programs.

Kentucky

Officials in Kentucky's MR division noted that they are in the process of working on the development of state regulations for small ICF/MRs. They have not yet received a firm committment on funding from the Bureau of Social Insurance. Three private vendors, however, have been issued a certificate of need. In addition, the State Health Plan in Kentucky has called for 600 beds of "Model B" type facilities (15 beds or less).

Maryland

Officials noted they were planning to develop small ICF/MRs. The Department of Health and Mental Hygiene has been working with Medicaid officials concerning this issue. A joint task force has been created and will make recommendations to the next legislative session (January).

New Hampshire

Officials indicated that they would like to develop small ICF/MRs, but are waiting both for their legislature to give some policy direction, and for a decision on a class action suit pending against the state.

Utah

Utah officials stated that they are in the process of bringing in the Director of NASMRPD to assist them with developing preliminary plans for small ICF/MRs.

Tennessee

Tennessee is in the process of developing small ICF/MRs. These facilities will be sponsored by private non-profit organizations. At the time of the interview they anticipated developing 84 beds to be distributed among eight homes. The range of beds will be from 6-12. Each home will offer a different level care, ranging from intensive care to a less restrictive environment.

Washington

Officials in Washington noted they are in the preliminary stages of developing small ICF/MRs. The state received four proposals at the time of the interview, and a certificate of need has been awarded for one.

California

On July 17, 1980, Governor Edmund G. Brown Jr. signed Assembly Bill 2845. This legislation gives the Department of Developmental Services authority to develop a system of small, 15 beds or less, intermediate care facilities program which will offer primarily habilitation services for persons with special developmental needs.

A new category of state licensing is established. Regulations under which intermediate care facilities are currently licensed are oriented toward providing skilled nursing services. All existing ICF-DDs are large and institutional in nature and the staff in these facilities concentrate more on medical care rather than on habilitation and developmental needs.

AB-2845 mandates that the Departments of Developmental Services, Health Services, and the Office of Statewide Health Planning develop and implement licensing, Medi-Cal and construction regulations to assure that persons with special developmental needs will have appropriate development and health services, in the least restrictive environment, with maximum use of community services, and that licensing and certificate of need fees are set to encourage the development of new facilities.

Two million dollars have been appropriated with this legislation. This money will provide community placement for clients in state hospitals who have been identified by the Department as being appropriate for placement in a small, residential, intermediate care facility.

The Department will allocate a portion of the $2 million to develop small intermediate care facilities and expend other funds for development of community programs including independent living for persons with special developmental needs.

C. Role of Compliance Plans in ICF/MR Development

The majority of officials noted that their state institutions would not meet the July 1, 1980 deadline for compliance with standards set forth in the federal ICF/MR regulations. The majority of these states are either in the process of receiving an extension until July, 1982, or already have been granted a waiver until that date.

The single greatest obstacle to meeting this deadline results from the physical plant requirements of the ICF/MR regulations. Although fewer staes mentioned "staffing problems" as their major difficulty in complying with federal regulations, many states did mention problems in this area as well.

Because most states have been involved in formal deinstitutionalization efforts for several years, it is unclear whether or not state compliance plans are directly tied to community residential development. In some states, officials were absolutely clear that the development of small ICF/MRs was directly tied to the state's compliance plan (**Florida, Illinois, Michigan, New Jersey, New Hampshire,** and **Vermont**). In other states, deinstitutionalization was already underway and officials stated that compliance plans were more of a side issue and had little direct impact on the development of small ICF/MRs.

Other state officials noted that their compliance plan served to upgrade and maintain their state institutions (**Montana, Wisconsin, Texas**) as well as develop residential facilities. **Montana** also noted that the compliance plan stimulated movement to regular nursing homes and regular group homes, rather than ICF/MRs. They also noted that the greatest effect on community arrangements was mainly due to their deinstitutionalization movement. **Washington** also

related their general deinstitutionalization policy as a major factor in the development of residential arrangements.

D. Certificate of Need

The certificate of need process has proven to be a burden to small, community ICF/MRs. This is attributed to the long and complicated process that is associated with CON applications rather than denial of those applications.

Two basic problems associated with CON were expressed by state officials:

- The criteria developed for CON are not suitable for ICF/MR facilities. They are more suitable for health and medical services. In addition, HSAs and SHPDAs are not familiar with ICF/MRs and therefore cannot judge them appropriately.
- The CON process is extremely time consuming. In **Vermont** for example, it takes 150 days at the minimum to get through the entire process. In **Florida**, it takes 141 days to receive a certificate of need. By the time approval is received, interest rates have increased and prices have changed, causing yet another complication in both the ICF/MR development process and the CON application procedure.

Some states like **Texas** and **Colorado** do not require the small, 15 bed or less facility to go through the CON process. The Texas Health Facilities Commission, for instance, has removed their role in the review of these facilities. Other states have tried to shorten the time problem by combining the numerous applications for facilities that are converting into one certificate of need (**Maine**). In **Rhode Island**, the SHPDA is allowing the MR/DD agency to submit a CON for their four-year plan. This has been approved with the stipulation that two years from now, MR/DD must present a progress report.

In a letter to Patricia Harris, Secretary of HHS, the Governor of Florida has asked that consideration be given to waiving CON review for all ICF/MRs and other facility expenditures which are primarily financed and operated by state government. Among the reasons cited for the waiver request by Florida officials are the following: the time consuming process associated with CON review; the fact that many of the ICF/MR projects are simply a replacement or conversion of existing state-owned and operated institutions; the applicability of the CON requirements to review only health services and expenditures when the primary services offered through an ICF/MR are habilitative in nature; and the duplicative nature of the process given the previous executive and legislative review and action taken by elected state officials.

The Commissioner of Ohio's MR/DD Division also has explored many of

the issues related to ICF/MRs and CON in a letter to Janice Caldwell, Director of the Division of Long Term Care, Health Care Financing Administration. Some of the issues cited in the letter include:

- Whether facilities serving MR/DD clients were intended by Congress to be reviewed in the CON process;
- The fact that existing facilities must receive CON approval prior to being certified as an ICF/MR;
- The nature of the review process—HSAs are unfamiliar with ICF/MRs. The letter cited one particular HSA area review meeting where members of the MR/DD Division were invited to provide some background information on ICF/MRs. During the meeting the question was raised, "What is an ICF/MR?"
- The nature of the criteria by which ICF/MRs are reviewed are inappropriate to those facilities.

III. PROGRAM OBSTACLES

By and large, most state officials agreed that the federal ICF/MR regulations tend to constrain the development of small facilities in the community. Most of these problems relate to the difficulties of adapting a small, community program committed to the concepts of normalization to largely medically -oriented service standards.

The following is a list of obstacles that were repeatedly cited by state officials:

- *Recertification of clients' need by a physician every 60 days.*
  According to state officials this seems unnecessary and wasteful. As noted by several states, a mentally retarded client's "condition" is not going to change every 60 days.
- *Initial diagnosis and evaluation is required but not reimbursable.*
- *Requirements for an array of services i.e., QMRP, pharmacist, dietician, etc., that are too costly in a small setting.*
  Approximately 75 percent of the states noted that staffing was a significant problem in small residential facilities. Many believed that the requirements for certain full-time professionals (i.e., pharmacist, Qualified Mental Retardation Professional, dietician, occupational/physical therapist) were unnecessary and too costly for small facilities. This was particularly true in rural areas where there were few qualified health professionals to assume these positions.

- *Fire safety requirements present major problems in development of small ICF/MRs.*

There appears to be a significant amount of confusion and frustration among states concerning the application of Life Safety/Fire Safety code provisions in small ICF/MRs that house mobile, non-ambulatory clients capable of self-preservation, as well as other clients who are either mentally or physically incapable of self-preservation. For example, **Texas** continues to use the institutional section of the 1976 Life Safety Code for mobile, non-ambulatory clients capable of self-preservation even though a U.S. Department of Health and Human Services memorandum in 1978 permits states to request waivers of the institutional code. The Lodging and Rooming House section of the code can be used for mobile non-ambulatory persons capable of self preservation.

Other states, however, (**Michigan** and **Minnesota**), have applied the Lodging and Rooming House provisions of the Life Safety Code (LSC) for those clients who are mobile, non-ambulatory and capable of self-preservation. **Michigan** for instance, has developed guidelines which require one attendant to be on duty at all times for every two non-ambulatory residents in a small ICF/MR. Even though **Michigan** is attempting to use a less restrictive version of the LSC, state officials indicated there are still problems in meeting fire safety and life safety requirements. For example, the requirement for 40 inch doorways; the inability to have basements unless they are closed during the duration of the ICF/MR lease; the required thickness of the dry wall; as well as other technical aspects of the code, all present obstacles in the development of such residences. As noted by **Michigan** staff, new construction is almost always necessary which will directly result in higher costs. (See "Additional Requirements for Non-Ambulatory AIS/MR Facilities Housing 12 or Less Residents," published by the Michigan Division of Community Programs, undated.)

Massachusetts has encountered difficulties in developing ICF/MR residences for clients who are not capable of self-preservation. These residences would include clients both physically and mentally incapable of exiting a building within two and one-half minutes. In order to avoid developing residences with only persons who are not capable of self-preservation the Department of Mental Health, Divison of MR, has proposed a modified group residence (MGR). This home would have a maximum of 12 residents, with no more than eight persons who are not capable of self-preservation. Of those eight, not more than two would be non-ambulatory. If there are more than two non-ambulatory clients, the residence would then have to comply with the more restrictive institutional provisions of the 1976 LSC. In addition, one staff person must be available for each client certified as not capable of self-preservation.

Rhode Island officials also noted that they are experiencing problems similar to those in Massachusetts as they move clients from the institution into the community.

- *Accessibility Requirements—Section 504 and American National Standards Institute (ANSI) standard present major obstacles.*

Several states including **Colorado, Michigan** and **South Carolina** noted difficulties in applying the ANSI standard for accessability to small ICF/MRs. All federally funded facilities, including ICF/MRs, must meet the ANSI standard. Although the ANSI standard has recently been revised to include residential facilities, traditionally, this standard has been oriented toward public facilities.

As a result, many of the design criteria present serious cost and programmatic implications when applied to small community residences. For example, a Colorado Division of DD official noted that ANSI standards require large parking lots and 40 inch wide hallways. In addition, these standards must be applied to apartments as well as to single family homes.

The implication of ANSI and Section 504 are two-fold. First, many of these criteria, such as the parking lot requirement, constrain agency efforts to promote normalization. It is clear, as noted by Colorado staff, which home on the block is occupied by disabled persons from the size of the parking lot outside the home. Second, if all small ICF/MRs are required to meet these accessibility criteria, officials noted that building new facilities may be the only mechanism for meeting these requirements. This clearly implies a tremendous cost problem. Colorado staff have been working with their Department of Health to obtain waivers on a case-by-case basis, if necessary.

- *General Medical Orientation rather than Habilitative Orientation with Medical Support.*

As mentioned earlier, a major problem expressed by all state officials for the future development of residential facilities is the difficulty of adapting a primarily medically-oriented program to the needs of clients who require a more developmental model. This orientation not only adds significant costs to the program unnecessarily, but it lacks the primarily developmental services that are needed by mentally retarded clients.

The Indiana report cited earlier describes this schism between services and needs as follows.

"*Intermediate care facilities are primarily health care facilities and tend to be judged by medical standards which are irrelevant to the major needs of most developmentally disabled people. For the most part medical/nursing needs of developmentally disabled persons can be met in the same ways that typical people meet their needs: by health education, adaptive health aids and equipment, private doctors and clinics, visiting nurses, private and public hospitals. For those very few individuals who need to actually live in a health facility full time, 24 hours a day, seven days a week, adequate beds currently exist.*

...Regulations demand a high degree of medical intervention since ICF/MRs are a) funded through a federal health care plan administered by federal and state employees who have medical backgrounds, b) surveyed and

licensed by people with medical backgrounds or generalists, c) and operated (usually) under the guiding auspices of health care trained staff. This often results in the provision of health services to mentally retarded persons whose primary need is social and developmental...

... The bottom line analysis reveals the fact that current ICF/MR regulations and standards are fundamentally the outcome of a series of compromises; unfortunately the compromises are of the rights and needs of people who have no voice in the compromise. These compromises have taken ICF/MR standards from being clearly and undisguisedly a totally medical type facility, to what might now best be referred to as a "pseudo-medical" facility, or at best a non-specific facility which has strong medical tendencies..."

The result is often an attempt to fit a "round peg into a square hole," because the type of standards required for the program often do not fit the needs of the client. Consequently, many state officials suggested that either the program standards be changed so that states can attempt to meet deinstitutionalization goals, or that other funding mechanisms be made available so that they can develop programs more responsive to the needs of the client.

- *Requirements that medication must be administered by medical personnel.*
  Some states do not have a certification program for the administration of medication by nonmedical staff.
- *Other problems related to ICF/MR development.*
  A. Funding Issues — For example, the reduction of SSI payment to $25 when the client receives 50 percent of his or her support from Title XIX.
  B. Lack of Start-Up Funds — There was overriding agreement throughout the states that one of the major obstacles to developing community facilities was the lack of start-up funds.

IV. FUNDING

A. Reimbursement Policies

1. Reimbursement and Rate Setting Methodologies

Twelve state officials noted that reimbursement for ICF/MRs is provided on a retrospective basis, while seven states (**Tennessee, Montana, Kentucky, Louisiana, Washington, California and Arkansas**) indicated they utilize a prospective reimbursement methodology. In addition, almost all states utilize a historical based rate setting methodology, adding inflation factors and certain price indexes to the historically based costs.

In general, rates for small and large ICF/MRs are determined in the same manner. However, some states indicated that small facilities could not utilize the historical based methodology since there are no historical costs. In **Vermont**, for instance, rates for small facilities are determined on an actual cost basis, according to an approved budget.

2. Reallocation of Institutional Resources

Most states agree that devastating effects would occur if current federal rules were changed to reduce Title XIX reimbursement rates to large state facilities. They also believe this policy would not necessarily stimulate the development of community residences unless a concurrent increase in reimbursement was applied to community facilities.

Outside of a few states that have already begun to make large investments in community living arrangements and have relatively few institutional beds, most state officials believed that a reduced reimbursement rate would have drastic effects on their state program. The most immediate and dramatic effect would be a major reduction in the quality of care provided at the institutions. In general, the states believed that there would be virtually no means to maintain the standards that have been imposed by the federal government without concurrent federal financial support. Thus, a drastic reduction in services would probably result, along with a few law suits. For those states like **California** and **Michigan** that have made substantial investments in community care, the effect of this policy would be less consequential. In **California** for instance, federal payments are not as important as elsewhere: the state is already pumping $50 million into communi-

ty care, on top of the SSI federal payment.

Despite the predicted disaster for large public institutions, most states were not sure if this policy would stimulate the development of community programs. Some states believed that only a concurrent increase in community reimbursement rates would serve to foster the development of residential arrangements. Yet even in this case, many officials maintained that community care still may not develop. They attributed this prediction to the large sums of money already committed to state institutions, political pressures, permanent overhead costs, and the general feeling that small ICF/MRs are not the only answer given the constraints of the current federal regulations.

An official in **Texas** indicated that their ICF/MR program may be in jeopardy as the federal Medicaid match decreases each year in that state. The official stated that the ICF/MR program is becoming "more hassle for less money" as the federal government is placing pressure on the state agency for stricter standards. He went on to point out that it may get to the point where a 45 percent state match is not worth the trouble, and cause the state to eliminate the ICF/MR program entirely. He noted that this has been a topic of discussion in the state legislature.

B. Alternative Financing

States were asked to comment on funding mechanisms other than Title XIX that are used to support community facilities for the mentally retarded.

Many state officials expressed frustration that they have reached their Title XX ceiling. They believed that this funding stream could be utilized for residential living arrangements, if it was available, and could help develop less intensive models for care. Basically, many officials felt that other community routes would be better suited for this type of care, (i.e., HUD). At this time, however, officials stated that the Medicaid program provides the greatest amount of financial support for care rendered to mentally retarded individuals. The underlying lesson is that the Title XIX ICF/MR program offers a convenient funding mechanism, which provides strong economic motivation for states to participate in the ICF/MR program.

Some states, however, have begun to utilize HUD (Sec. 8) funding to develop residential arrangements for mentally retarded persons.[1] **Tennessee** for example, has worked with their Tennessee Housing Development Agency to build 37 homes. They have arranged with HUD that the homes could be certified as ICF/MRs. Under this agreement, the mortgage is to be paid by Section 8, and the

[1] HUD central office staff are developing a policy on the use of ICF/MR funding to be used in conjunction with their own resources (Sec. 8, Sec. 202).

houseparents are to be paid with Title XIX money. At the present time, they have only received a verbal acceptance, and are awaiting written approval. **Rhode Island** also is becoming involved in HUD housing development. Under this program, between 20-40 slots will be available for MR individuals, and like Tennessee, the mortgage will be paid by Section 8, and Title XIX will reimburse for services. The HUD program will be run by institutional employees.

Virginia also has financed four complexes that are to be certified as ICF/MRs through HUD (Sec. 8) funding. By 1972, they expect to have 135 certified beds under this program. These developments are financed through the Virginia Housing Finance Agency, utilizing Section 8 to repay the mortgage.

V. POLICY COORDINATION

A. Federal Ambiguity in ICF/MR Policy

Within the last two decades, the federal government has consistently urged state and local governments to deinstitutionalize mentally retarded persons. In 1971, for instance, President Nixon proclaimed a national goal to reduce the nation's public mental retardation facilities by one-third within a decade. Almost ten years later, however, and despite the support of successive administrations, there is still no coherent federal policy to assist states in accomplishing this goal.

The Title XIX ICF/MR program typifies many of the problems states have encountered in dealing with an ambiguous federal deinstitutionalization policy. Robert Gettings points out some of these problems in a 1980 issue paper concerning the Title XIX ICF/MR program.

"Despite the fact that a growing number of states have begun to certify small community residences as ICF/MR providers, DHEW has never spelled out a clear, unambiguous policy regarding the desirability of developing such alternatives to large institutional settings, or the circumstances under which such small facilities may be certified as Title XIX providers. As a consequence, states which have elected to take advantage of this option have found that they face numerous impediments—the most significant being the absence of clear federal policy in this area."

One state official expressed similar sentiments in our survey. After extensive analysis, he concluded that the administration of Medicaid from region to region was so varied that he could not make any definitive recommendation to the state legislature concerning whether to follow the lead of other states (e.g.,

Minnesota), or to reject a plan to provide appropriate services in small facilities. He also felt that regional officials did not have enough experience to help states develop small residential programs for mentally retarded persons without guidance from Washington.

Other state officials echoed these statements. Their overriding feeling was that the position of the federal government on small ICF/MRs was ambiguous and unclear, creating many impediments to the certification of small residential ICF/MR facilities as eligible Medicaid providers. At the core, the problem is fairly easy to diagnose — without a regulation defining and setting standards for small ICF/MRs, states must fit their small, residential facilities under standards originally designed for large state hospitals.

B. Health Planning

Another example of the absence of a clear and coherent federal policy and its effect on all states results from the national health planning structure established by P.L. 93-641. This act has, in particular, created problems with the implementation of small, community-based ICF/MRs. These problems have not stopped outright the development of new community facilities. At the same time, however, delays caused by the CON process have slowed deinstitutionalization efforts and have undoubtedly increased construction costs.

The basic problem is an inherent conflict between a comprehensive planning mechanism that has little understanding of mental disability issues and is cost containment oriented, and a deinstitutionalization effort that is attempting to move individuals into new facilities as fast as possible, and is very expansionistic in philosophy. The goals of cost containment and deinstitutionalization are not necessarily antagonistic (indeed, they may be complimentary). The few occasions, however, where health planners and DD officials meet — new construction — is bound to lead to conflicts. Nowhere in federal law, however, has there been an attempt to resolve these apparent contradictions in federal policy. As a result, state and regional officials are left to interpret what few policy statements do exist, and it should not be surprising that they sometimes arrive at different results.

C. New Definition of Developmental Disability

Another example of the lack of a coherent federal policy is the new definition of developmental disability. Current federal law requires that if states offer ICF/MR services through their Medicaid program, they must cover the mentally retarded and developmentally disabled. The expanded definition of developmental disability, however, requires states to cover specific groups such as the learning disabled and the chronically mentally ill, for whom ICF/MR standards were never intended. In addition, few state departments in charge of serving mentally retarded citizens are knowledgeable about or able to serve these new groups of people with developmental disabilities — many have troubles even keeping their own commitments to the mentally retarded.

As a result, many state officials were unsure what effect the new definition of developmental disability would have on their ICF/MR program. Many were worried that the new definition would deluge their program with an unmanageable number of clients. **California**, for example, completed an analysis which concluded that the new definition could potentially increase their population two-fold — adding between 70,000 and 80,000 more people. Still other officials reported they simply were not going to adopt the new definition (e.g., **California**, **Illinois** and **Oregon**). **California** statutes, for example, specifically exclude the chronically mentally ill from the definition of developmental disability.

In general, many state officials believed they would not know how to handle some of the new groups of clients in the ICF/MR program who became eligible as a result of the new definition of developmental disability. All officials believed the new definition would result in increased costs in the ICF/MR line item. Whether these costs would be offset by savings elsewhere — especially in the budgets of state governments — was not estimated.

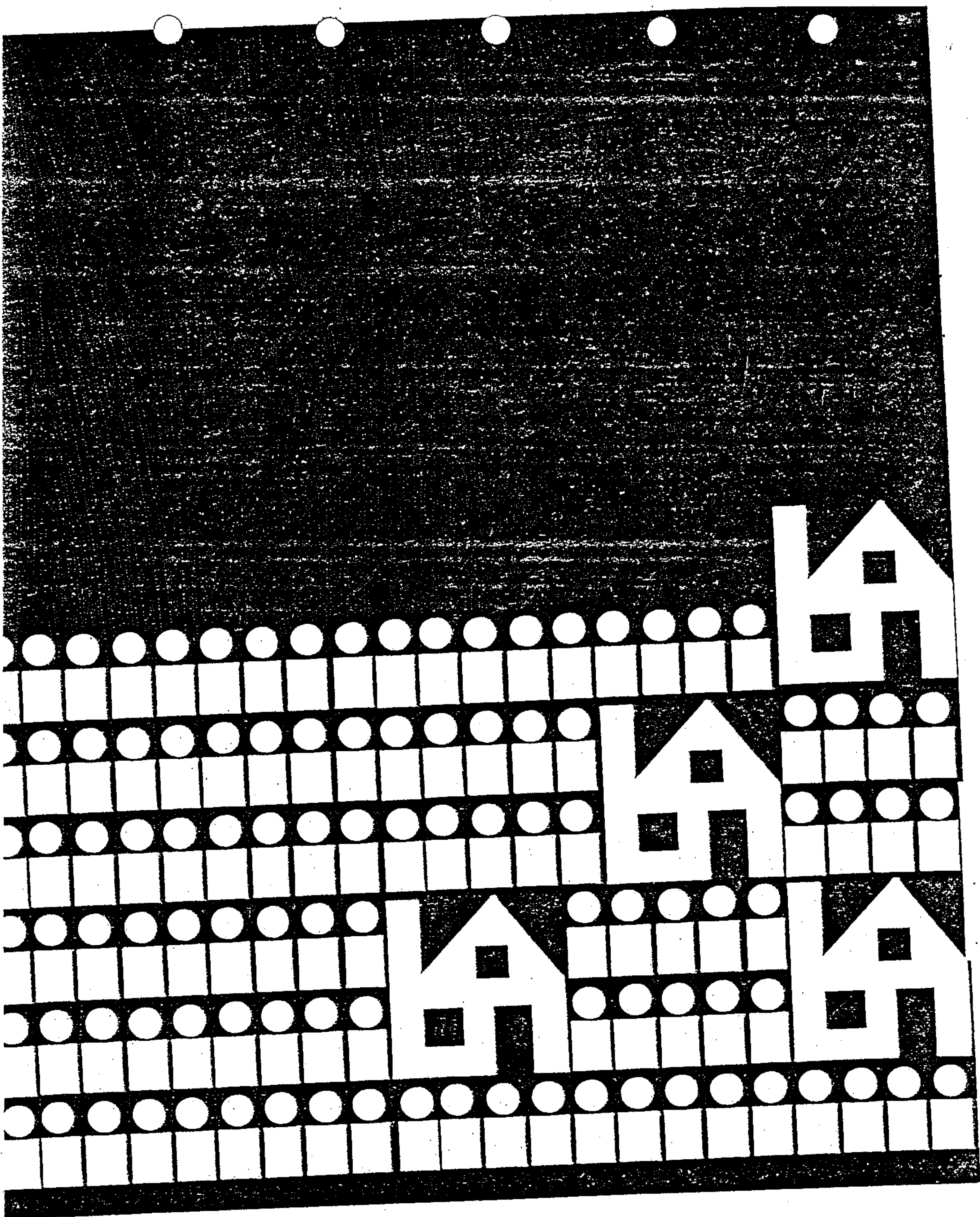
D. The Effect of Lawsuits and Court Decrees on the Development of Small ICF/MRs

A number of states responding to the survey noted that they were either under a consent decree, in the midst of litigation, or under some type of court order affecting the development of community residences for mentally retarded and other developmentally disabled persons. Some states, such as **Maine,** indicated that as part of their consent decree, the state cannot develop any new residence larger than 20 beds. Existing facilities in that state which are larger than 20 beds, however, will be grandfathered in. In addition, the decree specifies that small ICF/MRs and other community programs must take 50 percent of their clients from the class members (i.e., those currently residing in state hospitals).

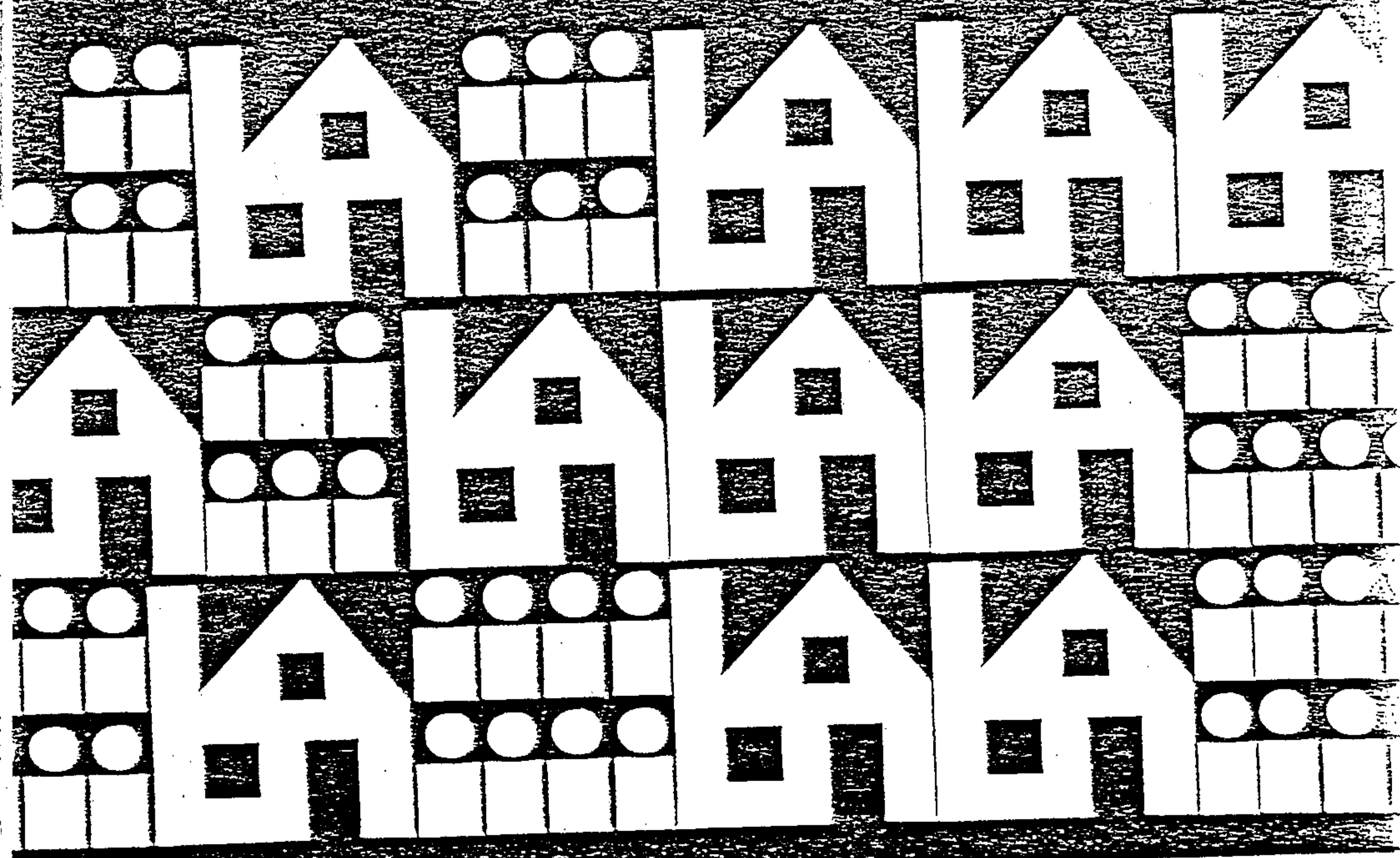
In **Nebraska**'s consent decree, the judge strongly urged the development of small community residences. As a result of this judgement, the governor requested that the state Division of MR develop a residential program consisting of homes with 15 beds or less to meet the community requirements under the consent decree.

Many other states, such as **Michigan, Massachusetts, Pennsylvania, New York** and **Rhode Island,** either have consent decrees or court orders dictating that the state government develop a significant amount of community residences, with the emphasis on small, homelike environments. Many of those state officials interviewed indicated that the court rulings have stimulated them to use Title XIX to develop small ICF/MRs.

The future impact of court decisions on the small ICF/MR residential networks is difficult to pinpoint. By implication, however, the Title XIX ICF/MR program will continue to be utilized to develop small residential facilities, because it is one of the few federal financing programs available to meet the demands of the courts.



IV. SUMMARY



Section IV—Summary

In summary, the ICF/MR program continues to pose many burdensome problems for both federal and state officials. Most of the trouble appears to stem from use of Title XIX funds to develop small, community-based ICF/MR facilities. There is much less ambiguity about the use of Medicaid funds in large state institutions that have been substantially renovated to meet ICF/MR standards. Even in the latter area, however, problems with high cost and compliance with federal standards continue to exist.

As the results of this survey of state officials clearly show, the Title XIX ICF/MR program is becoming a significant — some would say the significant — source of federal revenue to implement both state and federal policies aimed at "deinstitutionalization." A few states, like **Minnesota**, already are utilizing ICF/MR monies to fund a significant amount of community care for the mentally retarded. Other states, like **California, Massachusetts** and **Michigan**, expect to greatly expand their use of this program in coming years. In the next five years, it is reasonable to expect a nationwide increase of *at least* 500 percent in the number of small ICF/MRs — an estimate that does not include additional potential clients who may be entitled to the service as a result of the new federal definition of developmental disabilities.

Because the ICF/MR program was never envisioned as a major federal deinstitutionalization effort, however, and because its roots are in a medical assistance program designed to upgrade care in large state mental retardation institutions, there are some significant problems with the current federal policy that inhibit the development of small, community-based ICF/MRs. For instance, federal licensure and certification requirements require little or no input from mental retardation agencies, yet impose an array of medical requirements that are costly and sometimes inappropriate and unnecessary. In addition, mandatory utilization review requirements in their current format generally have proved of little value in ICF/MRs. So too, recertification requirements, non-reimbursable initial diagnosis and evaluation requirements, extensive service requirements, and even some life safety and ANSI code requirements have proved costly and sometimes inappropriate to meeting goals of deinstitutionalization, habilitation and normalization. Other problems concern the application of the federally-mandated certificate of need process to the ICF/MR program; ambiguity stemming from the new definition of developmental disability; and variation in regional interpretation of Congressional and departmental policy.

The clear message that emerged from interviews with a large number of state officials was that the federal government has provided little guidance to state governments who utilize the ICF/MR program to engage in deinstitutionalization efforts. State officials believed that few federal offices were capable of conducting technical assistance in this area, and that too many federal officials were concerned solely about meeting the purely medical and cost containment imperatives of the Medicaid program without understanding the needs of the mentally retarded.

Moreover, there was a vague uneasiness among state officials that the entire program, as it stands today, is not the most appropriate method of serving their clients. It is, however, the only readily available source of money and as a result, is expected to be used quite heavily in the future.

The first major policy consideration that should be undertaken is a major rethinking of the entire ICF/MR program itself, i.e., is the ICF/MR program a health program, or should it be funded as some other program? Current statutes and regulations continue to reflect the primarily institutional and medical intent of both the ICF/MR program itself and Medicaid more generally. Doing away with the ICF/MR program's basic status as a medical/health program and recasting the community care portion of ICF/MR as a new program—in line with the social rehabilitative and normalization goals of deinstitutionalization—would eliminate many current problems. For instance, if a small community-based ICF/MR was not considered a "health" facility or funded by a "health" program, it obviously would not have to obtain a certificate of need or meet the structural specifications of a nursing home.

On the other hand, the current open-ended entitlement nature of Medicaid makes it an enormously attractive program for both states and advocates of the developmentally disabled. Enacting a separate non-medical deinstitutionalization program that has the same financial provisions as Medicaid (entitlement plus open-ended) for the same client group may be politically difficult, if not impossible.

Consequently, if the ICF/MR program is to continue to work within the current statutes and regulations, and if it is to proceed in a more rational manner in the future, a number of changes need to be made in federal policy. They include the following:

- Clear differentiation between institutional and community requirements for certification as ICF/MR providers;
- Flexibility in community ICF/MR standards to permit centralized provision of management and staff services to small, community ICF/MR facilities;
- Programmatic and financial incentives to tie both institutional and community ICF/MRs to a comprehensive network of care for the mentally retarded, including both case management and day care;
- Programmatic and financial incentives for state mental retardation agencies to participate in Independent Professional Reviews and Utilization Reviews, as well as licensing and certification decisions;
- Recognition in institutional compliance plans that extensive physical plant renovation may be inappropriate where extensive deinstitutionalization is planned;

- Clear incentives in institutional compliance plans to promote further deinstitutionalization, including development of small ICF/MRs, such incentives might include easing of physical plant standards providing certain numbers of residents are deinstitutionalized; provision of bonus payments for deinstitutionalization; separate funding for start-up costs; etc.

- Improvement in regional office understanding of the ICF/MR program and development of ability to provide technical assistance to states;

- Provision of more technical assistance to mental retardation agencies, Medicaid agencies and community providers concerning the requirements of P.L. 93-641 and each state's applicable certificate of need law, such assistance might include development of model applications; explanations of how some states make exemptions for small facilities; advice concerning how to group facilities under one application; technical assistance on applications for renovation or conversion; etc.

- Flexibility in fire safety and other building code requirements to comport with the needs of residents (this may be provided in a forthcoming report to be completed by the National Bureau of Standards describing a life safety evaluation system for developmentally disabled persons);

- Development of a clear standard concerning how the definition of developmental disabilities applies to the ICF/MR program.

ICF/MR Survey Background Questions

1. Which agency serves as the single state agency to administer the federal—state Medical Assistance program in your state?

2. Which agency serves as the State Medicaid survey agency in your state?

3. Do you fund the development of small (15 or less) ICF/MRs in the community?

    - If yes, how is the program operationalized?

4. Has the state developed a policy limiting the size of ICF/MR facilities in the community?

    - If yes, please describe.

5. Has the state limited the sponsorship of ICF/MR facilities in the community?

    - If yes, in what ways (e.g., to non-profit or limited individual providers)?

6. What eligibility criteria has the state established for individuals placed in small ICF/MR facilities?

7. What is the role of the state mental retardation/developmental disabilities agency in conducting ICF/MR surveys and ultimate certification (e.g., training surveys, exercising formal sign-offs)?

8. Are any of the procedures used to survey and certify community ICF/MRs different than those used for large facilities?

    - If yes, please describe.

9. Does the state have any additional standards/requirements for community ICF/MRs?

   - If yes, what are they?

   - How do you require that community ICF/MRs meet minimum programmatic requirements for certification?

10. In most states one state agency is responsible for licensure and another for certification under Title XIX. What is the relationship between these two processes for ICF/MRs in your state?

11. Does your Title XIX program provide day services for mentally retarded persons?

   - Does your state certify providers of daytime habilitative services to Title XIX-eligible retarded clients?

   - How do you certify these providers?

12. What, if any, are the major obstacles in the current federal ICF/MR regulations that constrain the development of small facilities in your state (e.g., fire safety standards applicable to community ICF/MR facilities)?

   - If yes, have you requested waivers of any of the ICF/MR regulations that have proven to be obstacles?

   - What were the outcomes of the requests for the waivers?

13. Has the need to upgrade the state institutions to meet XIX standards served to stimulate the development of small ICF/MRs in the community?

14. Will your state be able to comply with the federal ICF/MR standards by July, 1980?

   - If no, will you request an extension and for what reasons?

15. How are rates determined under the Title XIX, ICF/MR program?

   - For small facilities?

   - For large facilities?

- What method or reimbursement is used (e.g., retroactive, prospective payments)?

16. A number of federal officials believe that current reimbursement policies for state run ICF/MRs provide incentives to maintain large institutions. Do you think this is true?

    - If current federal rules were changed to reduce Title XIX reimbursement rates to large state facilities, what effect would this have on the state's progam? Would this policy stimulate the development of community residences?

    (*Note: Obtain any suggestions on how to accomplish the above.*)

17. Have the Independent Professional Reviews and Utilization Reviews of ICF/MR providers been helpful to you in monitoring their performance?

    - Have you encountered any problems with these review procedures?

    - If yes, please describe.

18. Have you developed any specialized management information systems applicable to ICF/MR programs?

    - If yes, please describe.

19. Have you encountered any particular problems with the certificate of need process as it applies to small, community ICF/MR providers?

    - If yes, please describe.

20. What proportion of beds (or if not available, proportion of funds) available to mentally retarded persons in the community is supported by: (please indicate a percentage)

    ____________________SSI
    ____________________Title XIX
    ____________________Title XX
    ____________________State funds
    ____________________County/local government
    ____________________Other, please specify__________

21. What proportion of beds in the state's institutions for the mentally retarded is funded by: (please indicate a percentage)

    ____________________Title XIX
    ____________________State funds
    ____________________County/local government
    Other, please specify____________________

22. How would changes in other funding streams (e.g., SSI, federal housing, etc.) enhance the development of residential arrangements for developmentally disabled persons in your state?

    - How would such changes reduce current or potential reliance on Title XIX for such purposes?

    (*Note: If time allows, please ask the following two questions.*)

23. Under the current definition of developmental disability as defined in the ICF/MR regulations, how many additional ICF/MR beds would be needed to meet unmet demand? (Please give your best guess/estimate.)

24. As you know, there is a new definition of developmental disability which has been interpreted to include several new groups, including the chronically mentally ill. What will be the impact of this new definition on the ICF/MR program in your state?

    (*Note: Ask for any additional contacts if certain data or information could not be supplied.Also, ask the interviewee to send any relevant materials.)*

Privately Administered MR Residential Facilities

Less Than 16 Beds

ICF/MR Facilities	PRESENT: As of June 30, 1979	PRESENT: July 1978 to June 1979	FUTURE: As of June 30, 1984	FUTURE: July 1983 to June 1984	Clarifying Comments
Total no. of facilities					
Total no. of licensed/certified beds					
Range of beds per facility					
Percent of clients referred from public MR institutions					
Percent mildly/moderately retarded					
Percent non-ambulatory					
Percent mobile non-ambulatory					
Total cost (operating)					
Federal share					
State share					
Local share					
Average per diem					
Per diem range					
Total conversion costs (July 1974 - June 1979)					
State share					
Local share					
Total conversion costs (July 1979 - June 1984)					
State share					
Local share					

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State/County Administered MR Residential Facilities

Less Than 16 Beds

ICF/MR Facilities	PRESENT: As of June 30, 1979	PRESENT: July 1978 to June 1979	FUTURE: As of June 30, 1984	FUTURE: July 1983 to June 1984	Clarifying Comments
Total no. of facilities					
Total no. of licensed/certified beds					
Range of beds per facility					
Percent of clients referred from public MR institutions					
Percent mildly/moderately retarded					
Percent non-ambulatory					
Percent mobile non-ambulatory					
Total cost (operating)					
Federal share					
State share					
Local share					
Average per diem					
Per diem range					
Total conversion costs (July 1974 - June 1979)					
State share					
Local share					
Total conversion costs (July 1979 - June 1984)					
State share					
Local share					

State/County Administered MR Residential Facilities

(including state operated institutions)
16 Beds and Over

ICF/MR Facilities	PRESENT: As of June 30, 1978	PRESENT: July 1978 to June 1979	FUTURE: As of June 30, 1984	FUTURE: July 1983 to June 1984	Clarifying Comments
Total no. of facilities					
Total no. of licensed/certified beds					
Range of beds per facility					
Average no. or percent of beds occupied					
Percent of clients referred from public MR institutions					
Percent mildly/moderately retarded					
Percent non-ambulatory					
Percent mobile, non-ambulatory					
Total cost (operating)					
Federal share					
State share					
Local share					
Average per diem					
Per diem range					
Total conversion costs (July 1974- June 1979)					
State share					
Local share					
Total conversion costs (July 1979 - 1983)					
State share					
Local share					

Privately Administered MR Residential Facilities

(including privately operated institutions, nursing homes, intermediate care facilities, etc. either certified as ICF/MRs or serving primarily mentally retarded clients)

16 Beds and Over

ICF/MR Facilities	PRESENT: As of June 30, 1978	PRESENT: July 1978 to June 1979	FUTURE: As of June 30, 1984	FUTURE: July 1983 to June 1984	Clarifying Comments
Total no. of facilities					
Total no. of licensed/certified beds					
Range of beds per facility					
Average no. or percent of beds occupied					
Percent of clients referred from public MR institutions					
Percent mildly/moderately retarded					
Percent non-ambulatory					
Percent mobile, non-ambulatory					
Total cost (operating)					
Federal share					
State share					
Local share					
Average per diem					
Per diem range					
Total conversion costs (July 1974- June 1979)					
State share					
Local share					
Total conversion costs (July 1979 - 1983)					
State share					
Local share					

Glossary of Terms

Intermediate Care Facility for the Mentally Retarded (ICF/MR)

A facility serving mentally retarded persons and others with related conditions whose primary purpose is to provide health and rehabilitation services. Within such facilities, each resident for whom payment is sought must have an approved plan as stipulated in Title XIX regulations and must be receiving active treatment.

Public MR Institutions

A state or county administered comprehensive institution, residential school, hospital or state center providing services on a 24-hour, seven day per week basis to more than 16 individuals. Such facilities may or may not be ICF/MR certified.

State/County Administered ICF/MR Facility—Less Than 16 Beds

A state or county administered ICF/MR facility serving less than 16 individuals *off the grounds* of a public MR institution.

State/County Administered ICF/MR Facility—16 Beds and Over

That portion of a public MR institution that has been certified under Title XIX to receive reimbursement for ICF/MR services. This category should include the sum total of all such units even though any given unit may number less than 16 beds.

Non-Ambulatory Clients

Individuals whose physical impairments make it impossible for them to walk and/or move without assistance and who are incapable of survival without such assistance.

Mobile, Non-Ambulatory Clients

Individuals who are capable of walking and/or moving with the assistance of a mechanical device (e.g., wheelchair, walker, etc.) and who are capable of survival without assistance.

Total Cost (operating)

Total yearly operating budget(s) excluding capital improvements or repair costs amounting to more than $25,000.

Per Diem

Operating costs or charges per client day for residential arrangement.

Total Conversion Cost

Total amount of funds in the given time period required to bring residential facilities up to certification standards for Title XIX reimbursement for ICF/MRs. Costs are further broken down according to state and local (public) shares of such expenses.

Clarifying Comments

Any significant factors that could lead to the misinterpretation of the data. For instance, it may be noted that the average per diem for the state/county administered MR residential facilities in a given state does not include a depreciation factor, whereas such an allowance is included in the privately administered MR residential facility per diem figures.

AN OPTIMIZATION APPROACH TO REFORMING AND REFINANCING STATE PROGRAMS FOR THE MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED

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February 23, 1981

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Preface

Current approaches to planning and financing MR/DD services in the United States are fragmented, tend to keep important parts of the funding for services "invisible" to planners at the state level of government, tend to promote fiscal incentives diametrically opposed to what program theory and court decisions say they should be, and generally lack a coherent budget and program strategy. The result is a large, incoherent, "non-system" of public and private bureaucracies, budgets, and services which is highly resistant to change.

In the arena where change must take place -- the state government -- there are only very few instruments available for use in securing massive program reform in a system as large and complex as is the publicly-financed MR/DD system in which $10.8 billion in Federal, state, and local tax funds were spent for about 1.7 million people in 1979. These are:

- A clear national policy, with financing which backs up the rhetoric of the policy, rather than undercuts it.
- A massive, unrelenting wave of public demand for reform.
- A reform strategy which includes a detailed plan and enough new money to buy off or neutralize most of the opposition and to pay for the new initiatives.

A cohesive MR/DD policy at the national level is a preferred option, of course, and some changes in national policy already have taken place. However, it is not yet clear to what extent the new Administration will support an MR/DD-targeted reform policy and the financing needed to achieve reform. With respect to public demands for reform, whatever demands there have been in the past have not been enough to secure reform, and it seems unlikely that a new wave of public outrage is in store. This leaves only the third option, and the four sections of this paper focus on precisely such strategies.

It appears possible to link program optimization to fiscal optimization. In other words, it should be possible to maximize and reform MR/DD programs to meet the requirements of modern program and legal theory, such as the most normalized treatment in the least restrictive environment, while at the same time reducing the total costs in such a way that the costs of the reorganized and reformed system of MR/DD programs actually costs less (at each participating level of government) than did the pre-reform system.

The approach recommended in this paper calls for organizing programs along a *continuum of care*, adopting an *interagency budgeting* approach to financing them, and establishing a *continuum management* function to ensure continuing program and fiscal optimality. These concepts are defined, and discussed at length, as the basis for a state's redesigning, reorganizing, and refinancing its MR/DD programs in a manner consistent with modern theory and program practice.

INTRODUCTION

AND

SUMMARY

A community-based program of services for the developmentally disabled can be funded through intertitle transfers, client entitlements, and more effective leveraging of state and local revenues. New state or local funds are not needed. Properly managed, the program should achieve a net reduction in operating costs.

The funding strategy calls for: first, a rational approach to program design *(the continuum of care)*; second, the means to link this approach to a reasonable set of budget incentives *(interagency budgeting)*; and, third, a management method that employs the budget incentives to advantage in program development *(continuum management)*.

A. *The Continuum of Care*

A myriad of concepts have evolved to address the question of what must be done for the developmentally disabled -- prevention (primary, secondary, and tertiary), continuum of care (or need, or services), normalization, deinstitutionalization, communitization, integrated services, community-based services, various combinations of these, and others -- but there is as yet no unifying theme to satisfactorily replace that of institutionalization. A part of the problem (or, more likely, its consequence) is the lack of a completely consistent technology for coping with the developmental disabilities at any level, whether prevention, treatment, long-term care, or other (more peripheral) services. This lack is reflected in the diverse array of service systems that have come into being as alternatives to institutions.

In the past, among the competing service systems, only the institutions have enjoyed a stable professional hierarchy, uncomplicated funding, and the confidence of state agencies and legislative bodies, the judiciary, the affected families, and other groups involved in decision-making in behalf of developmentally disabled persons. Despite the many successes in normalization programs over the past decade, and the movement of judicial opinion against institutions, any movement away from institutionalization promises to be slow without the strong

backing of elected and appointed officials, legislative leaders, and others in a position to effect change. They must first be convinced that investments in alternatives to institutionalization are both fiscally attractive and programmatically sound.

The continuum-of-care concept was selected by the authors as the one that best embodies the others and thus may be considered one of the more rational approaches to program design. It calls for housing, care, and services consistent with each client's capabilities. A configuration approaching the full range of options -- from institutional care to independent living -- must be available.

B. *Interagency Budgeting*

The method of tying program design to a reasonable set of budget incentives is interagency budgeting. Its elements are:

1. Treatment of all human service budgets as a single budget,

    - ending program fragmentation through budgeting by program (Aging, MR/DD, MI, Physically Handicapped, Child Welfare, and others),

    - avoiding "single-account blindness" in which savings are achieved in one account at greater cost to another or in which truncated pricing is used to hold down state spending (thus shifting costs to other state accounts or to county governments and at the same time curtailing their opportunities for Federal reimbursement), and

    - using continuum management as an adjunct to, and integral part of, budget management.

2. Maximization of client entitlements through integrated eligibility and referral.

3. Intertitle transfers, to the extent permitted by client eligibility for more than one entitlement program, to help finance continuum management.

C. Continuum Management

Continuum management requires a strong client orientation and is conducted for programs and clients simultaneously. At the program level, it is best illustrated by example. Using a midwestern state as a case in point, the following data apply:

Living Arrangements	Number of Clients	
	Alternative 1	Alternative 2
Institutions	2,700	1,700
Community ICF/MR's	3,500	3,500
Supervised Apartments	0	1,000

Alternative 1 is the present situation. An estimated 1,000 institutionalized developmentally disabled persons are ready for community ICF/MR's and an equal number of ICF/MR residents are ready for at least semi-independent (supervised) apartment living. The move to Alternative 2 can be expected to reduce the total cost of care from approximately $121 million to approximately $109 million, with the $12 million in savings distributed as follows:

Federal -- $3 million
State -- 5 million
County -- 4 million

At the client level, continuum management calls for options along a continuum of care that are consistent with each client's capabilities. Such options include ICF/MR's, group homes, and other forms of congregate care. They also include various forms of assisted and unassisted independent living, such as supervised apartment living and family subsidy programs.

Client movement along the continuum of care, historically, was generally toward long-term institutional care, in the absence of clear programmatic objectives to the contrary. The deinstitutionalization, communitization, service-integration, prevention (secondary and tertiary), and normalization movements all have evolved to reverse the institutionalization trend. Despite their successes and demonstrations of cost-effectiveness there has never been a convincing demonstration that they have a place in funding strategies. With continuum management, on the other hand, the following results are achieved:

- Clients can live at higher levels of independence than before.

- Savings objectives are met, and all levels of government enjoy savings from the move to community services.
- There is enough in savings to provide financing for the program's capital needs.

D. *Organization*

There are two organizational requirements for implementing interagency budgeting and continuum management. The first is a budget organization capable of treating a large number of budget streams as part of a single, integrated budget for developmentally disabled persons. This will be a state budget office, a state office for human services, or a multi-agency task force with some form of budget authority. The second is a program organization capable of coordinating client placements and of budgeting for all program components along the continuum of care -- from the institutions, down through all of community programs, and into the home.

The budget organization is essential to the process. The program organization, unfortunately, is not. It is nevertheless a highly desirable component, for otherwise much of the coordinative program process will be carried out indirectly through the budget process.

THE CONTINUUM OF CARE FOR MR/DD PERSONS:

DEFINITION

AND POLICY OPTIONS

A. *Definition and Introduction*

A continuum of care is a set of care opportunities (for a group of persons characterized by similar or identical problems), which are ordered according to their intensity of care, their cost, their restrictiveness of environment, or some other dimension.

Such continua can be implicit (they simply grew up as a set of fragmented care opportunities that can be described according to the various levels of the continuum) or they can be explicit (they are organized for programmatic or fiscal purposes -- least restrictive and most appropriate placement, or least cost to one or more of the major fiscal actors).

In most areas, the continua of care are implicit. They "just grew". In the MR/DD area, the continuum's growth was influenced by fiscal history (especially Section 1121 and Title XIX, ICF/MR legislation, and Title XVI of the Social Security Act), program theory (the rise of habilitation approaches and normalization goals), and court decisions (right to treatment in the least restrictive environment).

The current continuum of care for MR/DD includes the following care opportunities, running roughly from most to least restrictive: State institutions, SNF/ICF's, ICF/MR's (community-based -- both large and small), supervised group and apartment living, foster care, independent living and living at home.

It seems established that the great majority of those housed at the more restrictive end of the continuum can be housed (and served) at the less restrictive end of the continuum; and, once having moved into that end of the continuum, there is noticeable improvement in function. It is less well established, but nevertheless strongly asserted, with fragmentary evidence, that: the more restrictive the program (holding amount of service constant) the more expensive it tends to be.

If these assertions are true (and we believe them to be true), one would wonder why MR/DD persons continue to be housed in state institutions and nursing homes in such great numbers (more than 250,000 in 1979). We can identify some of the reasons:

1. The historic position of the institutions. Until recently, the "burden of proof" was on community placement, not on the institutions (i.e., an MR/DD person was considered eminently institutionalizable, and the burden of proof was on those who claimed that the person would be more appropriately placed in the community). Beyond this, the institution was well-organized, had an appropriations history, and had an agreed-upon model of "treatment", none of which was available in the community until recently.

2. The funding of institutions was administratively easy and clean, requiring only one major Federal account -- Title XIX and one State account; the funding of community services required many accounts and was "messy".

3. Federal funding tended to provide perverse incentives. That is, Federal funding, and especially Medicaid, tended to encourage (and still does) institutional, non-normalized forms of care, and to discourage the more normalized forms of care in the community.

4. Even when the fiscal incentives might be reorganized to provide incentives for normalized, community care, standard Federal and state budget and management practices tend to make that more difficult.

The first of the above reasons is weakening under the power of new approaches in habilitation and attacks through the courts. The others continue.

If there is to be a well-managed, explicit continuum, where all incentives tend toward the most appropriate level of care for each MR/DD person in the system, the other three factors must be changed. The last factor can be modified, but the task is not related to Medicaid. The other two factors are so related, and we will discuss what must be done with Medicaid and the probable fiscal effects of moving into an adequate continuum-funding approach for MR/DD persons.

B. *Should There Be Some Alternative Approach?*

Having defined the strategy, we should deal with the question: Why not some alternative approach?

1. *Why not a "deinstitutionalization" strategy?* In the developmental disabilities service delivery process, the main concern is with the provision of the least restrictive, appropriate care opportunity. *One* of the implications of this objective is the transfer of all persons out of institutions for whom such programs are not appropriate. However, merely to "deinstitutionalize", i.e., transfer out, can be an error, if the person does not move to a less restrictive, more appropriate care program. This can and does happen in the developmental disabilities area, as evidenced by the large number of persons in nursing homes, who were formerly in state institutions, and who are receiving little or no active treatment.

2. *Why not a "communitization" strategy?* In developmental disabilities, one of our objectives is the development of an adequate community network of programs, designed according to the dictates of the normalization metaphor. However, if we concentrate on it alone, we forget about those in institutions and nursing homes, and what may be an inappropriate continuing flow of persons out of the community into nursing homes and institutions. The same problem occurs with an "independent living" strategy, if that strategy is considered in isolation of all the other levels of care and opportunities along the continuum of care.

3. *Why a "continuum of care" strategy?* In the history of the developmental disabilities service programs, an implicit continuum of care has grown up, which ranges from more to less restrictive, from more to less normalized, and -- in general -- from more to less costly. There are three major dimensions: Fiscal, Programmatic, and Managerial.

Because Federal funding has been "cleaner" and more adequate for the more restrictive part of the continuum, the fiscal incentives tend to support the more restrictive end of the continuum. In each state, the DD State Agency's and the DD Planning Council's policy and practice should be to turn these incentives around, so that there is more adequate funding from the Federal government at the less restrictive levels of care. If fiscal strategy concentrates upon just one level of care, then fragmented budgeting practice tends to take over, so that there tends to be a series of incremental decisions about funding each level of care, the sum of which may be entirely opposite to the public policy of the agency.

Programmatically, if we are to consider that our goal is the least restrictive, appropriate form of care, then only a continuum of care makes sense. If we consider only one form of care, in our decision-making, then we can run into irrational conditions. In Minnesota, the major (and virtually only) systematically-supported community form of care had been the ICF/MR. This system has been revolutionary in its effects; however, it also has been overbuilt, because a number of persons for whom that form of care was probably inappropriate could only go there from where they had previously been, in the community or in the institution, because there was no full continuum, with a healthy non-medical residential level of care.

C. Advantages of the Continuum of Care Approach

This approach has a number of advantages:

1. Instead of requiring legislation and administration covering all of "long-term care" at once, it calls for separate legislation for the separate target groups of interest. ("Massive" legislative changes tend to be almost impossible in the Congress.)

2. It permits the Federal government to deal simultaneously with a number of interest groups having relatively harmonious concerns. (Dealing with all mental retardation groups alone, for example, is possible. Dealing with *all* aging, *all* mental health, and *all* mental retardation groups at once is almost impossible.)

3. It forces Federal, state, and local governments into total program budgeting. This is important because no level of government knows its own costs or the total costs of any one system. The recent news which came out of our own project, that mental retardation and related problems cost more than $10 billion per year in public funds came as a surprise to Secretary Harris, who believed she had only one small $65 million per year MR/DD program. In California, for example, the "official" state budget lists MR as costing about $500 million per year in Federal and state funds. However, this sum represents only about one-third of the approximately $1.5 billion of the Federal, state and local MR funding. Most of the remainder is concealed under other account rubrics, such as SSI, SSDI, State SSI supplement, Medicaid, Medicare, HUD, and local housing authority budgets, Title XX and its associated state budget, VR, State Mental Health, PL 94-142, and state and local education costs.

4. It forces states into a posture of integrated placement, case management, financing, and evaluation for each identified target group.

5. It helps to align Federal and state policy and programs with the currently accepted principles of preference -- i.e., least restrictive environment, most normalized appropriate placement, and least costly appropriate behavior on the part of state and local governments in program development and client placement. (Since current Federal financing policy tends to encourage law-breaking by states, through providing financing for institutions and nursing homes which are providing inappropriate care and refusing to provide financing for appropriate community services because they are "social" and not "medical" in nature, the continuum of care approach also clarifies where the problems are and how to fix them.)

6. In the intermediate to long term, a continuum of care policy will save all actors money. In the short term, it saves only the states money -- but this is precisely the stimulus needed to ensure the massive program changes required at the state and local levels. (About 15 states are responding to these stimuli now, and more will soon.) In the long term, because of the higher cost of institutional and nursing care (which, due to regulation-induced costs, will become increasingly more expensive than community care), continuum of care programs having a set of built-in deinstitutionalization incentives will cost less for all actors.

D. *Funding: "Neatness" and "Messiness"*

In general, the more "institutional" the care, the "cleaner" its funding. State institutional care is funded under a single account -- Title XIX. Less restrictive forms of care invariably require multiple accounts -- one or more for the residential component and one or more for day programming and other generic services. As a result, multi-funded services, even when the money available in the separate accounts is adequate, are difficult to develop and organize. The general rule of civil service behavior, therefore, is: when possible, organize services only around clean funding.

Consider the table on the following page. Here we see that the further we move into the community end of the continuum of care, the more diverse the funding. The need for normalized, separated, community-based services may require a large number of different funding sources.

Sources of Funding

Level of Continuum	Residential R&B and Service Cost	Service Cost Outside Residence
Institution	Title XIX	NA
Community ICF/MR	Title XIX	Title XX, Title XIX (for regular medical costs), State grants, County levy, BEH or local school levy, VR
Supervised Living	SSI, HUD Sec. 8, Food Stamps, Title XX	Same as above
Home Care	SSI or SSA, State subsidy, Title XIX	Same as above
Family	Family subsidies from state	Same as above

One or more changes can be made in national policy to make community services administratively neater:

1. Put all generic services outside the residence (i.e., respite care, transport, social development, work preparation, infant stimulation, work activity, etc.) under Title XIX.

2. Put Supervised Living care, in toto, under Title XIX. The activities of a supervised living approach are very close to those in an ICF/MR (for persons of higher functional capabilities). Alternatively, fund only the habilitation/supervision activities of the staff (about half the budget), while allowing the room and board function to be funded under SSI, HUD, Sec.8, and Food Stamps. (The second alternative provides a higher Federal matching rate in most states, thus making the increased administrative complexity "worth it" to the state.)

E. Funding: Correcting Perverse Incentives

If we are to have a continuum of care where the incentives are toward normalized, community-oriented kinds of care and services, then the following two rules should hold:

1. The more normalized the level of care, the less it should cost, in total.

2. The more normalized the level of care, the less it should cost each relevant fiscal actor.

Under current funding, the first rule nearly always holds, but the second is violated constantly by the "design" of the system. An example of a truncated continuum is given in the Table below, where the levels of care are laid out from least to most normalized.

TABLE 1

Cost Per Client Per Year in a "Perverse-Incentive" Continuum

Level of Care	Federal	State	Local	Total
Institutions	12,000	12,000	0	24,000
SNF/ICF [1]	7,000	3,500	3,500	14,000
Community ICF/MR	7,500	3,750	8,750	20,000
Supervised Living	2,500	4,750	4,750	12,000
Home Care with Family Subsidy	0	4,000	0	4,000

[1] This level of care has no active treatment program, as required by law and regulation.

The continuum in Table 1 is in a state with 50% Medicaid matching, with active treatment in all levels but ICF/SNF, and with separated active treatment in the community ICF/MR and the Supervised Living levels. In many states, counties share certain costs (e.g., 50% of non-Federal Medicaid costs) with the state government.

For such states, the incentives for the Federal government are ordered almost as one would want; however, the incentives of the state governments are toward community ICF/MR's or toward SNF or ICF programs. The incentives of the counties are the worst -- their fiscal preferences would be the institution or home care first, and the ICF/MR last. In states where there are no local shares, the state's incentive is toward

care in SNF or ICF programs (and in most cases, those programs do not include active treatment programming). From that sort of state's point of view, community ICF/MR's cost them as much as institutions.

Even if the SNF's and ICF's offered active treatment programming, but on an "internal" basis only, as the state institutions do, this less normalized level of care would still be fiscally preferable from the state's point of view. Community ICF/MR and supervised living programs would cost the state more.

How can the incentives be made less perverse? There are a series of actions that could be taken by HCFA, vis-a-vis Medicaid:

1. An "intergovernmental" provision for state-local matching; in those states where there is state-local Medicaid sharing for other than state institutions, there should be the same matching formula for state institutions.

2. An enforced requirement for active treatment, in a place physically and administratively separate from the SNF or ICF, but funded by Medicaid.

3. The required funding of day activities, workshop activities, and related activities as physically and administratively separate from ICF/MR's in the community (as is now permitted in New York, Massachusetts, and Michigan, but on very narrow grounds).

4. The optional funding of personal care staff (now allowed) and rehabilitation staff for Individual Habilitation Plan forms of activities, in supervised living programs; and the funding of related day programs, as needed (as in 3 above).

A further action could be taken by OHDS/HHS in giving families with a DD person the same status as day care providers, under Title XX, so that Title XX funding could be used for family subsidy programs.

With that series of policy actions, the fiscal incentives of the continuum displayed in Table 1 would more nearly fit the preferences of the normalization approach. That is, the fiscal results would be as in Table 2, on the following page.

At this point, the total cost criterion is more nearly met, and the second (the more normalized the environment, the lower the cost to each actor) is also almost met. This approach also meets the "administrative neatness" criterion in the previous section. Thus, the fiscal incentives for a normalized care-oriented continuum of care would be more nearly met.

TABLE 2

Cost Per Client Per Year in the "Reformed-Incentive" Continuum

Level of Care	Federal	State	Local	Total
Institutions	12,000	6,000	6,000	24,000
SNF/ICF	9,500	4,750	4,750	19,000
Community ICF/MR	10,000	5,000	5,000	20,000
Supervised Living	8,000	2,000	2,000	12,000
Home Care with Family Subsidy	2,000	1,000	1,000	4,000

F. Funding: General Managerial Design Requirements

Continuum of care design requires that we understand the "epidemiology" -- flow, costs, placement requirements, and the like -- if we are to get the best results. Some specific requirements:

1. There must be a financing scheme which provides incentives in the preferred direction of the flow of persons.

2. A placement, or placement monitoring, organization is required (this includes case management).

3. A technology of appropriate placement, e.g., an activities-of-daily-living scale, the scores on which correspond to different level-of-care needs must be developed.

4. Defined levels of care, each of which serves distinctly different level-of-care needs, must be developed.

5. For operational and strategic planning, data on the current placement of persons in the target group, the flow of persons into the system, the flow of persons among parts of the system, and the flow of persons out of the system must be developed.

6. Data on the costs of care for each level of care, with projections of future cost and expected revenues by source, for each defined subpopulation within the system must be developed.

Given these requirements, it would seem to be the Federal government's responsibility to see how policy and regulation concerning program, financing, and management help the states move the system in the right direction. There is, however, much that the states can do on their own in reforming and refinancing their MR/DD systems along continuum of care lines, and the next two sections of this paper present a number of options.

MAKING A CONTINUUM OF CARE STRATEGY WORK

AT THE

STATE LEVEL

A. Introduction

The "natural" incentives of state government agencies are toward separate turfs, with separate funding of programs, program design of individual programs without reference to others existing, and management of programs without reference to the existence of others. When notice is taken, it is usually for turf protection reasons rather than for cooperative reasons. Thus, the "natural" incentives mitigate against any explicit planning, programming, and management of the whole continuum. Is there a set of incentives which will make state governments and their component agencies want to cooperate?

B. Fiscal Incentives

There is one set of incentives which tends to override the fragmentation implicit in the system. This is the ability of the state to purchase a total continuum of care for less, in terms of net state costs, than it must pay for the current fragmented system. This is carried out through continuum budgeting and management approach. The key point here is that, if any level of care is missing, it will cost the state more to provide care.

C. Unif ed Budgeting and Planning

Given the fragmented budgets and programs at the Federal level, this fragmentation communicates itself to the states. As a result, differing elements of the continuum are funded in different agencies at the state and local level which do not talk to each other. For example, Title XX may be in the Department of Public Welfare, Title XIX in the Health Department, Vocational Rehabilitation in the employment services agency, grants for special education in the education agency, and so on. Even within agencies, programs will

be in neighboring divisions which do not talk to each other (in many states, the mental retardation division, the health licensure division, and the Medicaid division may spend years fruitlessly attempting to get agreement on a given policy).

What continuum of care strategies do is to recognize the low probability of neighboring agencies at the same level of authority being able to coordinate a major ongoing, multiagency, multiaccount policy; and then move to locate the overarching continuum *strategy* planning and the budget planning for it into a group at a higher level of authority (e.g., state budget office, governor's office, state planning agency, permanently-staffed interagency task force; once, however, the strategy is developed in some detail and institutionalized in the appropriations process, the operational planning should be done in the responsible line agency).

D. Continuum of Care Organizing : The Tasks.

Moving into the continuum of care approach requires a systems orientation to policy change and implementation. Some of the tasks involved are:

1. Defining the levels of care, from institution through to independent living, with both residential and non-residential components represented.

2. Developing a registry for all programs.

3. Estimating the numbers (by service need) in each level of care; estimating current flow into, through, and out of the system; estimating future effects of demography and epidemiology -- both with and without policy change -- on number and type of services needed.

4. Estimating the costs of each level of the system, by source of payment, for current conditions, and in the presence of policy changes (e.g., effect of ICF/MR policy on institution costs; effect of nursing home enforcement on costs of care for those developmental disability persons in nursing homes; effect of emphasizing a community ICF/MR policy versus an assisted or supervised community living policy; effect of providing out-of-school system services by non-school providers to 94-142 populations versus the fiscal effect of providing those services entirely through the school system).

5. Defining a set of policy options involving the whole continuum; choosing one option for a long-term plan (usually three to seven years).

6. Setting up the financing for the plan (state plan and rule changes, capital and operating plans for the legislature, appropriation requests and program legislation change requests).

7. Setting up an operating plan (numbers and location of programs; long-term transfer planning for institutional and nursing home persons; agreements and operating plans for necessary eligibilities for transferees with SSI, HUD, county and district offices of public welfare; necessary extra appropriations to line agencies, etc.).

8. Staffing an operating organization to do the planning and the coordination of agencies.

E. The Role of the Developmental Disabilities Council

There are several possible basic roles here for developmental disabilities councils in the states. The first is organizing a continuum of care approach -- and paying for the initial planning of a continuum of care approach up through the first legislative appropriation. This is an important area because of the nature of state bureaucracy. By nature, appropriations for "planning" in state agencies tend to be for ongoing, narrowly-defined incremental tasks. As a result, there is never any money in agency appropriations for planning wider policy changes and all of their implementation needs. This makes any "discretionary" dollar extremely important -- and Developmental Disabilities Council funds are discretionary. Indeed, given the way states are organized and behave, the existence of a discretionary dollar for a given task -- if that task is well-defined -- makes the probability of the task being attempted very high. Therefore, if the mission for which the funds exist is very well defined, there are a number of states which will want to do it (given the already-existing pressures toward solving a group of developmental disabilities "problems" in the states).

The second role for a Developmental Disabilities Council is to provide for the ongoing measurement of location, costs, and condition of clients in the developmental disabilities continuum of care. Given the current existence of a number of operating data systems in the state (SDX for SSI, Title XX, MMIS, R-300 for VR, state BEH counts and budgets, etc.), it would not be the Council's

role to operate a *primary* data system, but to operate a derivative one, which aggregates the data from the various other systems into its own. This can be done by:

a. Assisting current systems to fill in missing data types.

b. Assuring that all relevant systems are "confederateable" -- i.e., there is a cross-system linkage element (e.g., Social Security number), and that confidentiality questions are worked out.

c. Making financing arrangements for the necessary data processing needed.

At the state level, this would assure that the data are available for continuing continuum of care planning and budgeting. With that role as one of the state roles of the Developmental Disabilities Council, it assures the Council of a continuing role in the development of a deinstitutionalized, normalized, well-funded, well-managed continuum of care.

At the national level, it should be noted, the existence of such a system would assist the ADD in its continuing role in the wider task of Developmental Disabilities planning, using the only integrated data available for a number of programs (e.g., Medicaid, BEH, Title XX, SSI, RSA, Medicare, HUD, and other funding at the Federal, state and local levels) for this population to assist HHS, OMB, and the Congress in ongoing policy-relevant planning.

COMBINING PROGRAM AND FISCAL STRATEGIES

TO

REFINANCE AND REFORM A STATE MR/DD SYSTEM

A. *Introduction*

Ideally, we would want to know the full public MR/DD costs for a state: budget allocations by location, need, and condition of the MR/DD persons in the state; the actual costs, by client condition, for each level of care; and the outcome, by client condition, for each level of care. We are far from that goal. Nevertheless, there are still some very effective methods for budget planning that we can use.

1. We can define a continuum of care for a state, as a start -- even though it may be rough and incomplete. This would be a great advance over the present fragmented approach of solving problems one at a time. The latter approach can, and often does, produce some very odd-looking "non-systems" of care, in which some less desirable types of service are overfunded at the expense of other more desirable ones.

2. We can define the full budget over a large portion of the continuum. For example, we can define the continuum to be the MR/DD residential service system, together with all day programming and other non-residential services provided to clients receiving residential services. We can look at current costs, unit costs, and revenue sources for each level of care in the continuum that we have defined. This leaves out the costs of providing services to all who are *not* clients of the residential service system. However, it does allow us a close look at the entire residential (and related non-residential) cost picture.

3. We can look at costs -- both total and net -- over more that just one or two years. This is important for two reasons:

- Significant changes in a state's continuum of care take more than one or two years. The state must understand its options and the fiscal impacts of each option up to five or six years into the future.

- Significant changes in the continuum of care have variable effects on funding and funding incentives.

In the short-term, one can expect increases in Federal funding, and decreases in the state funding. Over the longer term, Federal funding decreases as well, relative to what it would under less efficient approaches. From an incentive point of view, this is very important. States respond to short-run incentives. The Federal government can wait a bit longer. As a result of planning over the longer term, we can satisfy what under other circumstances would be disharmonious incentive problems. (The problem is simply this: The states will not move in large reforms without large incentives. The Federal government people tend to suspect any increase in Federal reimbursements to a state as being a "rip-off" -- unless they can be satisfied that there are cost controls which will eventually produce substantial Federal savings).

4. We can examine alternative strategies. This is essential in planning for a continuum of care. Most state plans for mental retardation do not include all relevant budget items and accounts. They do not examine the whole continuum. They do not examine the effects of the plan over enough years. And, perhaps most critically, they do not examine enough alternatives. Often one plan is laid out -- and that is all. However, there are a number of policy options and combinations of policy options that we would want to evaluate:

- Deinstitutionalization goals in terms of numbers of patients affected.
- Deinstitutionalization goals in terms of timing -- speed of phasing down or phasing out.
- The effects of varying the speed and scope of upgrading residual institutional beds.
- The effects of deinstitutionalizing nursing homes as well as state institutions.
- The effects of alternative patient choice policies (i.e., who is selected first for transfer? the best-off patients? the worst-off? a mixture?).
- The effects of alternative community residence policies (i.e., all ICF/MR's? all non-medical? a "balanced" policy? will there be size constraints?).
- The effects of alternative revenue development policies (i.e., Medicaid all residential? Medicaid all non-residential? Medicaid care and treatment staffs only?).

- The effects of alternative housing development policy in the community (i.e., emphasize existing housing or new? state grant and loan policy or depend on HUD and/or private market?)

- Any underlying assumptions about the relationship between community services supply and the demand for those services by persons living at home (sometimes called the "out-of-the-woodwork" phenomenon).

Depending upon what kinds of models and data we have, we can look at a few or many combinations of policies through simulation (which may be pencil-and-paper or computerized). When we do that, we can start to understand the fiscal and other effects of following any given set of policies in deinstitutionalization. With that understanding, it will be much easier to justify and to sell a given policy course in a state, whether to the governor, the budget director, or the legislature.

B. The Analytic Background

To understand the problem of reforming and managing a large, complex program area in the public sector, we must first understand that we are limited to a handful of basic strategies. Potentially, the most powerful is that in which we develop large sums of "up-front" money from sources other than a state's general revenue fund (GRF) to be used as incentives for reforming the total program structure. Thus, we must understand:

- how to "create" that money needed to reform the state's MR/DD system, and

- how to use it in such a way that we get program reform and long term cost containment.

The first place to look for this money is in Federal accounts already accessed by, or potentially available to, the state. Most states fail to take maximum advantage of all Federal funds available, simply because the state's departments prepare individual budgets and the legislatures vote on individual program appropriations, without taking into account the interactions between the Federal accounts. If the entire state human services budget were considered as an investment portfolio, and both a gross and a net GRF budget were to be developed, there would be far greater opportunities for maximizing Federal reimbursements than now exist. Maximization is possible whenever five basic conditions of Federal and Federal-state financing programs exist in a state.

The five conditions necessary to develop new funding for any service system for a target or categorical group are as follows:

1. *Service definition.* Although different programs provide different patterns of goods and services to their clients, examination shows that there are a considerable number of services in different programs that are the same or similar (various kinds of counseling, residential services, transportation, and other services). Also, the goods received are often the same, or they are complete or partial substitutes for one another (medical care, food, cash, and housing). For example, family planning is identically specified in both Titles XIX and XX of the Social Security Act.

2. *Overlapping eligibilities.* Although different programs are intended to service different groups of people, there are significant overlaps among the groups defined to be eligible for each program. For example, a person who is on the Food Stamp rolls will be eligible, on the average, for more than two other means-tested programs as well.

3. *The irregular match of people and services.* Added to the overlaps mentioned above is the fact that neither the service definitions nor the service eligibilities are completely precise. As a result, there is much room for maneuver in deciding which services people need or should receive. There is a whole literature of studies of the different placements (e.g., home care, group residence, intermediate care facilities, skilled nursing facilities, acute general hospital) that a person can have, depending upon who is making the placement decision, and what criteria are used.

4. *Matching ratio differences.* Most of these programs involve some form of Federal financing, with a matching ratio of Federal and state (or local) funds. Others, which are non-Federal, involve a match between state and county or state and city. Such ratios generally vary between 40% and 100% of the money made available by the higher-level jurisdiction. At the local level, this means that a 40% non-local match returns 67¢ for each $1.00 of local money put into the program, a 75% match returns $3.00 for each dollar, and a 100% match is "free" (i.e., requires no state or local funds).

5. *Open and closed-ended programs.* Most Federal programs are closed-ended; that is, there is an appropriations ceiling, and no more than the ceiling can be spent. Thus, Title XX is a closed-end program; $2.9 billion is its current annual spending limit in Federal funds. Some of the most important programs in human services, however, are open-ended: AFDC, Medicaid, and Supplemental Security Income, for example. Housing and Food Stamps programs, among others,

have been "quasi-open-ended" (in that Congress has decided to treat them as if they were open-ended). The open-ended characteristic means that if a person is entitled to receive benefits under the program, he must be provided those benefits. There is no ceiling.

All five conditions must be satisfied in order to maximize a financial reimbursement program for a given target group. Since they are satisfied in all 50 states, we can lay out a general example of how to move program dollars across different Federal programs to achieve a higher overall Federal match.

Consider a "worked example" of how the basic principles operate for program sizes of the kind found in the ten largest states. Table 1, below, represents a program involving three Social Security Act accounts for children's services: Title XX, Titles XIX and IV-A (considered as one account with, at the beginning, no expenditures), and Title IV-B. The first and third are closed-ended; the second is open-ended. The Federal matching ratios are 75%, 50%, and 10% Federal, respectively. The overall Federal match initially is 50%. There is good communication between Title XX and Title XIX/IV-A. (There are many services provided under Title XX which are similar to, or identical to, services provided under Titles IV-A and XIX. Further, many persons eligible for Title XX services are also eligible for Title IV-A and XIX services). There is poor communication between Title XIX/IV-A and Child Welfare Services -- little program-service overlap and very little overlap with IV-A eligibility. There is good communication between Title XX and Child Welfare Services. (Foster care, adoption, and child protective services, for example, can be provided under either program; and most children eligible for the one program are eligible for the other.)

TABLE 1

CURRENT ALLOCATIONS

Source of Funds	Title XX	Title XIX/ IV-A	Child Welfare	Total Funding
Federal	240	0	20	260
State	80	0	180	260
TOTAL	320	0	200	520

Table 2, on the following page, represents a move of some of the Title XX services (e.g., some health-related services) into XIX and some (e.g., day care services) into IV-A funding which results

in an open-ended match rather than dealing with the current ceiling on Title XX. At the same time, it frees up $120 million in Title XX funding to be used for other services. This move *lowers* the average Federal match -- but only temporarily.

TABLE 2

MOVE 1 -- MOVING SERVICES FROM TITLE XX TO TITLES XIX AND IV-A

Source of Funds	Title XX	Title XIX/ IV-A	Child Welfare	Total Funding
Federal	150	60	20	230
State	50	60	180	290
TOTAL	200	120	200	520

In the second move of program dollars, presented in Table 3, below, Child Welfare Services are placed into the "hole" left in Title XX by the first move, in order to move from the 10/90 match to the 75/25 match. As a result of this move, the total program is still the same, but (compare Tables 1 and 3) the state share has decreased 60 million dollars from current allocations.

TABLE 3

MOVE 2 -- MOVING CHILD WELFARE SERVICES INTO TITLE XX

Source of Funds	Title XX	Title XIX/ IV-A	Child Welfare	Total Funding
Federal	240	60	20	320
State	80	60	60	200
TOTAL	320	120	80	520

At this point, we have achieved only a substitution o Federal and state funds. If the exercise goes only this far, it is basically sterile, because it has not yielded any program reform or service increases in the needed areas. Up to now, it has only been a paper exercise in finance, for the benefit of the state's general revenue fund. Moving to a reasonable programmatic outcome requires further steps. These are:

- agreeing with budget officials to reduce net state investment from the original $260 million to $240 million (a saving of $20 million); and

- agreeing to put the remaining state money saved ($40 million) in move 2 into an $80 million expansion of community-oriented Title XIX and IV-A services to support a deinstitutionalization initiative.

The last table (Table 4) reflects the use of the additional funds for reform -- in this particular model $100 million of new Federal money. The net budgeting effect of these moves -- which can be seen by comparing Tables 1 and 4 -- is a program total increase of $80 million while the state has managed to recoup $20 million for general revenue savings or other areas of need.

TABLE 4

MOVE 3 -- ALLOCATING SAVINGS TO A COMBINATION OF STATE BUDGET OFFSET AND COMMUNITY PROGRAM EXPANSION

Source of Funds	Title XX	Title XIX/ IV-A	Child Welfare	Total Funding
Federal	240	100	20	360
State	80	100	60	240
TOTAL	320	200	80	600

The operating premise in such models is that negotiations can occur between the Governor's office, the Director of the Budget, and the Legislature, who must agree on a joint utilization of state general fund money for buying reform and/or improvement in the target group delivery system. In order for this to occur, it is assumed that *there is interagency planning and coordination over the whole system of interest!* Normally, this is impossible. However, if such negotiations are made the precursor of large savings and program expansions, they are quite feasible. Our experience is that a number of states have been able to enter into multi-year, temporary or permanent, arrangements of this sort. Most states could receive an additional 10 to 20% in new Federal funding of their public human services system expenditures if they would systematically rework their human services system over a three to five year period.

The maximization approach can be applied in a more limited, but still very powerful, way to "rational chunks" of the human services system. For the rest of this section, we will limit our analysis to an individual MR/DD system, so as to provide a "worked example" of how the combination of short-term money creation, combined with long-term system-oriented expenditure controls, can result in an MR/DD system configuration that more nearly resembles the kind

of system that program theorists and practitioners, (and the courts) tell us we should have.

C. *A "Worked Example" for a Developmental Disabilities System*

1. The Current Total MR/DD Budget For An Exemplary State.

We first estimate the total governmental budget in our state for persons with developmental disabilities. Figures which are similar to, but not identical to, those of several of the larger state governments, are used here for illustration. Such a budget, *by source of revenue,* is needed to understand fully the budgetary and program consequences of state and Federal policies and actions. If this full set of costs is not known or is incomplete, the results of state or Federal actions may be perverse.

It should be noted that our estimates do not include any of the voluntary, private, or not-for-profit agency dollars involved in community programs, whether for totally-private programs, for subsidizing low reimbursement rates, or for non-public capital development. The estimates in Table 5 are based on the following assumptions:

a. That 8% of the state's Division of Rehabilitation clients would be classified as developmentally disabled.

b. That 16% of the children in foster care institutional placements are classified as developmentally disabled.

c. That 19% of the individuals receiving Supplementary Security Income (SSI) in the state are classified as developmentally disabled. (Nationally, 50% of children and 13% of adults receiving SSI are developmentally disabled).

The estimates are low since they do not include housing, food stamps, and incidental Medicaid medical expenses which could be thirty to forty million dollars.

The first four items consist entirely of out-of-home care (with related day services). The remainder of the items mainly pay for non-residential services and income maintenance in the community. However, significant portions of these items as well are for out-of-home care.

TABLE 5

THE FULL STATE MR/DD PUBLIC BUDGET, 1980

($ Millions)

Item	Federal	State	County	Total
State Hospital	100.0	200.0	0	300.0
SNF/ICF	16.8	16.8	0	33.6
ICF/DD (Community)	12.5	12.5	0	25.0
Inst'l FC	5.7	16.7	0	22.4
Div of Rehab.	8.0	2.0	0	10.0
County Welfare Depts.	2.4	7.1	0	9.5
Regional Centers	0	160.0	0	160.0
Spec. Ed.	90.0	180.0	200.0	470.0
SSI	110.0	30.0	30.0	170.0
SSDI	73.5	0	0	73.5
XX	20.0	35.0	0	55.0
TOTAL	438.9	660.1	230.0	1,329.0

2. Decision-Making Within the Residential Care (and Related Services) Budget

It would be useful to analyze alternative sets of policies over the whole budget; but, as yet, we do not know enough to do so. Therefore, we will look at a key part of that budget only -- a part of the budget which is largely under state control. Here, we should focus on residential services for persons with developmental disabilities, as a portion of the total $1,329 million budget to illustrate how increased Title XIX and other funds could be used. That portion consists of the first three items of Table 5 ($300.0 million, $33.6 million, and $25.0 million, plus $150.0 million in the non-medical parts of the residential care system).

The following three tables (Tables 6, 7, and 8) represent the 1980 expenditure pattern by category and two alternative projections for 1985. It should be noted that the unit costs in the institutions and the ICF/DD's are "bundled" (i.e., they include all supportive services). The unit costs for SNF/ICF's are "unbundled" and thus

probably two to three thousand dollars per unit too low.

Table 6 presents the current expenditures in the residential-care and related services portion of the MR/DD system in 1980. Then, projecting the effects of service changes and inflation on per-patient costs over the next 5 years and applying the projected 1985 costs to each of two different residential configurations of patients in the continuum of care in 1985, we generate two different sets of fiscal projections.

Alternative I (Table 7) presents a model of the fiscal effects of proceeding under current plans of the state's department for MR/DD for changes of patient/client location over the next five years under this alternative. This alternative gradually deemphasizes institutional care.

Alternative II (Table 8) is a model for reducing net state costs (and at the same time lowering *total* costs) of MR/DD services through use of non-medical residential alternatives which provide greater budgeting flexibility for providers and increase continuity and stability for individuals and families receiving services. This alternative rapidly deemphasizes institutional care. Both alternatives assume the state has become more efficient in billing for Federal reimbursements.

TABLE 6

PUBLIC EXPENDITURES IN 1980 FOR RESIDENTIAL AND RELATED SERVICES FOR MR/DD PERSONS IN THE STATE

($ Millions)

	No. of People	Cost Per Patient	Federal Costs	State Costs	Total Costs
Inst.	8,700	$34,480	120.00	180.00	300.00
SNF/ICF	2,800	$12,000	16.80	16.80	33.60
ICF/DD	1,000	$25,000	12.50	12.50	25.00
Non-Med	10,000	$15,000	40.00	110.00	150.00
TOTAL	22,500		189.30	319.30	508.60

TABLE 7

ALTERNATIVE I FOR 1985 - CURRENT DEPARTMENTAL PLANNING[1]

($ Millions)

	No. of People	Cost Per Patient	Federal Costs	State Costs	Total Costs
Inst.	8,000	$60,000	240.00	240.00	480.00
SNF/ICF	2,200	$19,320	21.25	21.25	42.50
ICF/DD	7,800	$40,000	156.00	156.00	312.00
Non-Med	7,000	$24,150	108.22	60.78	169.00
TOTAL	25,000		535.47	478.93[2]	1,003.50

[1] Assumes an inflation rate of 12 percent per year, in state institutions (due to a combination of general inflation plus staff upgrading requirements.) Assumes 10 percent per year for all other services. Assumes the state is more aggressive in receiving full state hospital reimbursement in non-medical residential programs. Assumes 2,500 more people in system.

[2] 296.92 million GRF in 1980 dollars -- or a savings of about $22 million over 1980 in 1980 dollars.

TABLE 8

ALTERNATIVE II FOR 1985 - ACCELERATED DEINSTITUTIONALIZATION[1]

($ Millions)

	No. of People	Cost Per Patient	Federal Costs	State Costs	Total Costs
Inst.	4,000	$64,000	128.00	128.00	256.00
ICF/SNF	2,000	$19,320	19.32	19.32	38.64
ICF/DD	4,000	$44,000	88.00	88.00	176.00
Non-Med	15,000	$24,150	231.84	130.41	362.25
TOTAL	25,000		467.16	365.73[2]	832.89

[1] Inflation assumptions same as in Table 7. Assumes some increases in unit cost over alternative I, due to establishment of new behavior-shaping programs in institutions and ICF/DD's, so that there is much greater use of non-medical facilities and less use of ICF/DD's. Federal reimbursement and service-population assumptions same as in Alternative I.

[2] 227.16 million GRF in 1980 dollars -- a savings of about $92 million over 1980, in 1980 dollars.

Court decisions and program theory would lead us from the most restrictive to the least restrictive residential setting. Yet, fiscal decisions have driven us the other way, because current Federal-state funding patterns, as currently understood in state budgeting practice, provide the incentives for institutionalization. Table 8 shows us how to move funding (and thus program) decisions in the direction we want to go.

In reviewing Alternatives I and II, several results become apparent. The projected 1985 costs of Alternative II are $170 million less than those of Alternative I. The projected 1985 costs of Alternative II are $58 million less to the Federal government than those of Alternative I. Therefore, there is an incentive for Federal support for this alternative. Last, the projected 1985 costs of Alternative II are about $112 million less to the state GRF than those of Alternative I. This comparison of the two alternatives is presented below in Table 9.

TABLE 9

COMPARISON OF CURRENT AND PROJECTED COSTS UNDER TWO ALTERNATIVES IN 1985 FOR A STATE'S MR/DD RESIDENTIAL AND RELATED CARE SECTOR

($ Millions)

	Federal	State	Total
1980	189.30	319.30	508.60
1985 Alternative I	525.47	478.03	1,003.50
1985 Alternative II	467.16	365.73	832.89

When adjusted for deflation (i.e., converted to 1980 constant dollars), the state totals become even more encouraging. The deflated figure for Alternative I is $296 million in state spending. For Alternative II, the deflated figure is $227 million in state funds -- a savings of $69 million. When the inflation-adjusted GRF for the two alternatives is compared to the current (1980) funding of $319.5 million, Alternative II saves $92 million and Alternative I saves $23 million.

From a fiscal policy prospective, as well as from programmatic and legal perspectives, it would seem that Alternative II should be aggressively pursued by the state. For this to occur, there must be solid interagency coordination and planning with specific targets set out by the Budget Division, the Department, and the Legislature.

D. Accessing Federal Funding for Non-Medical Residential Facilities

To understand the possibilities for a 70 percent Federal reimbursement for non-medical residential programs (and a 64 percent overall match when the costs of associated non-residential services are included), consider a model for non-medical apartments or group homes for individuals who might be classified as mildly or moderately developmentally disabled. The model is a residential group of apartments or small facilities with 24 residents and 6 staff. One of two approaches for staff organization can be used in this model:

1. The staff may be either self-employed certified providers, or they may be employees of a medical service agency different from the shelter/food/maintenance provider agency, in order to use Title XIX funding, or

2. The staff may be employed by the same organization (as long as the staff costs are less than 50% of total costs).

The second approach has been implemented in New York. Texas and Arkansas also have adopted it, and these two states have been working to install it with the help of the HCFA Regional Office.

An example of the funding configuration under either approach is presented below in Table 10.

TABLE 10

NON-MEDICAL GROUP HOME FINANCING : TWENTY-FOUR RESIDENTS AND SIX STAFF

Cost	Federal Costs				State	Total
Item	XIX	SSI	Sec 8	Food Stamps	Costs	Costs
Staff	60,000				60,000	120,000[1]
Rent		20,000	40,000			60,000
Food & Other		60,000		2,800		62,800
TOTAL	60,000	80,000[2]	40,000	2,800	60,000	242,800[3]

[1] Less than 50% of cost (consistent with Medicaid regulations).

[2] $10,880 state supplement included.

[3] Total is slightly more than 10,000 per resident.

In order to implement this model under Title XIX, individuals and/or agencies would have to be certified as personal care providers or as rehabilitation services providers. This could include individuals from the paraprofessional positions, all the way through trained professionals, including occupational therapists, physical therapists, etc. Behavior modification could also be purchased as clinic services or out-patient services. The facility need *not* be a medical institution or a Medicaid certified facility.

An important issue here, regarding the Title XIX model, is how can a state obtain personal care services for persons with developmental disabilities without "contagion" (i.e., having to develop the same services) for other groups. Three options would seem to be possible:

1. Personal care services could be defined in such a way as to be limited by clinical and professional criteria, so that only persons with developmental disabilities could be eligible. This could be done through a new licensing category similar to New York's approach, and similar to what is being pursued in California in establishing day clinics for diabetics.

2. A second approach is simply not to limit such services to persons with developmental disabilities. If a state starts continuum of care planning for its MR/DD persons, this can serve as a model for doing the same type of planning for all other target groups. This approach makes planning, financing, and implementing services for persons with developmental disabilities and persons with mental illness much easier than current approaches. It may be somewhat more difficult to do for other groups (e.g., the aging, the physically handicapped and children's services), but we have enough demographic historical data where trends are evident and could be laid out for all target groups. A number of states (e.g., Massachusetts, Vermont, Illinois, Minnesota, Michigan, and New York) are doing this type of planning -- some more systematically than others.

3. It may be possible to get Federal legislation under Title XIX that allows planning separately for the different target groups, without having to provide exactly the same services for all Medicaid-eligible groups, regardless of need. There have been discussions at the Federal level of allowing categorical service planning for defined target groups under Title XIX.

E. *Maximizing Federal Allowable Cost Reimbursement*

There are numerous methods allowable in Federal regulations for maximizing reimbursement for individual accounts and groups of accounts. One powerful approach is found in the cost allocation process. In general, states do this in a "single-possibility" fashion. That is, although there are whole sets of alternatives, only one possibility is considered in designing the cost allocation plan. Actually we have great freedom, along at least four major dimensions, to change our total plan in order to maximize Federal reimbursement.

1. *Item Allocations:* Minutely examine item allocations in current charts of accounts. Many can be put into either overhead or "production" departments. This changes reimbursement amounts.

2. *Pooling:* Examine the organization's structure for the possibility of pooling of accounts. Changing the organizational structure itself affects reimbursements.

3. *Allocation Bases:* There is a choice of cost allocation bases available for any given department, and different bases yield different reimbursement amounts.

4. *Mathematical Method:* Most states use a primitive direct allocation formula in social services plans. The state has other choices: "sophisticated" direct allocations; step-down formulas (most hospitals use these); double apportionment formulas; or the "golden rule" (a system of linear equations). These can all be tried *simultaneously* and compared to determine which will maximize reimbursement.*

If the different possibilities in each of the four dimensions listed above are tried simultaneously and if the MR/DD department of the state ensures that state central charges, departmental overhead, and full depreciation and amortization are included, then full cost reimbursement for individuals in state hospitals can be calculated more precisely than any state is presently doing for ICF/MR/DD beds, and could generate approximately 25 to 30 million dollars more per year in Federal reimbursement, in the larger states, for state hospital beds and departmental administrative overhead attributed to the state's community-based MR/DD operations.

* A computerized model for carrying out this simulation was developed by the authors and others at the Humphre Institute, University of Minnesota, under a Title XX training grant, and is available for use by state governments.

F. Recommendations for Implementation

The following points are important, in looking ahead to maximizing a state's Federal reimbursements for the costs of services to persons with developmental disabilities, in a way that produces substantial increases in the community level of care. Recommended changes are:

1. *The establishment of a permanent project and budget planning group.* It is essential that someone be responsible for laying out the entire mission statement, doing the estimates, and overseeing implementation. The group must include participation by all appropriate entities, including the legislature and the Budget Division. The group must look at the effect of budget decisions on program decisions, and *vice versa*, and package these analyses in an appropriate way for the legislature. The Governor's office might also be involved and perhaps the legislative staffs, as well. Illinois recently formed such a group (DD Council, Governor's Office, Budget, and Department). Such groups are routinely in New York (Budget Office and Departments). The approach cannot work very successfully if housed in the line MR/DD department, given the multi-agency proglems involved in continuum-of-care planning, financing, and implementation.

2. *Integrated planning for individual transfer between levels of care, complete with projected cost.* This should be coupled with a speedup in the deinstitutionalization process. It would seem appropriate to set a goal of 15 to 20 individuals per hundred thousand population in many state institutions by 1985 or 1986, and certainly no more than 40 to 45 for any state, by that time.

3. *Modification of the state's Medicaid program and state plan:*

   a. Establish a personal care and/or rehabilitation program;

   b. Establish a medical transportation program;

   c. Establish a day activity and training program;

   d. Certify community-based MR/DD centers as medical providers for reimbursement for case management, medical diagnostic and therapy clinical services and proportional administrative overhead. Cost allocation can be a significant factor in generating federal reimbursements for the administration of the substate-regional centers, as well as for departmental central office administrative costs. This will usually require more sophisticated and uniform accounting throughout the developmental

services system than now exists -- and will require immediately increased resources for the department for its own systems, and for guaranteeing the uniform data needed at the community level.

4. *Development of a cohesive housing strategy:* The availability of housing is a significant problem nationally. Without adequate community housing, increased community services for the handicapped can be stalled. To solve these problems, the state needs:

a. Refinement and expansion of the Section 8 program and set-asides;

b. Development of a major 202 development program (which will require at least two years to even begin to produce results);

c. Establishment of revenue bond legislation in Congress, assuring exemptions for housing for the aging and for persons with developmental disabilities, mental illness, and physical handicaps in the community. The fiscal design here should ensure that real estate taxes be paid to the areas having new housing;

d. The development of a package for private market investors, including bonding and sale-leaseback components.

5. *Re-evaluation of current deinstitutionalization planning.* Specifically, the states should consider the following actions:

a. Speed up the deinstitutionalization process, if HCFA issues a deinstitutionalization-oriented regulation in this area;

b. Obtain post-1982 waivers for state hospital beds, tied to a meaningful phasedown plan;

c. Reprogram state hospital construction for the community if it is not already too late. Also, given the significant capital outlay which legislatures have invested in bringing state hospital buildings into Federal fire and life-safety compliance by July of 1980 (or, in some states, 1982) in order to protect Title XIX funding, plans should also be suggested to the legislature for transfering surplus buildings (which would no longer be used in the MR/DD program)

to other state agencies for alternative uses. One possibility, given current needs in the states, would be to transfer some of the facilities to state departments of corrections.

6. *Development of a Statewide Training Effort*

The current national Title XX training strategy is tied primarily to local county welfare agencies and graduate schools of social work, with little or no relationship to the MR/DD system. One of the original intents of Title XX training and Title XX service legislation was for training and retraining of workers in the deinstitutionalization effort. Funds were supposed to be marked for training and retraining of institutional and community service staff for community service programs.

Unfortunately, the Federal government didn't implement congressional intent in the regulations. As a result, any training in DD has to be paid for with other funds. This was a tragic outcome for the social services movement, since developmental programming is a treatment strategy which is effective and for which people can be trained, in such a way that their efforts have high payoffs. As such, it would have provided a politically popular example of effective training, coupled with the politically popular deinstitutionalization policy.

Since there never has been funding specifically earmarked for such a training approach, one of the deficits of the current, growing DD community service system throughout this country is that a large number of intelligent and enthusiastic people are employed who do not know a great deal about the developmental model and, as a result, some people with more severe disabilities who are returned to the community from the institution cannot be maintained in the community. The result is a return to the institution, or a lack of any further improvement, once the person is in the community. In the training area, several needs are evident:

a. The need to develop developmental training teams within the state MR/DD institutions to prepare people to return to the community and to train community staff in maintaining them in the community.

b. The need to train community-based MR/DD case managers in the area of resource development (and the need for a uniform resource development technology). At a minimum, a standard updated resource development workbook (later, a computer-aided eligibility calculation, referral, and

benefit and resource maximization system), resource advocacy, and the writing of individualized program plans, objectives and the monitoring of these plans.

c. Care provider training in the area of writing objectives and doing program planning and elevating expectations -- as well as behavior management.

7. *The development of supporting documentation.* Needed are service packages, including staffing models for both in-house and non-residential services, by level of care, with detailed cost and revenue expectations. In addition, drafts of needed state plan changes, state rule changes, pricing methodology, and provider concept must be developed.

8. *Assessment of OASDI eligibility.* The state should evaluate all persons in the system in relation to their SSI eligibility status. Apparently a large number of individuals currently receiving SSI are in fact eligible for OASDI, but have not been brought on the rolls. Increases in OASDI enrollment would have two effects in the state. First, the amount of state support is reduced. In addition, after two years of OASDI enrollment, individuals are eligible for Medicare, which is 100 percent Federally financed. There are 440,000 MR/DD people on OASDI in the United States. There may be another forty to eighty thousand now on SSI who would also be eligible for OASDI, thus reducing state-local costs. Further, if we could find those individuals currently in a state who have been on OASDI for at least two years, a Federally-funded home care program could be begun almost immediately. (The Medicare provisions of the Reconciliation Act of 1980 indicate that this is possible. It should be noted, however, that the current Administration is already moving to attempt to cut back on the "unlimited home health visit" provision of the Act. Even if this occurs, however, there are still some excellent fiscal and program reform possibilities here).

9. *Development of a Management Information System.* In order for any and all of the above to occur, there must be a solid data base for current and future need projections. This means that, if a state's management information system does not support the reforming and refinancing of the state's MR/DD system, it should be revamped to do so.