Developmental Disabilities Services

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Issue Statement

This paper assesses strategies to enable North Carolina to provide services to people with developmental disabilities more effectively and efficiently while converting to a community-based system.

Background

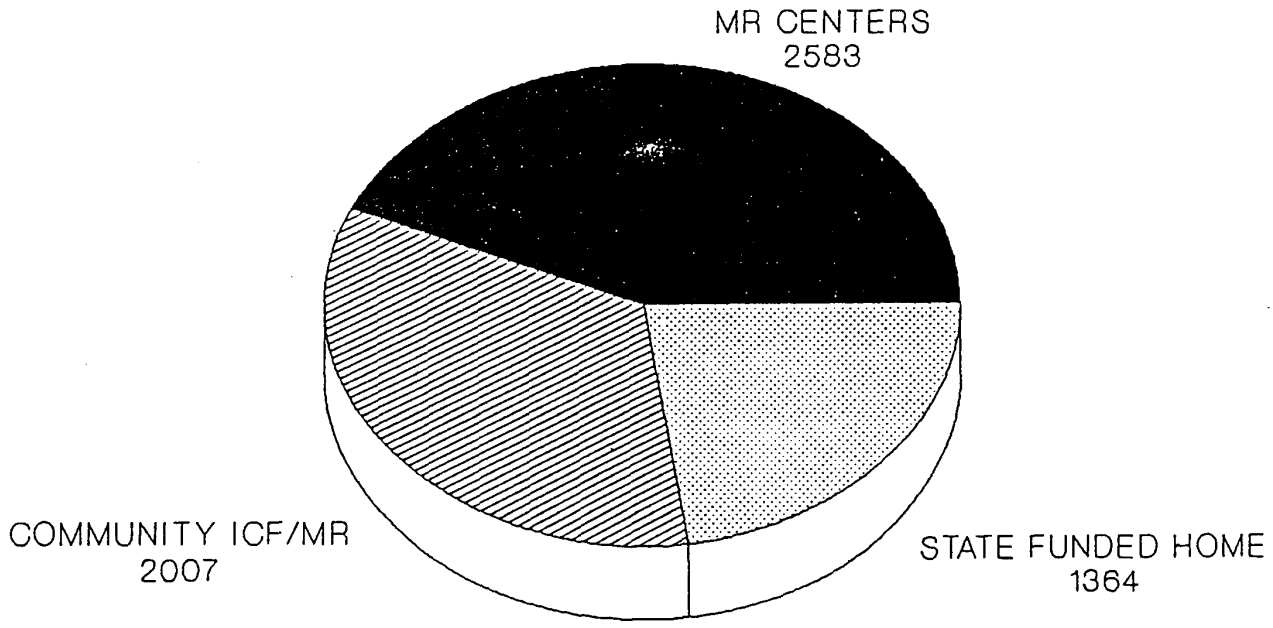
People with developmental disabilities in North Carolina are served by the Department of Human Resources (DHR). Within the Division of Mental Health of DHR, the Developmental Disabilities and Substance Abuse Services (DHR/DMH/DD/SAS) is the administrative component responsible to assure services are provided to all people with developmental disabilities in North Carolina. Structurally, DD/SAS coordinates developmental disability services through five regional Mental Retardation Centers (MRC) and 41 mental health area programs. Individual assessments, evaluations, and placement decisions are made at the MRC and area program level. Plans are underway to establish the MRC's as the single portal of entry for all persons with developmental disabilities. Policy planning and program support are provided by DD/SAS.

Currently, there are 5,954 people with developmental disabilities living in structured residential programs. (See Exhibit 1.) The five State-operated MRC's currently provide direct residential support to 2,583 people. Caswell Center serves the most people with a census of 809, and Black Mountain Center serves the fewest with 119 people. (See Exhibit 2.) Each of these facilities is certified as an Intermediate Care Facility for the Mentally Retarded (ICF/MR) and funded through the Federal Medicaid program. The MRC's also provide direct clinical support and training for those community service providers in their respective regions. Critical services provided by the MRC's include crisis intervention and respite (temporary) care to people in the regions on an as-needed basis. The vast majority of the people living in the MRC's have a diagnosis of severe or profound mental retardation as well as other disabling conditions. The MRC's are operated almost entirely by State employees with virtually no private contracts for services. Currently, DD/SAS has developed the preliminary structure for an overall reduction of the number of people living in State MRC's at the rate of 4.0 percent per year. Capital expenditures for MRC's over the past six years exceeded $15.6 million.

In addition to the State-operated Centers, there are more than two hundred privately-operated ICF/MR group homes (mostly 5-6 people in each) throughout the State, currently serving 2,007 people and growing at a rapid pace. Generally, those people currently served in community ICF/MR homes have disabilities less severe than those living in the State MRC's. All community ICF/MR group homes are operated by private entities, both non-profit

EXHIBIT 1

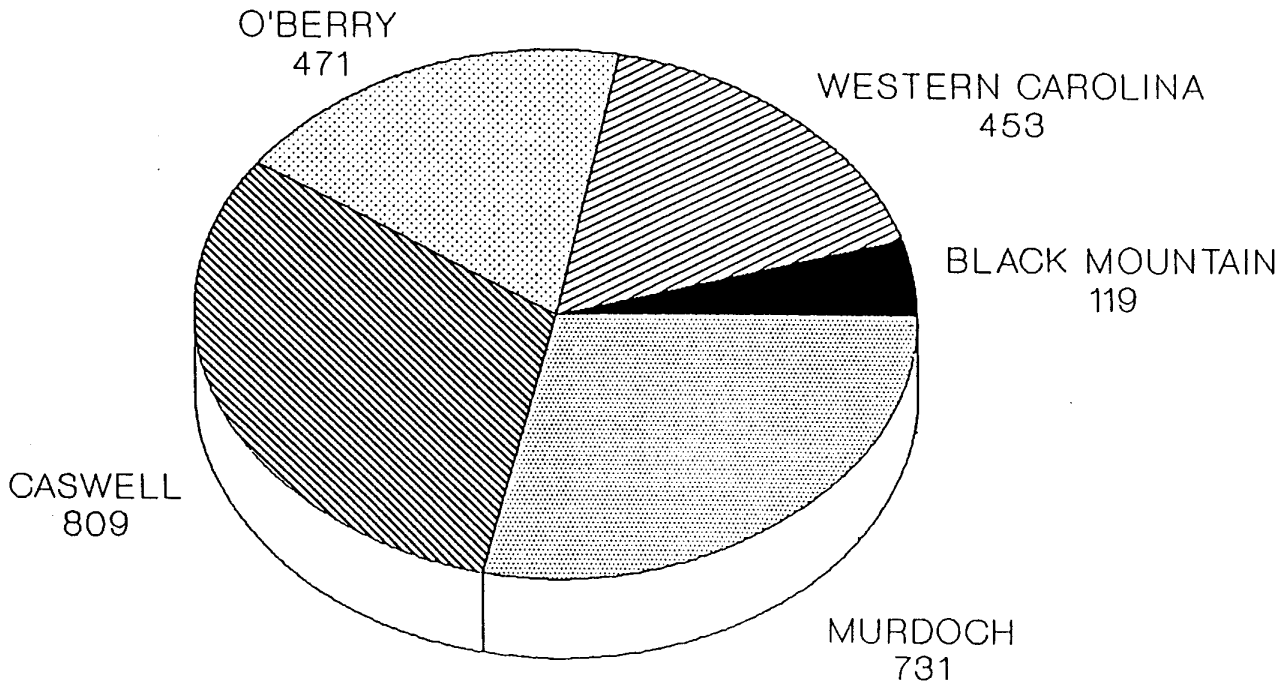
PEOPLE IN RESIDENTIAL PROGRAMS
TOTAL 5,954



Source: 1991 - 1993 North Carolina State Budget

EXHIBIT 2

STATE MENTAL RETARDATION CENTERS
TOTAL CENSUS 2583



END OF 1991

Source: 1991 - 1993 North Carolina State Budget

organizations and profit-making companies. The number of people served in small ICF/MR homes is expected to increase by nearly 25.0 per cent over the next two years. Other community residential programs not funded through Medicaid (DDA group homes) serve an additional 1,364 people with developmental disabilities.

The 1992-1993 funding level recommended for the State-operated MRC's is $192.4 million of which $156.9 million is paid with medicaid funds. The medicaid expenditures for this program have been relatively constant over the past four years. Funding for community-based ICF/MR homes, however, has escalated at a rapid rate in direct proportion to the increased number of people served. It is anticipated that the costs of supporting community-based ICF/MR homes will exceed that of supporting the State MRC's over the next two years. (See Exhibit 3.)

In addition to the funds for the ICF/MR program, North Carolina also receives support through the Medicaid Home and Community-based Waiver, a federal program designed to support services that are not facility-based in an effort to reduce the number of ICF/MR beds. In 1992 there were 1,147 people served through the Medicaid Waiver at a total cost of $13. 8 million. North Carolina has achieved a high degree of success in utilizing the Waiver, particularly in providing support to people with developmental disabilities who live with their families. The Waiver program is administered by the Division of Medical Assistance within DHR. Although the most recent Waiver was approved in 1987, there have been few substantive changes to those services originally requested.

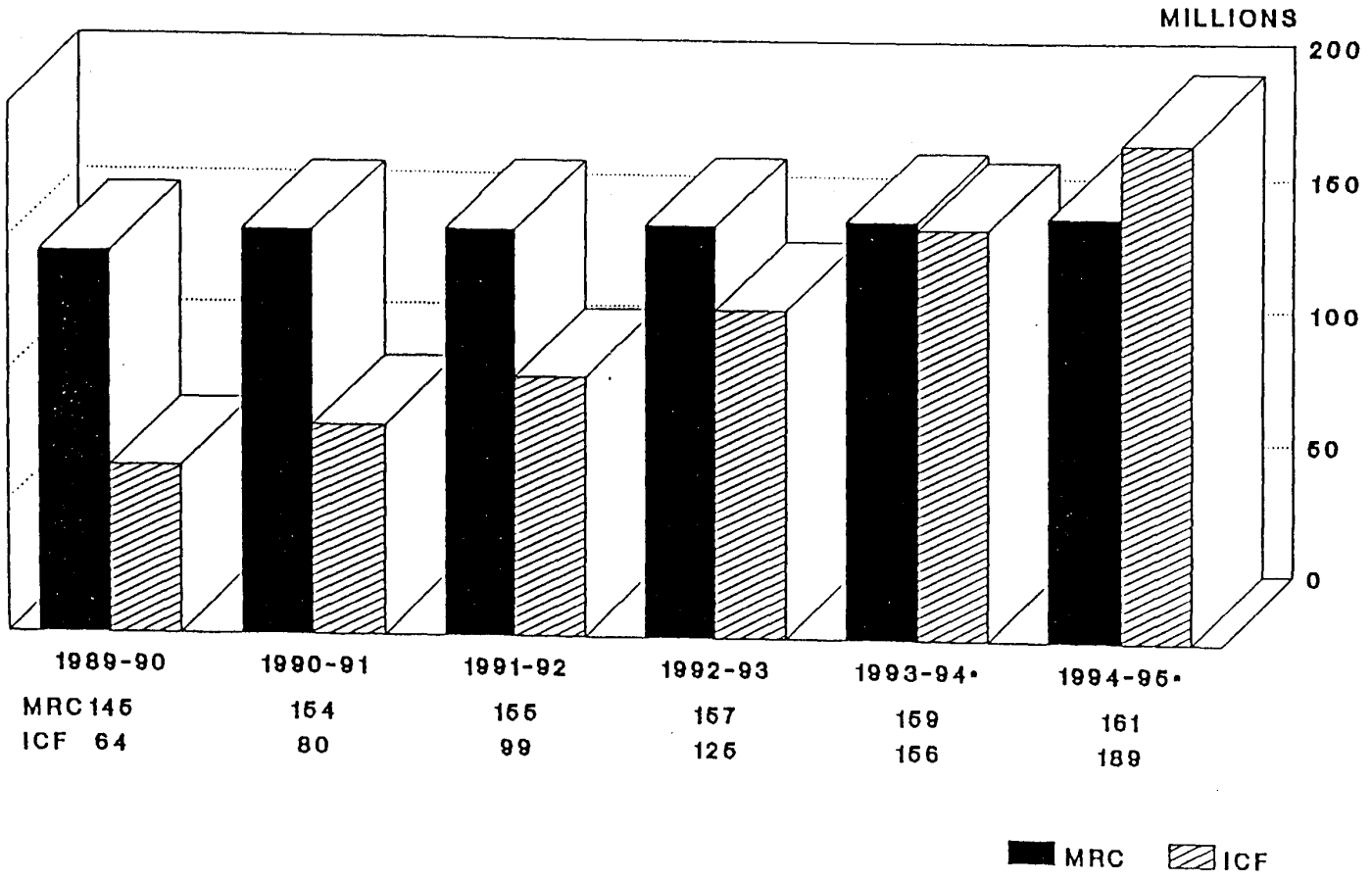
For the past three years, new admissions to State-operated MRC's have averaged 316 people per year, while discharges (including deaths) have averaged 380 people per year. (See Exhibit 4.) Between 1987 and 1991 the average daily census of MRC's has declined at the average rate of one percent per year.

A 1992 report by the University of Illinois at Chicago found that the average wage of non-management staff at the North Carolina MRC's exceeded the average wage of comparable positions in the community by more than 40 percent. While this can be partially explained by the longevity of staff in the MRC's, the low wage structure in community group homes is considered a leading cause of the relatively high staff turnover rate in the community programs.

The total number of recommended staff positions for the State operated MRC's for 1992-1993 is 5,910, the same as the number of positions authorized in 1991-92. Authorized positions for the Mental Retardation Centers have slightly increased over the past four years, even though the overall number of people served has slightly decreased. (See Exhibit 5.)

EXHIBIT 3

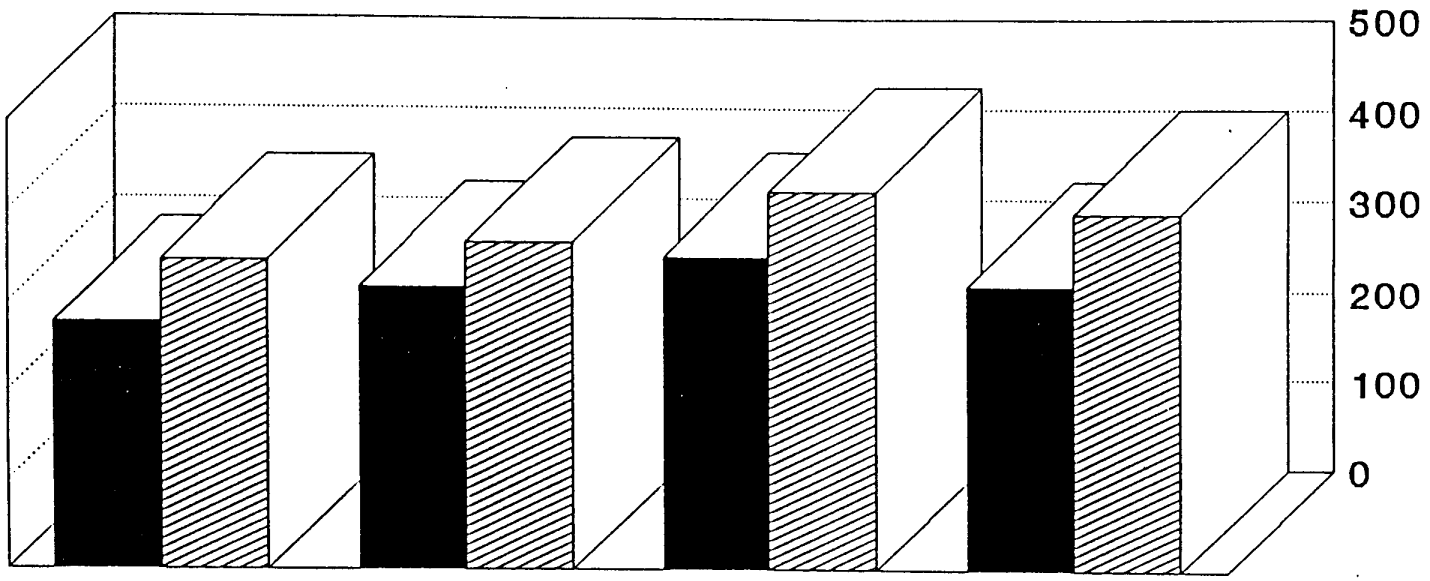
BUDGET GROWTH PATERN
MR CENTERS AND COMMUNITY ICF/MR HOMES



*PROJECTED

EXHIBIT 4

ADMISSIONS AND DISCHARGES
STATE MENTAL RETARDATION CENTERS



	1989	1990	1991	1992*
ADM	278	319	352	320
DIS	348	368	424	400

ADM DIS

*PROJECTED

EXHIBIT 5
STAFF POSITIONS IN STATE MENTAL RETARDATION CENTERS

MENTAL RETARDATION CENTER	1989-90	1990-91	1991-92	1992-93
Black Mountain	292	292	378	378
Murdoch	1,547	1,624	1,625	1,625
O'Berry	990	1,067	1,067	1,067
Caswell	1,671	1,805	1,805	1,805
Western Carolina	1,014	1,020	1,035	1,035
TOTAL	**5,514**	**5,808**	**5,910**	**5,910**

According to a plan developed in August of 1992 by the North Carolina Mental Health Study Commission, the current trend of services for people with developmental disabilities calls for "opportunities for full inclusion in the community." There were 28 recommendations in that report. Some of those goals which will have substantial cost implications include the following:

- Establishment of person/family-centered philosophy of services. This philosophy and approach ensures that training and support for systems change are provided and that such training and support utilize outside agencies as well as professionals and empower individuals and families as agents of change.

- Provisions for fiscal restructuring necessary to support a State policy committed to a community-based, family-centered approach to services and supports for persons with developmental disabilities and their families.

- Establishment of quality assurance mechanisms that provide for the internal and external review and monitoring of services.

At the National level, the current trend in services to people with developmental disabilities is the establishment of systems providing a full array of options in the community for persons with all levels and types of developmental disabilities. In fact, recent Federal funding initiatives include specific language which provides incentives for States to continue to create alternatives in the community. States across the country typically rely on the Medicaid Home and Community-based Waiver program as their primary agent for accessing Federal Medicaid funds to serve people with severe developmental disabilities in the community. Recently, eight states were selected to receive special block grants to establish a variety of natural support models which are not facility based. While North Carolina was not selected to receive such a grant, it was clearly demonstrated that North Carolina would be a prime candidate for

for such a program. Indicators for the future show that more Federal support will be forthcoming to support similar programs.

Findings and Recommendations

Finding 1: ***North Carolina Mental Retardation Centers continue to admit people with developmental disabilities who can be effectively served in community programs.***

As previously mentioned, the overall reduction of people in the State Mental Retardation Centers has been at the rate of one percent per year. This, coupled with the death rate in these institutions, which is nearly 0.6 percent per year (considered low by national standards), represents almost no size reduction at all. There is no specific State-wide plan for the overall reduction of the size of State MRC's. Now, however, a concerted effort exists within DD/SAS to significantly limit or eliminate new admissions of school age children and youth.

Recommendation 1: ***The General Assembly should establish a clear commitment to increase the use of community-based programs to serve the developmentally disabled, and to downsize State operated mental retardation centers.***

North Carolina offers residential services for the developmentally disabled population. Residential programs are the most costly and most restrictive methods of caring for this population. Persons with developmental disabilities can be served more effectively through a broad array of residential and non-residential services. Although the State mental retardation centers have plans to downsize, we believe that DHR's efforts could be impeded without clear public commitment from the State's leadership.

Recommendation 2: ***North Carolina should reduce the total number of people served in State operated Mental Retardation Centers by 500 people by the end of 1994 and 100 persons per year afterward.***

This represents an overall reduction in residents of less than 20 percent over the next two years. The reduction plan should include the following components:

- An immediate moratorium on new admissions of school age children and youth to MRC's
- A 50 percent reduction of all new admissions in 1993
- A moratorium on all new admissions in 1994
- Increased development of community placement slots for school age children and adults

- Establishment of 100 new community-based respite care slots per year
- Close Black Mountain Center by 1995
- Development of a comprehensive quality assurance plan for community services

By placing emphasis on the reduction of new admissions, the rate of outplacements can remain at nearly the same level as the present. As an example, the census at Black Mountain Center has consistently been between 115 and 120 since it began in 1983. In 1991 alone, there were 27 new admissions and 28 discharges. By maintaining discharges at the same rate together with curtailing new admissions alone, the census could be reduced by 50 percent in the first 18 months.

In addition to the above recommended action steps, North Carolina should develop a ten-year plan to continue to reduce the size of the State MRC's at a similar pace.

Recommendation 3: ***North Carolina should significantly increase proactive family support programs to further prevent out-of-home care and services for people with developmental disabilities.***

In the National movement to reduce the number of people living in institutions, the most under-utilized approach is the prevention or the reduction of the need for out-of-home care and support. Quite often, a relatively small amount of support at the family level can prevent long-term, costly services in a residential facility. These programs should support families of people with developmental disabilities to include at least the following:

- In-home support
- Direct family subsidies
- Comprehensive case management
- Family support coordination networks

It is important to note that both in-home support and case management services can be funded through the Medicaid Home and Community-based Waiver.

Finding 2: ***There is an inherent organizational and financial incentive to maintain State-operated MRC's at or near the current level.***

A problem that appears to be a significant barrier to reducing the size of the state MRC's is the natural financial incentive in maintaining per diem reimbursements. Per diem rates for MRC's average $190.00 with a Federal reimbursement rate of 66.0 per cent. This results in a significant influx of funds which can be applied in a relatively broad fashion. As a result, as

long as the MRC's remain certified under the ICF/MR program, an incentive remains to keep them open. Thus, this conflict-of-interest situation is wholly inconsistent with the current programmatic trends in the field of developmental disabilities.

Finding 3: North Carolina does not effectively utilize its Medicaid Home and Community-based Waiver (HCB), resulting in a proliferation of the community-based ICF/MR program.

According to a 1992 report by the National Association of State Mental Retardation Directors, North Carolina ranks 36th among the States in the number of individuals served in its program relative to state population. In fact, North Carolina has approximately 40 percent fewer individuals participating in the program than the average state. In contrast, the State has substantially expanded its use of the ICF/MR program, even though the costs of serving individuals is significantly higher than costs which the vast majority of states incur in supporting persons with similar needs by way of the HCB Waiver. Further proliferation of the ICF/MR program will strain State resources to the level where flexibility in services through the Waiver will diminish. North Carolina drafted revisions of their existing Waiver in 1990. These revisions, however, have not been approved by the Federal Health Care Finance Administration.

Recommendation 4: North Carolina should significantly expand the Medicaid Home and Community Based Waiver.

The Waiver can be expanded in both overall capacity as well as scope of services. In order to effectively expand the capacity of the HCB Waiver, it will be necessary to either invoke a moratorium on new development of ICF/MR programs or reduce the current number of ICF/MR placements in the State MRC's. If Recommendation #1 is implemented, the latter will be accomplished. Through this process, an overall increase in the Waiver capacity then becomes obtainable. As a result, the larger the capacity of the waiver, the more savings to the State. In addition to an increase in the total capacity of the waiver, support services should be expanded to offer a full menu of community supports for people of all levels of developmental disabilities.

Finding 4: There is a lack of a comprehensive needs assessment for citizens with developmental disabilities in North Carolina.

Effective long-range planning requires an accurate identification of the people with developmental disabilities throughout the State and their needs. Individual tracking systems are scattered throughout the State with no centralized system of planning and evaluation based on thorough information. As an example, there are a reported 2,500 to 3,000 people with developmental disabilities living in domiciliary care facilities (rest homes) throughout the state. There is no systematic approach, however, which has identified the needs of these people and whether they are living in appropriate settings. Situations such as this often lead to costly and protracted litigation requiring programmatic reevaluation of major proportions.

Recommendation 5: North Carolina should develop a comprehensive assessment of needs (both service specific and program) for all persons with developmental disabilities.

In order for effective long-range planning to occur, an effective data collection system is prerequisite.

This needs assessment should also:

- Include individuals who are unserved and underserved.
- Establish a state-wide automated tracking system for all people with developmental disabilities.
- Evaluate the needs of people with developmental disabilities living in domiciliary care facilities (rest homes).

Finding 5: Private sector service providers (both non-profit and profit making) are not adequately regulated in the areas of cost controls, movement, and placement of individuals as well as quality assurance.

North Carolina applies reimbursement and payment standards that are not adequately specific for allowable expenses in each cost center. In addition, they do not distinguish between large and small ICF/MR programs. As a result, determination of "reasonable" rates is often arbitrary and, therefore, not cost effective. Projections indicate that over the next two years, overall expenditures for community based ICF/MR programs will exceed those of the State MRC's. In 1983 federal regulations governing Medicaid reimbursement were greatly relaxed, requiring only that states pay facilities rates "which are reasonable and adequate to meet the costs which must be incurred by efficiently and economically operated facilities." North Carolina has not developed cost control mechanisms beyond the federal requirements. Per diem rates have continued to rise to a point where they now approach those of the State MRC's.

In addition to cost containment, North Carolina has not ensured that once people who live in Medicaid funded homes achieve the skills which may allow for increased self-sufficiency, they are given the opportunity to move to an environment which is less intrusive (and most often less costly). As a result, while there has been a rapid expansion of community ICF/MR programs, there has been little emphasis on the creation of other, less costly, alternatives. As a result, effective utilization review of the community-based facilities cannot be adequate without less intrusive (and less costly) programs available for referral. With more than 2,000 people living in community-based ICF/MR group homes, and more than 500 new slots in the plans for the near future, the system is being primarily controlled by the escalating demand.

A related matter is the manner in which community-based ICF/MR programs are inspected, licensed and certified. Currently, the Division of Facility Services (DFS) within the Department of Human Resources is responsible for the licensure and inspection of all ICF/MR programs. Clearly, this presents the potentiality of a conflict-of-interest situation. Should a community ICF/MR become decertified, DHR would have to either continue funding the facility from 100% State funds or close the facility and move the people to a different setting. It is not surprising, therefore, that with over 200 facilities operated by more than 50 different provider agencies, there have been no facilities decertified over the past two years.

*Recommendation 6: **North Carolina should establish comprehensive policies to develop reasonable standards for rates and payments for privately operated ICF/MR facilities.***

North Carolina should develop directly or contract for the development of reimbursement rates and payment standards to include at least the following:

- Quality of Service incentive payments and assessments
- Specific allowable costs within each cost center
- Limits and guidelines for rents and capital costs
- Specific standards for determining active treatment costs
- Special adjustments and exceptions
- Allowable profit margins
- Reimbursement policy for training and technical assistance

Without an effective reimbursement policy, base costs will continue to escalate with an inadequate level of control by the State.

IMPLICATIONS

Across the Nation, public policy for residential services for people with developmental disabilities has experienced change of nearly revolutionary proportions over the past 20 years. Services have gone from a system of almost exclusive institutional care to a broad array of service options. Unless North Carolina changes its current practices, the future of costs and programmatic implications for services are sadly predictable. People with developmental disabilities in North Carolina would be more effectively served through utilization of a broad array of residential and nonresidential services.

In the mental retardation centers, inpatient care staff will be reduced by about 3,200 positions over ten years. The staff reductions will be in proportion to the number of residents moved to community-based services. As a result of clients being served in the community, staff will increase in community-based programs. These community-based programs are not state organizations, and, therefore, employees moving between state institutions and community-based employment may require some training and placement assistance. (See Exhibit 6.)

EXHIBIT 6
Estimated Savings from Staff Reductions

	1993 - 95	1995 - 97	1997 - 99	1999 - 01	2001 - 02
Staff Reductions	915	686	686	686	229
Staff Increases	0	0	0	0	0
Net Staff (Reductions)/Increases	915	686	686	686	229
Net Dollar** (Savings)/Increases	$28.7	$13.4	$7.3	$7.3	$ 2.5

* 1992 dollars in millions.

** Dollar savings assume that the State will initial staff reductions will be targeted towards those positions that are 100 percent State funded before reducing medicaid supported staff positions.

Source: 1991 - 1993 North Carolina State Budget and KPMG Peat Marwick.

Through a combination of a phase-down of State Mental Retardation Centers, more effective utilization of the Home and Community-based Waiver, cost containment for ICF/MR programs, and family support initiatives, North Carolina can realize a net savings of $120.9 million over the next 9 years. (See Exhibit 7.) General fund savings include the following:

- $17.6 million savings in capital development of State Mental Retardation Centers ($2.7 million each of the first 4 years and $1.35 million each of the following 5 years).

- $70.8 million savings in conversion of ICF/MR beds to Home and Community-based Waiver services. This figure is based on the conversion of 200 beds per year for the first four years, 150 beds per year in the next three years, and 100 beds per year in the final two years at a cost savings of $9,500 per conversion each year.

EXHIBIT 7

Estimated Annual Savings from Downsizing MRCs and Restructuring Community-Based Services

	Fiscal Year Ending June 30 ($ in millions *)									
	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Current operating costs	$156.9	$156.9	$156.9	$156.9	$156.9	$156.9	$156.9	$156.9	$156.9	$156.9
(-) Operating Reductions	($23.9)	($37.4)	($47.7)	($58.1)	($67.1)	($77.4)	($87.8)	($98.1)	($108.5)	($118.8)
(+) Investments	$14.1	$26.6	$35.9	$45.2	$52.9	$62.2	$71.6	$80.9	$90.2	$99.6
(=) Net Savings	($9.6)	($10.8)	($11.8)	($12.8)	($14.2)	($15.2)	($16.2)	($17.2)	($18.2)	($19.2)

* 1992 Dollars.

- $43.3 million savings in the establishment and implementation of reasonable standards for Medicaid ICF/MR rates and payments. This figure is based on a savings of $7.50 per diem and 2,000 beds per year. While precise estimates for cost savings realized as a result of establishment of standards for ICF/MR reimbursement are virtually impossible, experiences in other states indicate that increases in per diem rates can be reduced as much as one half with effective cost containment policies.

- $58 million in staff reductions at the MRCs. This staff reductions assumes that the State will reduce those staff that are supported 100 percent with state funds before reducing medicaid supported positions.

The State will need to provide an investment into implementation of the above cost saving measures to include the following:

- $34.9 million investment over the next 10 years to establish non-Medicaid funded residential alternatives. (Costs exclude services provided through utilization of the Home and Community-based Waiver.)

- $28.1 million investment over the next ten years in the development of family supports and subsidies.

- $6.7 million investment in the first four years in the systems design. This includes development of a client tracking system, coordinating a state-wide needs assessment and policy revisions for reimbursement for community ICF/MR programs.

Increased use of community-based care will improve service. It will also reduce the probability of costly litigation. Numerous states across the country with a system of services profile similar to that of North Carolina have been plagued by costly and protracted individual and class action law suits. North Carolina has already felt the impact of the *Thomas S.* case, which affects a relatively small number of people with developmental disabilities in mental hospitals throughout North Carolina. The current profile of services in North Carolina, which includes informal waiting lists, limited options in the community, and limited access to services is ripe for litigation. In addition, because the full implementation stages of the Americans with Disability Act have just recently gone into effect, the litigation potential is virtually unpredictable. It would be fiscally and programmatically prudent for North Carolina to establish a mechanism to ensure that Federal and State rights for people with developmental disabilities are protected.

IMPLEMENTATION

The services and support systems for people with developmental disabilities in North Carolina are primed for effective change. The recent plan developed by the Mental Health Study Commission represents an excellent beginning, articulating 28 objectives, most of which are consistent with the recommendations contained herein. What appears to be missing, however,

is a process by which fiscal incentives can be incorporated to ensure implementation of the goals of the plan.

There are several steps of implementation which will be critical toward the realization of these objectives. First, the State must take actions to establish and pronounce a clear commitment to substantially reduce the size of the State-operated Mental Retardation Centers. This commitment should be articulated by all branches of government and reinforced by the advocacy community as well as private service providers. There is significant national experience regarding political and professional resistance to such a commitment. In those States, however, where there was a clear public policy toward the creation of community alternatives, a successful transition from the institution to the community is being achieved. States that have been successful in these efforts include Michigan, New Hampshire, Maryland, Nebraska, the District of Columbia, North Dakota and Colorado.

Secondly, North Carolina must place high priority on substantial revisions and modifications of the Medicaid Home and Community-based Waiver. In the immediate future, it is entirely possible for the capacity of the Waiver to be increased to as much as 2,200 people. If this is accomplished, the achievements for remaining years of this process will be much less complicated.

Thirdly, the involvement of community groups, families, consumers of services, and local providers into the planning process is paramount. There are numerous indicators that planning for people with developmental disabilities in North Carolina is often "from the top down," not adequately allowing for input at the local level until after the decisions have been made. Continuous efforts must be made to ensure early input at the local level.

Potential barriers to achievement of full implementation will include at least the following:

- Opposition by State employees of phase down of State MRC's. This barrier has been approached by many states through utilization of natural attrition as well as a comprehensive plan for retraining and redeployment of State employees to positions serving people in the community

- Additional expenditures required in the first two years of the plan

- Lack of implementation of a comprehensive quality assurance system for community services

REFERENCES

Comprehensive Plan for Services and Supports for Persons with Developmental Disabilities, Mental Health Study commission, August 1992

Renewal Request for Medicaid Home and Community Based Waiver, NCDHR, Division of Medical Assistance, March 1990

Department Plans--Outlooks and Objectives, State of North Carolina, January 1991

North Carolina State Budget, Volume 3, 1991- 1993

Closing Institutions in New York State: Implementation and Management Lessons, Paul Castellani, March 1992

Residential Service and Developmental Disabilities in the United States, Dave Braddock and Dale Mitchell, University of Illinois at Chicago, July 1992

Research on the Economics of Residential Services in Mental Retardation and Related Fields, H.A. Bersoni, G. Caruso, Syracuse University

An Analysis of Medicaid's ICF/MR Program, C.K. Lakin, R.Bruininks, University of Minnesota, Department of Educational Psychology

Enabling and Empowering Families - Principles and Guidelines for Practice, C. Dunst, C. Trivette, A. Deal, Brookline Books, 1988

Reasonable Standards for Medicaid ICF/MR Rates and Payments in the District of Columbia, John Trutco, James Bell Associates, Inc., August, 1990