

PREFACE

The "Active Treatment" Myth: People with Developmental Disabilities Trapped in Wisconsin Institutions is the second of two major reports developed by the Wisconsin Coalition for Advocacy in 1989 focused on Wisconsin's policies regarding nursing homes and similar facilities. In Behind Closed Doors: The Plight of Persons with Mental Illness in Wisconsin Nursing Homes (April, 1989), we documented a variety of abusive conditions, and a serious lack of appropriate mental health treatment for nursing home residents with mental illness in Wisconsin. Although The "Active Treatment" Myth is focused on a different population (people with developmental disabilities), and a specific federal definition of "active treatment" which only applies to this group, the two reports have certain points in common:

1. The State of Wisconsin has failed to adequately plan for the future of both people with mental illness and people with developmental disabilities residing in nursing homes, "institutions for mental disease," and ICFs/MR.
2. Neither the legislature, the Governor, nor the state Department of Health and Social Services have provided adequate policy and funding leadership to promote community alternatives to nursing homes and similar facilities. This has resulted in large numbers of people with developmental disabilities and people with mental illness living in institutions, even though they should not be there.
3. For the almost 10,000 Wisconsin citizens with developmental disabilities or mental illness currently residing in nursing homes, DD Centers, and ICFs/MR, the effects of these misguided state policies are severe and unjust.

TABLE OF CONTENTS

	<u>Page</u>
CHAPTER I: INTRODUCTION	1
A. What this Report is About	1
B. Background	4
1. "Wisconsin places an unacceptably high reliance on institutionally-based service..."	4
2. State legislation and policy commitments to deinstitutionalization and community integration for persons with developmental disabilities have led to small but important steps to developing community-based services in Wisconsin in the past decade	7
3. In its efforts to comply with federal active treatment requirements in institutions, the state has allowed itself to be diverted from Wisconsin's supposedly strong commitment to deinstitutionalization and community integration	9
4. Numerous serious problems have resulted from the state's response to problems of inappro- priate placement and lack of active treatment in nursing homes and ICFs/MR	10
C. What You Will Find in the Following Chapters	12
 CHAPTER II: THE DISCREPANCIES BETWEEN ACTIVE TREATMENT AND WISCONSIN'S GOALS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES	 15
A. Background on the ICF/MR Program and Active Treatment	15
B. Overview of Active Treatment Requirements	16
Capsule of Active Treatment Requirements	17
C. Comparison of Active Treatment Requirements with Wisconsin Law and Policy	21
Summary: Wisconsin Goals for Persons with Developmental Disabilities vs. Federal Active Treatment Requirements	22

	<u>Page</u>
CHAPTER III: "THE BEST BEHAVIOR PROGRAM WAS HAVING HER WALK OUT THE FACILITY'S FRONT DOOR": INTERVIEWS ON PEOPLE'S EXPERIENCES IN INSTITUTIONS AND COMMUNITY PROGRAMS IN WISCONSIN	32
A. Background	32
B. Individual Experiences in ICFs/MR, the DD Centers, and in the Community	33
C. Summary	54
CHAPTER IV: OFFICIAL EVIDENCE OF STATEWIDE ACTIVE TREATMENT VIOLATIONS IN WISCONSIN	56
Introduction	56
A. Evidence of Residents Receiving No Programs and Services or Minimal Levels of Programs and Services	62
1. Evidence of residents receiving no programs or services at all	62
2. Evidence of residents receiving programs and services at minimal levels and/or with major gaps	65
B. Evidence of Residents Receiving Programs and Services which are not Individualized or are Poorly Implemented	66
C. Failure to Provide Residents with Specialized Professional Programs and Services	69
D. Failure to Use Appropriate Resident Evaluations and Re-Assessments in Developing Programs and Services	73
E. Use of Chemical and Physical Restraints and Aversive Procedures in the Absence of Appropriate Programming	75
F. Obstacles to Active Treatment Related to Residents' Living Environment and Staff Treatment of Residents	80
CHAPTER V: CONCLUSIONS AND RECOMMENDATIONS FOR THE FUTURE	84
A. New Perspectives on Active Treatment	84

	<u>Page</u>
1. Active treatment is largely an empty goal	84
2. ICFs/MR and DD Centers are not nice places to live	85
3. Most, if not all, institution residents could "make it" in the community	85
4. Active treatment is full of contradictions	86
5. "The clock is ticking" for the people whose lives we are talking about	87
B. A Review of the Central Message of this Report	87
C. Recommendations for Action by the Governor, the Wisconsin Legislature, and the Wisconsin Department of Health and Social Services	89
D. Recommendations for Action Which Can Be Implemented Immediately by DHSS	92

Appendix A

CHAPTER I: INTRODUCTION

A. WHAT THIS REPORT IS ABOUT

Wisconsin, despite its progressive human service reputation, has continued to keep a large number of people with developmental disabilities in institutions. This particular aspect of our state's social policy offers nothing for others to admire or emulate: it is a policy responsible for the segregation of thousands of our fellow citizens long after many other states committed themselves to moving institutionalized persons with developmental disabilities back to their communities. It has also led to a gross misuse of Wisconsin and federal tax dollars—spending millions of dollars for people to live in places where they should not be.

This sustained commitment to institutionalization directly contradicts our state's officially-adopted goals for persons with developmental disabilities, expressed in statute and policy, which mandate and promote services in the "least restrictive environment," "integration into the community mainstream," and "full community membership." Regardless of what the state has said on paper, decisions regarding the lives of these people are increasingly being dictated by the crisis of the moment in our institutional facilities. The state's predictable and recurrent response: boost the funding for institutions and short-change the community alternatives.

The crisis of the moment has been precipitated by vigorous enforcement of federal active treatment standards by the federal Health Care Financing Administration (HCFA) in the state Centers for the Developmentally Disabled, in intermediate care facilities for persons with mental retardation and related conditions (ICFs/MR), and in general nursing homes. The increased enforcement activity has led to the disclosure of widespread, ongoing violations of active treatment requirements throughout the state. "Active treatment" is defined as:

"aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services...directed toward:

- (1) the acquisition of the behaviors necessary for the client to function with as much self determination and independence as possible; and

- (2) the prevention or deceleration of regression or loss of current optimal functional status."

The facilities that fail to meet these requirements face the possible loss of federal funds.

It should be noted that it is not the fault of the federal government that many facilities in Wisconsin fail to meet many of these requirements, nor is the federal government forcing Wisconsin to spend more money in these facilities to correct these problems, rather than move people to the community. It is the state which has chosen, on its own, to respond to this crisis in such an imbalanced way: pouring large amounts of funds into "fixing" institutions housing substantial numbers of people, but failing to simultaneously fund the community alternative which many of these people could utilize and which could greatly reduce the need to use institutions.

One of the most disturbing aspects of state policy in this instance is the de facto replacement of real community alternatives by the ICF/MR as the new "right place to be." An immediate negative outcome of this ad hoc policy change is the transfer of long-term nursing home residents with developmental disabilities to new "distinct-part" ICFs/MR¹ which are required to meet active treatment standards, once again disregarding the principle of least restrictive environment in the lives of many of these people.

Dramatic proof of our drift away from the state's officially-adopted goals is presented in Chart 1 (on the following page), which depicts state trends in per diem rates for distinct-part ICFs/MR compared with the rates for the program which provides community-based services for persons with developmental disabilities who move out of ICFs/MR and general nursing homes: the Community Integration Program-lb (CIP-lb).

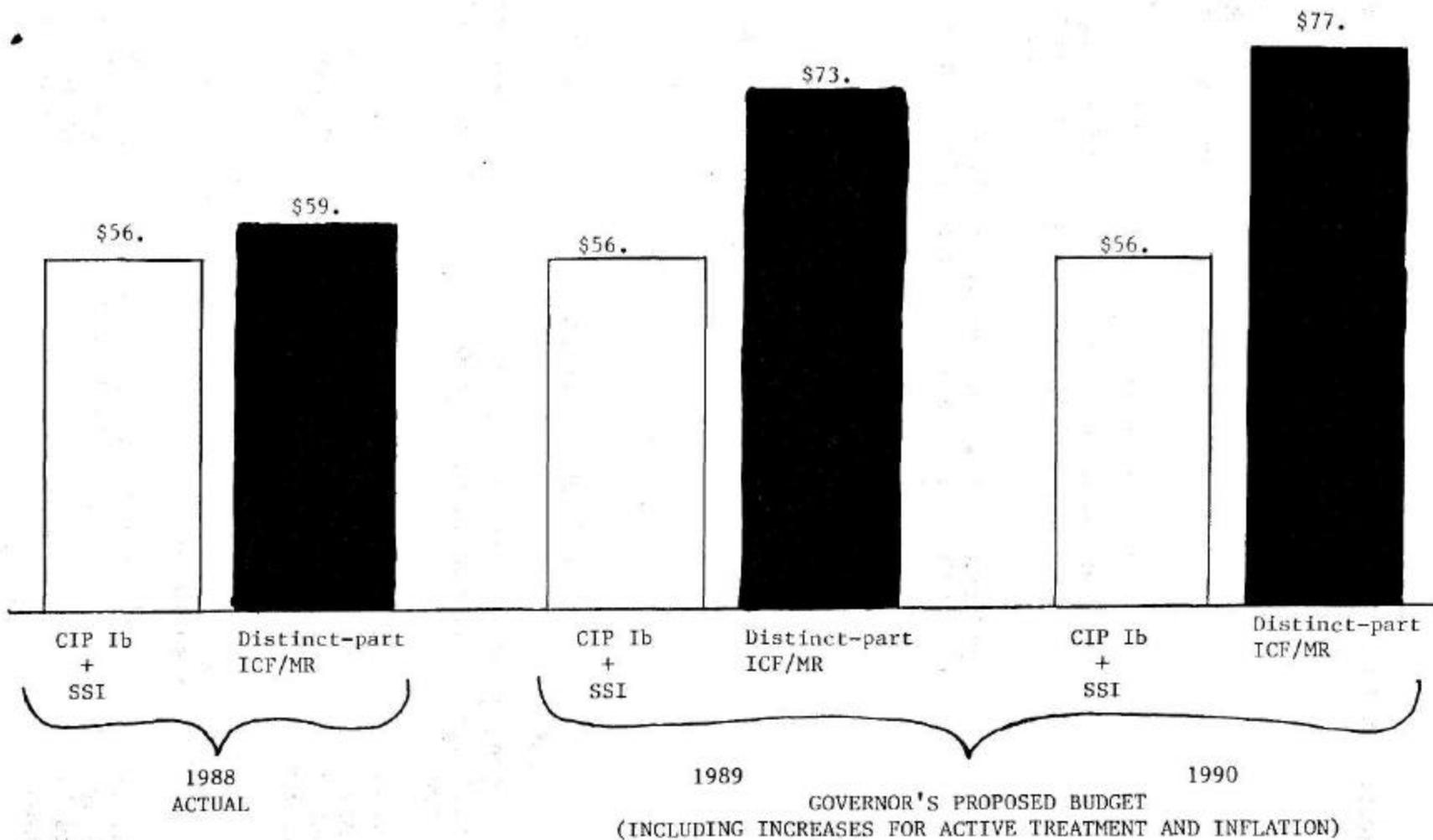
In "Out of Sight, Out of Mind" (May, 1986), the Wisconsin Coalition for Advocacy reported on the nature and extent of violations of the human and civil rights of residents of Wisconsin's three Centers for the Developmentally Disabled (DD Centers). That report demonstrated that the Centers fall far short of their protective and custodial obligations to their'

¹The term "distinct-part" ICF/MR describes a situation in which one part of a nursing home converts from nursing home to ICF/MR certification.

CHART 1

INSTITUTION VS. COMMUNITY FUNDING TRENDS

(DISTINCT-PART ICF/MR VS. CIP Ib PER DIEM RATES*)



* For comparability it is necessary to add Supplemental Security Income (SSI) income (approximately \$17.70/day) to the CIP-Ib rate (\$38.76/day), since this is additional funding available for community living but not available to cover ICF/MR costs.

residents. In this report we go beyond individual rights violations in the DD Centers, to examine what day-to-day life is like in both the Centers and private and public ICFs/MR. In this examination we will focus particularly on the implications for the lives of facility residents of our state's decision to focus the bulk of its resources on providing institution-based active treatment rather than supporting opportunities for community living.

We present this report to impact public policy affecting people with developmental disabilities in Wisconsin, and specifically to:

expose the myth that providing "active treatment" in institutions is "the right answer" for people with developmental disabilities in Wisconsin;

argue forcefully for re-affirming the state's original goal of enabling persons with developmental disabilities to move back to their home communities; and

present recommendations for the future consistent with this goal.

B. BACKGROUND

1. "Wisconsin places an unacceptably high reliance on institutionally-based service..."

In 1979, in its "Planning Guideline Number 1 (Long Term Support)," the Wisconsin Department of Health and Social Services (DHSS) acknowledged that:

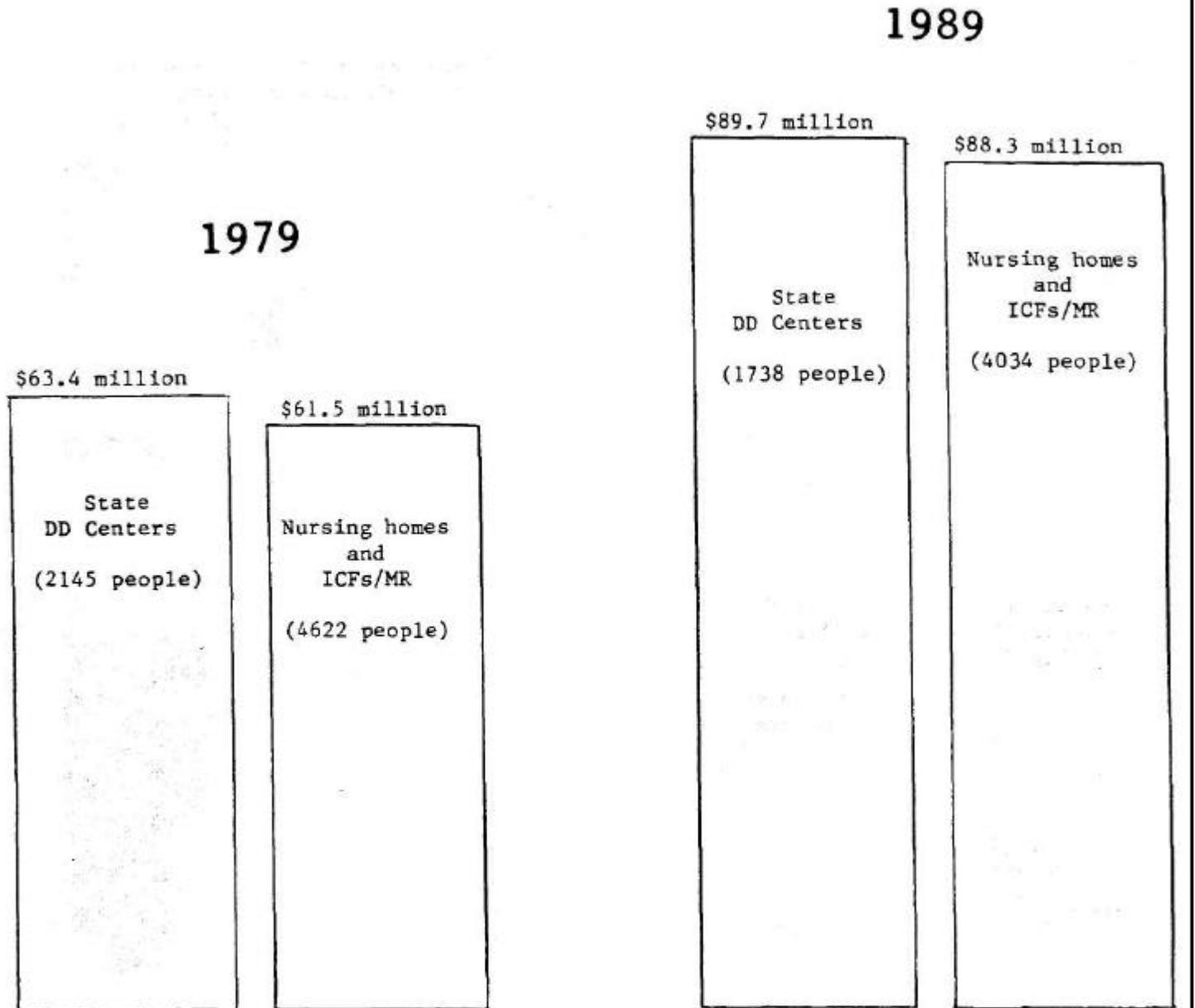
"Wisconsin places an unacceptably high reliance on institutionally-based service, in spite of...pronouncements supporting community-based services. We must strive to overcome the inertia of earlier systems, to understand all the ramifications of our individual policy decisions, and to implement and creatively integrate the best in our current understanding of appropriate services."

Almost a decade after this renewed commitment by DHSS to community alternatives, Wisconsin is still struggling, with mixed results "...to overcome the inertia of earlier systems..." This is graphically depicted in the charts on the following pages.

CHART 2

AGGREGATE PUBLIC EXPENDITURES FOR INSTITUTIONAL SERVICES
TO PERSONS WITH DEVELOPMENTAL DISABILITIES IN WISCONSIN

1979¹ and 1989²

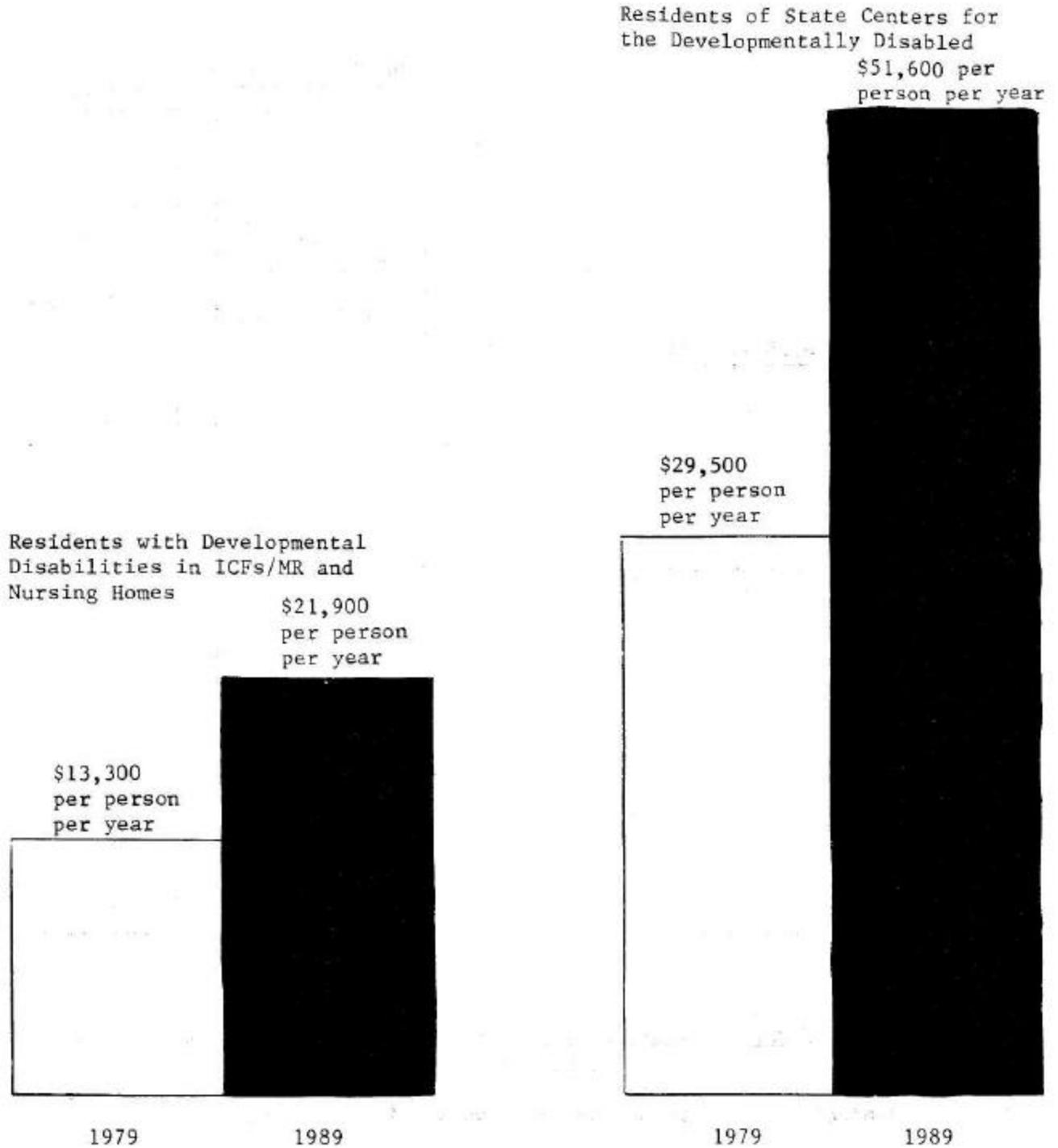


Source: "Funding for Alternative Residential Services for Persons with Developmental Disabilities," September, 1980 (DHSS)

Source: Projections from DHSS 1989-91 Proposed Biennial Budget

CHART 3

ANNUAL AVERAGE COSTS PER PERSON IN WISCONSIN
INSTITUTIONS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES



For the period 1977-1984, Wisconsin ranked thirty-sixth in the nation in the rate of reduction of the size of state DD Centers (i.e., most states are reducing state institution population faster than Wisconsin). The total population of our DD Centers, at 2079, ranked ninth highest in the nation in 1984; this total is approximately 1738 today. Michigan, with twice Wisconsin's population, has only 1305 people in state DD institutions.

2. State legislation and policy commitments to deinstitutionalization and community integration for persons with developmental disabilities have led to small but important steps to developing community-based services in Wisconsin in the past decade.

Explicit commitments to "least restrictive environment," "integration into the community mainstream," and the right to "a valued home in the community" can be found in various statutory and official policy statements in Wisconsin, i.e., Chapters 51 and 55 of Wisconsin statutes, DHSS Planning Guideline #1 (Long Term Support), and the operating guidelines of the Community Options Program and the Community Integration Program.

Fortunately, these statutes and policies have not been completely overridden by reflexive commitment to institution programs and services. Wisconsin has developed several progressive community programs in recent years:

the Community Options Program (COP), which provides service funds to support persons diverted from placement in or relocated from nursing homes;

the Community Integration Program (CIP-Ia), which redeploys Medicaid funds normally spent in the DD Centers to provide support services to Center residents moving back to their home counties;

the CIP-Ib program, which provides Medicaid funds to prevent unnecessary admissions to nursing homes and ICFs/MR and to enable people to move out of these facilities;

the Family Support Program, which provides services and funding to enable families to keep children with severe disabilities at home rather than placing them in a residential facility; and

the Katie Beckett program, which provides Medicaid coverage for children with severe disabilities living with their families.

The development of these programs is important in three respects:

- (a) There are persons with developmental disabilities who have clearly benefited from these programs. They have either been able to leave restrictive facilities for lives in the community, or have been able to avoid placement in such facilities because of community services offered under these programs;
- (b) These successes have shown us that it is possible for people with developmental disabilities (including people with "challenging behaviors" and/or severe impairments) to leave institutions and "make it" in the community; and
- (c) Every county in Wisconsin is participating in at least one of the programs described above, and some counties are actively participating in all of them. There has been a significant rise in recent years in the commitment of many Wisconsin counties to enable people with developmental disabilities to move out of institutions and into appropriate supported community arrangements. Almost 800 people with developmental disabilities are currently receiving services via the CIP-Ia and CIP-Ib programs combined.

One of the programs cited above, the second Community Integration Program, CIP-Ib, has major significance in relation to the issues addressed in this report. This program, which began in 1987, provides Medicaid² funds for community services to persons with developmental disabilities who move from nursing homes or ICFs/MR. The promise of CIP-Ib, however, has been diminished considerably by the state's decision to under-fund³ it, once again committing a disproportionate share of Medicaid funds to upgrade institutions while inadequately funding the

The origins of the federal Medicaid program are discussed in Chapter II.A.

³ See Chart 1 on page 3.

community alternative. Ironically CIP-Ib, if adequately funded and supported by the state, contains the potential to dramatically reduce the utilization of the very institutions on which Wisconsin is spending so much money.

3. In its efforts to comply with federal active treatment requirements in institutions, the state has allowed itself to be diverted from Wisconsin's supposedly strong commitment to deinstitutionalization and community integration.

Providing "active treatment" to residents has been a requirement of facilities with ICF/MR status since 1971. Active enforcement of these requirements was not a major federal priority, however, for many years. In 1985, the Health Care Financing Administration (HCFA) began its own "look-behind" surveys of the state's ICFs/MR and the DD Centers, to check on the quality of state surveys of these facilities. HCFA surveys in Wisconsin found that many residents were not receiving active treatment and that drugs and physical restraints were being misused. In 1985 HCFA also began enforcing a policy that persons with developmental disabilities in need of active treatment could be in general nursing homes only if they had skilled nursing needs and if their active treatment needs were also met. HCFA surveys of Wisconsin nursing homes found that the vast majority of residents with developmental disabilities did not need skilled nursing care and were not receiving active treatment, that physical restraints and medications were often used instead of treatment, and that screening for appropriateness of nursing home placements was either absent or ineffective.

Faced with possible termination of federal Medicaid funding to ICFs/MR and the three State Centers for "the Developmentally Disabled, and with the potential loss of over \$20 million per year in federal funding for people with developmental disabilities in general nursing homes, the state has responded with a number of actions. In 1986, Wisconsin agreed to a four-year plan under which the state would assure provision of active treatment to people who needed it, and also assure that by July 1, 1990, individuals who did not need skilled nursing care would be placed either in facilities certified as ICFs/MR or in community settings.

Key components of the plan include:

recertification of designated wards or floors of nursing homes as "distinct-part" ICFs/MR that would be licensed and certified separately from the rest of the

facility (DHSS' first estimate was that 500 distinct-part ICF/MR beds would be developed);

obtaining a federal waiver that allows the use of Medicaid funds via the CIP-Ib program for community alternatives to ICFs/MR and nursing homes; and

adoption of active treatment standards to apply in general nursing homes and adoption of a rule prohibiting new admissions of persons with developmental disabilities to general nursing homes, except where the person was in need of skilled nursing care. The nursing home must provide active treatment where needed, even when the person has skilled nursing needs, except for people over age 65 who have reached "maximum potential," are terminally ill, or who do not have mental retardation and are competent to handle their own affairs.

The state also has taken several actions to increase funding to institutional facilities:

allocating a special supplement of \$6.94 per person per day to upgrade active treatment in distinct-part ICF/MR facilities and regular nursing homes serving persons with developmental disabilities;

increasing funding to ICFs/MR facing the termination of federal Medicaid support, including Southern, Northern, and Central Wisconsin Centers; and

proposing in the Governor's current biennial budget bill to further increase ICF/MR rates by: an additional \$9.76 per person per day for meeting active treatment standards, a 7.7% inflationary increase for FY90; and a second inflationary increase of 5.2% for FY91.

4. Numerous serious problems have resulted from the state's response to problems of inappropriate placement and lack of active treatment in nursing homes and ICFs/MR.
 - (a) The CIP-Ib program has been actively utilized by only a small number of counties and has only-served a small proportion of nursing home and ICF/MR residents with developmental disabilities. The low per diem rate allowed for CIP-Ib participants (\$38.76) has not

provided a viable funding source for a community alternative for most nursing home or ICF/MR residents.

- (b) State efforts to "fix" ICFs/MR and the three State DD Centers because of their problems in meeting active treatment standards have also diverted funds--and the attention of state officials and legislators--from community programs.
- (c) The state has in effect "promoted" the distinct-part ICF/MR option to counties and facilities. In some instances this has taken the form of direct DHSS encouragement of counties to convert a large portion of their county nursing homes to distinct-part ICF/MR status, even though many of the residents with developmental disabilities could live in the community. The state has also indirectly promoted this option by disproportionately funding the distinct-part ICF/MR option over CIP-Ib and by failing to provide policy leadership encouraging counties to consider the community alternative for people. Now so many decision-makers and administrators around the state have been influenced by these "messages" from state government that they are getting used to the idea that ICFs/MR which meet active treatment standards are an acceptable place for persons with developmental disabilities to live, and to live for the long term. As a result, developing "high quality ICFs/MR" has become a de facto public goal which undercuts the sense of urgency for helping ICF/MR residents move back to their communities.
- (d) The disparity between the current CIP-Ib rate of \$38.76 (with no proposed increase in the coming biennium) and the proposed distinct-part ICF/MR rate of \$77 (by the second year of the biennium) will create an even stronger incentive for counties to continue to use distinct-part ICF/MR facilities instead of community alternatives. It also sends a strong message to counties that the state is not really serious about funding and supporting a community alternative.

The combined impact of these developments has led to two major outcomes. First, the state is creating over three times as many new ICF/MR beds (over 1700 at last count) as state officials originally envisioned -- and these facilities may well become a permanent feature of Wisconsin's human service system. The large majority of the people occupying these beds could and should live in the community.

Secondly, (unless there are significant changes in Wisconsin's current practices affecting people with developmental disabilities) it looks like most of the people who reside in these institutions are going to remain there for a very long time--perhaps the rest of their lives. Not only is this tragic for these people; it is likely that the state will continue to misspend an ever-increasing amount of tax dollars on institutional services we long ago decided were inappropriate. And we will have missed a promising opportunity--created by federal pressure on our institutions -- to develop viable and adequately funded community programs which meet our formal goals for the large-scale movement of persons with developmental disabilities to their communities.

C. WHAT YOU WILL FIND IN THE FOLLOWING CHAPTERS

Chapter II -- "The Discrepancies Between Active Treatment and Wisconsin's Goals for Persons with Developmental Disabilities"

In Chapter II, we provide a summary of the federal active treatment requirements. This is followed by a comparison of these requirements with Wisconsin's officially-adopted goals for persons with developmental disabilities.

Chapter III -- "The Best Behavior Program Was Having Her Walk Out the Facility's Front Door": Interviews on People's Experiences in Institutions and Community Programs in Wisconsin

In Chapter III, we present excerpts from interviews of former residents of the DD Centers and ICFs/MR, parents and guardians of current and former residents, current DD Center staff, and the staff of community programs. Through these interviews we attempt to provide a depth of understanding one cannot get from survey reports alone of what Wisconsin's continued investment in its institutions means to the lives of these

facilities' residents. We also show how life has changed for some former facility residents after they moved back to their communities.

Chapter IV -- Official Evidence of Statewide Active Treatment Violations in Wisconsin

In Chapter IV, we look at the lives of residents in DD Centers and ICFs/MR through the objective findings of state and federal survey teams. These findings not only demonstrate the continuing inability of the state to ensure that institutionalized persons with developmental disabilities are receiving active treatment; they also add to the reader's understanding of the overall quality of life in these facilities. This chapter is a strong reminder that ICFs/MR in Wisconsin are still first and foremost institutions.

Chapter V -- Conclusions and Recommendations for the Future

In Chapter V, we summarize what we believe "active treatment" is and what it means to our state and its institutionalized residents with developmental disabilities. We conclude with recommendations for immediate and long-term actions to be taken by the governor, the legislature, and the Department of Health and Social Services, to move us back to Wisconsin's officially-adopted goals for people with developmental disabilities.

THE CENTRAL MESSAGE OF THIS REPORT

1. THERE IS SOME MERIT TO ACTIVE TREATMENT: IF INSTITUTIONS COMPLY WITH THESE STANDARDS, EACH RESIDENT WILL HAVE AN INDIVIDUAL PROGRAM PLAN AND RESIDENTS MAY HAVE LESS "DEAD TIME" THAN WHEN THEY WERE LIVING IN FACILITIES NOT PROVIDING ACTIVE TREATMENT.

2. HOWEVER:

FOCUSING OUR PRIMARY ATTENTION ON ACTIVE TREATMENT COMPLIANCE DOES NOT FIT WITH -- AND DIVERTS US FROM -- OUR STATE'S OFFICIALLY-ADOPTED GOALS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: ADEQUATE AND APPROPRIATE SUPPORT FOR PEOPLE TO LIVE IN THE COMMUNITY, AS VALUED CITIZENS IN THEIR OWN HOMES AND NEIGHBORHOODS.

ADDING FUNDING TO PROVIDE ACTIVE TREATMENT CANNOT CHANGE THE FACT THAT DD CENTERS, NURSING HOMES, AND LARGE ICFs/MR ARE STILL INSTITUTIONS, NOR CAN IT CHANGE THE FUNDAMENTAL REALITY OF LIFE FOR INSTITUTIONALIZED PERSONS WITH DEVELOPMENTAL DISABILITIES: INSTITUTIONS ARE AND WILL REMAIN INAPPROPRIATE AND OFTEN INHUMANE ENVIRONMENTS, REGARDLESS OF THE TIME AND MONEY WE POUR INTO THEM; AND

ACTIVE TREATMENT IS INTERNALLY INCONSISTENT -- IT AIMS TO TEACH SKILLS FOR COMMUNITY LIFE IN ISOLATION FROM THE COMMUNITY, CONSEQUENTLY ELIMINATING MOST OR ALL OPPORTUNITIES FOR NATURAL USE OF THESE SKILLS; AND IT ATTEMPTS TO CHANGE "INAPPROPRIATE BEHAVIOR" IN AN INSTITUTIONAL ENVIRONMENT WHICH MAY ITSELF BE A MAJOR CAUSE OF THIS BEHAVIOR.

3. CONSEQUENTLY:

WE MUST RENEW OUR COMMITMENT TO THE INTEGRATION OF INSTITUTIONALIZED PERSONS WITH DEVELOPMENTAL DISABILITIES INTO THEIR HOME COMMUNITIES, A GOAL WHICH HAS ALREADY BEEN SHOWN TO BE ATTAINABLE IN WISCONSIN;

WE MUST FINALLY TRANSLATE THIS COMMITMENT INTO CONCRETE POLICY AND FISCAL ACTIONS WHICH MOVE LARGE NUMBERS OF PEOPLE OUT OF INSTITUTIONS AND ENSURE ADEQUATE SUPPORT FOR THEM IN THE COMMUNITY; AND LASTLY

WE MUST FIND WAYS TO MEET ACTIVE TREATMENT REQUIREMENTS WITHOUT EXPANDING AND LEGITIMIZING INSTITUTIONS IN WISCONSIN.

CHAPTER II: THE DISCREPANCIES BETWEEN ACTIVE TREATMENT AND WISCONSIN'S GOALS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

A. BACKGROUND ON THE ICF/MR PROGRAM AND ACTIVE TREATMENT

The federal Medicaid program (Title XIX of the Social Security Act) was established by Congress in 1965 as a means for providing federal funding to states for health care and other services to public assistance recipients and other medically needy persons. In 1971 Congress, under Section 1905(d) of the Social Security Act, gave states the option of using Medicaid funds for services to persons with developmental disabilities who were living in facilities which met federal standards for "intermediate care facilities for the mentally retarded" (ICFs/MR). Today, 25 public and private institutional facilities⁴ in Wisconsin, including the three DD Centers, are funded through the Medicaid ICF/MR program. (Generally, this report will use the term "ICF/MR" to refer to facilities other than the DD Centers. The DD Centers' operation by the state and their substantially higher rates of Medicaid reimbursement distinguish them from private and county-run ICFs/MR.)

To be certified as ICFs/MR, facilities had to meet health, safety and sanitation standards and provide "active treatment" services to their residents. Regulations for the ICF/MR program were first issued in 1974. State and facility compliance with active treatment requirements received little attention until the mid-1980's, when state efforts to correct violations disclosed in federal "look-behind" surveys led to rapid acceleration in Medicaid expenditures in ICFs/MR and the DD Centers.

In June, 1988 HCFA issued new Medicaid program regulations intended, in part, to improve state efforts to comply with active treatment requirements. Updating the regulations was certainly an appropriate action for the federal government to take. However, the issuance of these regulations and the corresponding increase in compliance activities have already intensified Wisconsin's preoccupation with active treatment compliance. We expect this preoccupation to increase in the months to come.

⁴This number refers to "free-standing" ICFs/MR and does not include the new generation of so-called "distinct-part" ICFs/MR in Wisconsin.

B. OVERVIEW OF ACTIVE TREATMENT REQUIREMENTS⁵

To examine what Wisconsin is committing to by putting "active treatment" at the center of the vision of the future for its institutionalized citizens with developmental disabilities, it is essential to provide in this report more than a cursory overview of the "active treatment" concept. In Appendix A we provide a summary of active treatment requirements which represents a review of 190 pages of federal source documents. In that Appendix, all major elements of active treatment are covered. In addition, client rights and some related areas of programming which bear directly on learning, skill development, and the management of challenging behaviors are also included. It is these programming areas in which people with developmental disabilities generally require the most unique and intensified services.

Beginning on the following page, we provide a Capsule of Active Treatment Requirements, based on Appendix A. This capsule is not intended to be a thorough discussion of active treatment and related areas, but is provided as background to the remainder of this chapter, in which we compare active treatment to Wisconsin's statutes and officially-adopted policies.

"Active treatment" is a term to which people may attribute a variety of meanings. In this report we use the term strictly as it is defined in the Medicaid program regulations. (42 C.F.R. Part 483)

CAPSULE OF ACTIVE TREATMENT REQUIREMENTS*

1. The definition of active treatment.

For a facility to meet the federal condition of participation requiring active treatment services, each resident of an ICF/MR "must receive a continuous active treatment program, which includes aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services...directed toward:

- (1) the acquisition of the behaviors necessary for the client to function with as much self determination and independence as possible; and
- (2) the prevention or deceleration of regression or loss of current optimal functional status."

2. Key elements of the active treatment process.

- (a) Admissions, transfers and discharge: Persons admitted to the DD Centers and ICFs/MR must need active treatment. Decisions must be based on formal evaluations which include client needs and likelihood of benefit from placement. Admissions are not to be seen as permanent.
- (b) Individual Program Plan (IPP): Active treatment must be based on an IPP for each resident which identifies needs and appropriate services. The IPP must be based

The source documents used in preparing this capsule are: (a) Medicaid program regulations for ICFs/MR (42 CFR Part 483, issued June 3, 1988); (b) "Discussion of Comments" preceding the regulations; and (c) "Survey Procedures and Interpretive Guidelines for ICFs/MR" (dated October, 198'8) All quotations in this capsule come from these official sources.

(This capsule was prepared by Wisconsin Coalition for Advocacy Staff, May, 1989.)

on a comprehensive functional assessment and specify program objectives, methods for reaching the objectives and for ending "inappropriate behavior."

- (c) Implementing, monitoring and changing the IPP: The activities required in the IPP must be implemented by all staff who work with the resident. The resident should be given "...a broad range of options...and... engage in...(program activities) as independently as possible." "...The facility must document significant events..." relating to resident progress. The IPP must be revised and reviewed accordingly, at least annually.
- (d) Ensuring clients' rights: The regulations stipulate, primarily in the "Client Protections" condition of participation, a list of rights to be provided throughout the active treatment process. They include rights to: due process and citizenship; protection against abuse and the use of unnecessary drugs and restraints; privacy; freedom of association; the exercise of personal choice; the use of personal possessions.
- (e) Communications with clients, parents, and guardians: The facility must promote "participation of parents... and legal guardians...in the active treatment process...unless their participation is unobtainable or inappropriate"; "...visits by individuals with a relationship to the client" (including close friends and advocates); and "...frequent and informal leaves from the facility for trips, visits, or vacations."

3. Policies related to the delivery of services.

- (a) Placement in the least restrictive alternative and integration into normal home and community life are not part of active treatment requirements. Requiring the placement of residents in the least restrictive alternative available "...would go beyond the intent of Congress...There is nothing...that suggests that the size or location of a facility, or whether a facility is the least restrictive alternative, should determine whether...(it) qualifies for (funding). The only statutory requirement is that a client receive active treatment at the facility." (Emphasis added)

- (b) Medicaid program regulations do not require that ICF/MR residents benefit from active treatment. "We believe the state of the art is such that we can hold facilities accountable (only) to implement, review, and... modify the strategies they use to improve client functional abilities..."
- (c) Management of "inappropriate client behavior": The policies and procedures of each facility must specify all approved interventions, prioritize them and document that less intrusive means were used before more restrictive means are attempted. Procedures must cover the use of time out rooms, physical restraints, medications, "...and the application of painful or noxious stimuli." Any use of these behavior management techniques must be included in the IPP. They may never be used to discipline residents, for staff convenience, or as a substitute for active treatment. Drugs may not be used for behavior control until it can be shown that the harmful effects of the behavior are greater than the potentially harmful effects of the drug.
- (d) Resident grouping: The grouping of facility residents should be "in keeping with their level of functioning..." Priority consideration should be given to social and intellectual development, friendships and interests.
- (e) Access to professional program services (such as psychological services, occupational and physical therapy, and speech therapy): "Each client must receive the professional program services needed to implement (his or her) active treatment program."
- (f) Requirements for staff: "The facility must provide sufficient direct care staff to manage and supervise clients (as indicated in their IPPs). All staff who work with residents must receive the training necessary for them to be able to manage challenging behaviors and implement IPPs.
- (g) Requirements for dining areas and service: "To the maximum extent possible, individuals should...eat routine meals...in dining areas (like) those afforded to their peers without disabilities." Tables, chairs, eating utensils and dishes should be designed for the needs of each resident. Residents should receive direction in self-help eating procedures.

4. There are some individuals with disabilities;
- (i) for whom active treatment is not required; and
 - (ii) who are not appropriately placed in ICFs/MR.

Active treatment does not apply to "...generally independent persons." This definition includes persons who: are generally able to take care of, and communicate, their needs; are usually able to conduct themselves appropriately when out of the facility; and do not need the range of services needed by other people with more severe impairments.

C. COMPARISON OF ACTIVE TREATMENT REQUIREMENTS WITH WISCONSIN LAW AND POLICY

In Chapters 51 and 55, in legislation creating the Community Options Program and the Community Integration Program, and in officially-adopted state policies, Wisconsin has defined certain goals for services to persons with developmental disabilities. In the following section, we compare these goals with the federal government's active treatment requirements.

This comparison is critical to an understanding of where Wisconsin's service system for persons with developmental disabilities is headed. Many people are unaware of the major discrepancies between services based on federal active treatment concepts and services based on the underlying values in Wisconsin law and policy. Without this understanding it is impossible to fully grasp how damaging it would be for Wisconsin to seize upon "active treatment" and long-term use of large ICFs/MR as our major approach to services for people with developmental disabilities .

We have not cited source documents in this analysis of active treatment. However, each active treatment-related requirement to which we refer is included in Appendix A. Appendix A also provides citations of the original source documents throughout.

On the following page there is a summary chart showing the highlights of the comparison between federal active treatment requirements and Wisconsin statute and policy. The left side of the chart identifies five overriding goals for persons with developmental disabilities indicated by an analysis of Wisconsin statutes and officially-adopted policies.⁶ The right side of the chart indicates the essence of what federal active treatment requirements have to say on the same issue. This analysis is developed in more detail in the pages following the chart.

⁶Our analysis included Chapters 51 and 55 of Wisconsin Statutes; DHSS Planning Guideline #1 (Long Term Support); and the initial legislation, design principles, and guidelines for the Community Options Program and Community Integration Programs.

Summary: Wisconsin Goals for Persons with
Developmental Disabilities vs. Federal
Active Treatment Requirements

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Wisconsin's Goals for Persons with Developmental Disabilities	Federal Active Treatment Requirements
<p>1. <u>"Integration into the community's mainstream"</u> (including the objectives of): "placement...in the least restrictive environment"; and (returning) "developmentally disabled persons to the community when their needs can be met at the local level."</p> <p>2. <u>"A valued home in the community"</u> (including the objectives of): "movement to less structured living in smaller facilities or individual residences"; and "blending in with appropriate neighborhoods."</p> <p>3. <u>Emphasizing "skills, behaviors, and service settings which foster maximum feasible participation in community life"</u> (including the objectives of): "services...designed and modified to 'fit the person'"; and (participation) "in valued roles in society, such as work or schooling in community settings."</p> <p>4. <u>Enabling people to be "part of a network of personal relationships with valued people"</u> (including the objective of): "contact between people requiring long-term support and others not requiring this support."</p> <p>5. <u>Achieving "maximum feasible control over their own lives"</u> (including the objectives of): (ensuring) "the same rights as other citizens"; and (placing) "the least possible restriction on personal liberty and exercise of Constitutional rights consistent with due process."</p>	<p>1. <u>No reference to "least restrictive environment"</u> except to clarify that it is not required; marginal references to off-grounds activities and helping residents develop skills they will eventually need for community life.</p> <p>2. <u>No reference to a "valued home" (or even a similar concept)</u>; no requirement or preference for small residences or "blending in with appropriate neighborhoods."</p> <p>3. <u>Requires individualized program plan focused on the development of skills and behaviors necessary for independence; but ignores fundamental learning principles by trying to teach these skills and behaviors in isolation from the community.</u></p> <p>4. <u>No requirement to actively promote personal contact or residents' relationships with people outside the facility</u>; client protections include rights to communicate and associate freely, and to participate in social and community group activities -- but this only means that the facility cannot obstruct residents from making contact with the outside world.</p> <p>5. <u>Several important rights included in Medicaid regulations, but generally they are the rights of people who are kept behind closed doors</u>; many rights afforded most citizens are not included.</p>

The summary analysis in the preceding chart is further elaborated on below.

1. "Integration into the community's mainstream"

(a) Wisconsin policy

The importance of integration is a pervasive theme throughout Wisconsin's policy pronouncements regarding people with developmental disabilities. Wisconsin statutes declare that "There shall be a unified...provision of services which assure all people in need of care access to the least restrictive treatment alternative appropriate to their needs..." § 51.001(1), Wis. Stats. The first goal in DHSS' Planning Guideline #1 (Long Term Support)⁷ refers to "services...which facilitate or maintain the person's integration into the community's mainstream." (emphasis added)

Integration has been defined as meaning that "a person lives in...ordinary or only slightly modified housing; is engaged in culturally-valued/age-appropriate work...communicates, socializes, and moves around in ways appropriate for his/her age; and is able to utilize community resources in culturally typical ways."⁸ (P.G. 1) Wisconsin has also established the principle that (the DD Centers are to) "return developmentally disabled persons to the community when their needs can be met at the local level." § 51.06(1), Wis. Stats.

(b) Active treatment

Federal active treatment requirements make virtually no reference to "integration" or "least restrictive environment," except to clarify that these concepts have nothing to do with active treatment:

"...Requiring (placement of residents in the least restrictive environment) would go beyond the...intent of Congress...There is nothing in...the Act...that

⁷DHSS Planning Guideline #1 (Long Term Support) is an official policy document developed by the Wisconsin Department of Health and Social Services. It is the conceptual foundation for the later design of the Community Options Program and Community Integration Programs.

⁸Planning Guideline #1

suggests that the size or the location of a facility, or whether a facility is the least restrictive alternative, should determine whether or not a facility qualifies for (funding). The only statutory requirement is that a client receive active treatment at the facility." (emphasis added)

Active treatment does require that the individual assessment and plan address skills or behaviors "necessary for the client to be able to function in the community," but there is no requirement that the facility systematically enable residents to experience the community now, nor that they move to less restrictive environments when they learn to function more independently.

Ostensibly, residents of ICFs/MR do have the right to participate in "social, religious, and community group activities." Unfortunately, this only means that: (a) the facility should not obstruct a person's participation in such activities; and (b) HCFA surveyors will, at best, gently urge institution staff to do a better job of getting residents off-grounds for recreational activities. It does not mean that residents actually get frequent opportunities to take part in such activities. Consequently, most residents of DD Centers and ICFs/MR in Wisconsin rarely leave the institution grounds.

2. "A valued home in the community"

(a) Wisconsin policy

Wisconsin policies affirm the principle that people should be able to live in a real home, as distinguished from an institution or a "homelike environment." Planning Guideline #1 is quite clear about "movement to less structured living in smaller facilities or individual residences," and about the service system being:

"one in which people are served in the community in buildings and settings which look like what they are supposed to be (i.e., a residence looks like a house or an apartment), are located in (blend in with) appropriate neighborhoods...and are small and arrayed so that people needing long-term support are not congregated in numbers larger than the surrounding community's social system can support."

The Community Options Guidelines state that:

"Too often, human service systems ask people to live in impersonal institutions or community facilities which are distinctly unhomelike. Every person should be able to live in a comfortable setting which looks like, feels like, and is a valued home in the community." (emphasis added)

(b) Active treatment

The basic message about "home" in the Medicaid program requirements is that home is not an active treatment issue. The standards make no reference to buildings looking like "what they are supposed to be" nor to "blending in with appropriate neighborhoods." HCFA's only clear-cut statements about people's residences run contrary to what we all know is important about our homes: HCFA states explicitly that size of residence is not an issue which can be addressed in Medicaid program regulations.

The fact that size is not a consideration in the ICF/MR program is plainly illustrated by Chart 4 (on the following page), which shows the size distribution of ICFs/MR in Wisconsin.

3. Emphasizing "skills, behaviors, and service settings which foster maximum feasible participation in community life"

(a) Wisconsin policy

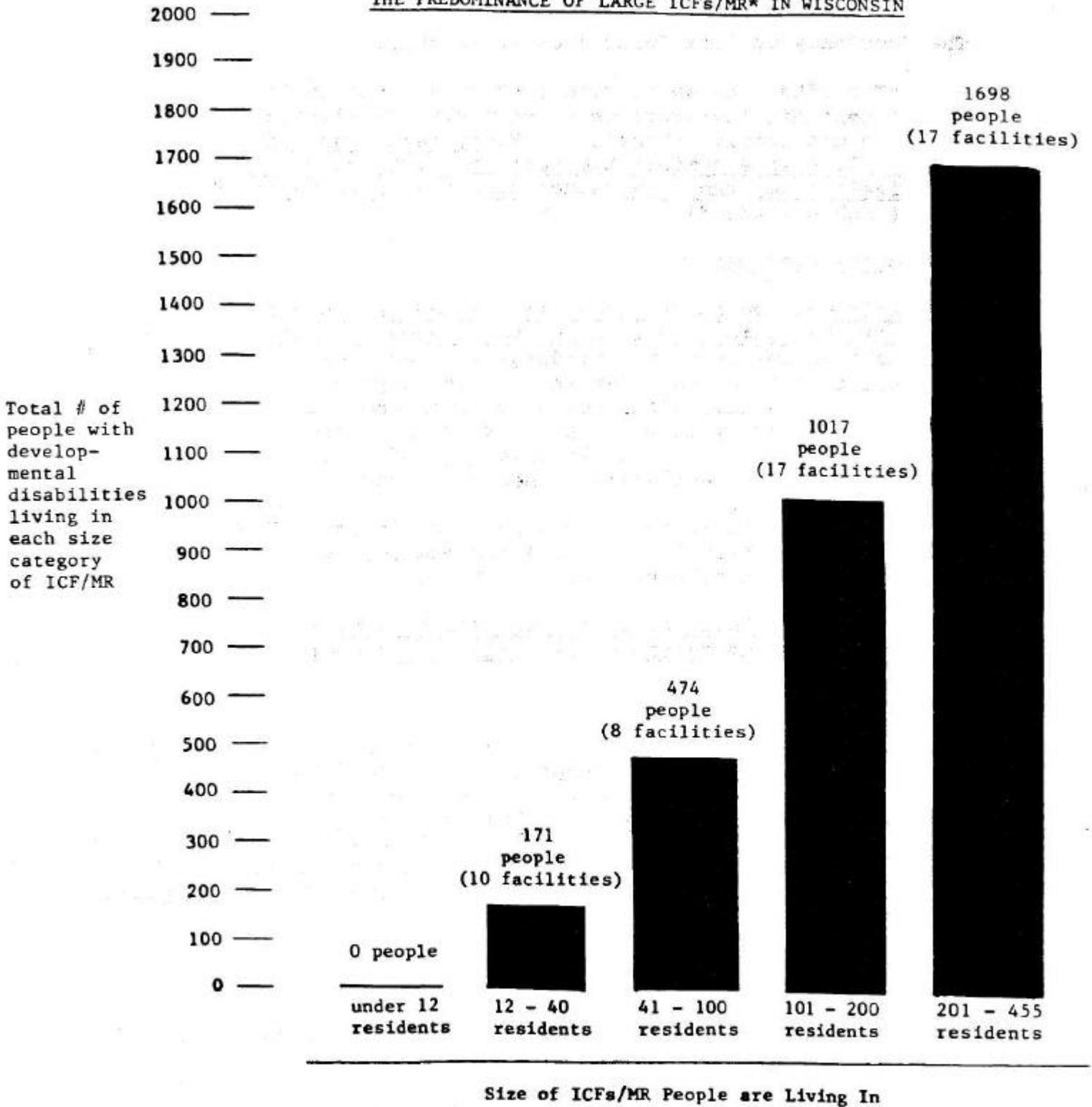
The responsibility of the service system to help people learn and develop was established in Chapter 51, by creating for each recipient of services "a right to receive prompt and adequate treatment, rehabilitation, and educational services appropriate for his or her condition." § 51.61(1)(f), Wis. Stats. Since the enactment of Chapter 51, this responsibility has been further clarified. Planning Guideline #1 asserted that "Programs should emphasize skills, behaviors, and service settings which foster maximum feasible participation in community life..." (emphasis added)

The CIP guidelines emphasize the importance of "individualization," i.e., that "services must be designed and modified to 'fit the person' and meet that person's unique needs." The Community Options Program guidelines are also quite clear about where people should learn the skills they need:

"People should not spend their days in the same areas that they call home, and, except when individual needs

CHART 4

THE PREDOMINANCE OF LARGE ICFs/MR* IN WISCONSIN



* Both free-standing and distinct-part ICFs/MR are included. For distinct-part ICFs/MR the size of the entire facility (not just the size of the ICF/MR portion) was used for the calculations. Regular nursing homes and state DD Centers were not included.

are so substantial as to make it impossible, they should participate in valued roles in society, such as work or schooling in community settings."

(b) Active treatment

Active treatment standards do include requirements related to residents' skills and behaviors, such as:

an individualized program plan for each person's needs;

programs and services focused on the development of skills and the acquisition of behaviors necessary for the resident to become as independent as possible, and to be able to function in the community; and

programs and services focused on preventing or decelerating residents' regression or loss of current optimal functioning.

However, it has become increasingly clear in recent years that it is impossible to enable people "to become as independent as possible" and "to be able to function in the community" by only trying to teach them skills in the institution. The only effective place to teach people the skills they need to live in the community is in the community. There are several reasons for this:

the differences between the institution environment and the community environment in which the person is expected to use the newly acquired skills are so marked that the skills are often not transferrable;

many of the skills people need to learn to "make it in the institution" may not be useful in the community (e.g., adapting to institutional dining procedures and settings); conversely, many skills people need for community life (e.g., menu planning, grocery shopping, and cooking for 1-2 people) are difficult to learn in the institution;

for most people, learning new skills is largely dependent on the opportunity to be around positive role models; in institutions there are often few or no positive role models except staff. In the community people with disabilities often have contact with many people who have, and are applying in real life situations, the skills they need to learn; and

the institution often is a place where practices and routines get in the way of people's learning (e.g., overuse of physical and chemical restraints, heavy reliance on group activities).

In other words, the fundamental principles of learning community skills and appropriate behaviors are largely ignored in active treatment requirements. These requirements seem to assume that environment is irrelevant to learning. Consequently, active treatment essentially pertains to programs and services provided within segregated settings, which are generally isolated from the community. It is important to point out that it is quite possible to meet active treatment requirements without involving the person in any aspect of community life, and by teaching skills whose primary relevance (if any) is to enable the person to function in the institutional setting.

4. Enabling people to be "part of a network of personal relationships with valued people"⁹

(a) Wisconsin policy

Wisconsin's officially-adopted policies emphasize that it is vital for people with disabilities to have opportunities to interact with (and, if possible, to develop relationships with) other people in the community. Related to this is the importance of "natural supports" for people, and freely given relationships, in addition to support provided by paid human service workers.

This goal is stated clearly in Planning Guideline #1:

"The service system should be designed and operated in a way which maximizes contact between people requiring long-term support and others not requiring this support."

This principle has been re-affirmed in the design and guidelines developed for the Community Options Program:

⁹The reference to "valued people" highlights the fact that being institutionalized tends to rob people of their status, and make them "devalued" in the eyes of society. It is therefore important that opportunities for personal interaction are not limited solely to interactions with other people similarly "devalued" by society.

"Full community membership requires that people be active participants in a variety of individual and group relationships."

"Even people whose capacity for communication and mobility is very limited can and need to be part of a network of personal relationships with valued people."
(emphasis added)

(b) Active treatment

The active treatment standards are virtually silent on the importance of relationships and natural supports. Other than the vague requirement that individual assessments and plans must address a person's "social development," the only references to this issue in Medicaid regulations are not in the active treatment sections but in the client protections section of the regulations. These protections include:

the right to communicate, associate, and meet privately with individuals one chooses

the right to participate in social, religious, and community group activities

the right to communicate with parents, guardians, and others, including the right to take leaves from the facility

Unfortunately, in actual practice, the impact of these rights is quite different from "maximizing...contact" with typical citizens. The rules are largely passive. Carrying them out basically means that the facility cannot obstruct residents from making contact with the outside world. Active treatment does not require the facility to systematically help residents learn about or participate in community activities, to introduce residents to people outside the facility, or to promote opportunities in which relationships with typical people might naturally occur. In fact, these rights do not in any way ensure that residents will ever leave the facility or that they will have any contact with anyone other than other institution residents or staff.

5. Achieving "maximum feasible control over their own lives"

(a) Wisconsin policy

A central goal of services to people with disabilities in Wisconsin is to afford people as much autonomy in their lives, and in decision-making about the services they receive, as can reasonab-

ly be achieved. This is a major theme in Chapter 55 of Wisconsin Statutes:

...services should, to the maximum degree of feasibility, allow the individual the same rights as other citizens... "This chapter is designed to...place the least possible restriction on personal liberty and exercise of constitutional rights consistent with due process..." § 55.001, Wis. Stats. (emphasis added)

Planning Guideline #1 carries this concept one step further:

"Long-term support should enable...persons to achieve maximum feasible control over their own lives and to minimize reliance on others in making decisions and in performing everyday activities...The long-term support for an individual should be developed with the active participation and advice of that person, and should be consistent whenever possible with the wishes of the person." (emphasis added)

Control over one's life is also an important feature of the Community Options Program:

"As much as possible, each person should be able to choose with whom to live, and as much as possible each person should be able to control the conditions of the home environment. Every person should be enabled to individualize their home setting so that the home becomes truly their own."

(b) Active treatment

The Medicaid regulations (in a separate section from the active treatment standards) do include several important rights provisions, but it is important to note that these rights generally relate to the conditions of a person's confinement in a facility, i.e., they are the rights of people who are kept behind closed doors.

This is not to say that these rights are inconsequential, or that it is unimportant to establish and enforce the rights of institution residents. On the other hand, when one remembers the larger context in which these rights are provided, it becomes obvious that they do not enable residents "to achieve maximum feasible control over their own lives" nor do they "allow the individual the same rights as other citizens."

The reality of this point can be empirically observed by anyone who is familiar with the inner workings of Wisconsin DD Centers or ICFs/MR. For example, residents of these facilities generally do not have the right to choose (or have input into choices about) where or with whom they will live, what type of job they will pursue, how and where they will spend their leisure time, how service dollars will be spent on their behalf, or even what they will eat or when they will go to bed.

CHAPTER III: "The Best Behavior Program Was Having Her Walk Out the Facility's Front Door":¹⁰ Interviews on People's Experiences in Institutions and Community Programs in Wisconsin

A. BACKGROUND

In 1986, WCA released "Out of Sight, Out of Mind: A Report on the Human and Civil Rights of Residents of Wisconsin's Three State Centers for the Developmentally Disabled, 1982 to Date." In that report we presented evidence of widespread violations of the human and civil rights of DD Center residents. That report was based almost entirely on official documents. Here, where we focus on what daily life is like for the residents of private and public ICFs/MR in Wisconsin, as well as the DD Centers, we are relying on two sources:

1. Federal and state surveyors' findings of active treatment violations (Chapter IV); and
2. Interviews concerning the experiences of persons with developmental disabilities in institutional facilities and in community programs (in this chapter).

Although we can learn much about quality of life in institutions from an analysis of individual active treatment violations, active treatment requirements are silent on life experiences which are important to all of us -- experiences which are included in Wisconsin's officially-adopted goals for services to people with developmental disabilities.

To better understand the impact on residents of life in Wisconsin institutional facilities, and how and why experiences change when residents move to their home communities, we began interviews concerning life in the DD Centers, ICFs/MR, nursing homes, and in Wisconsin's communities in 1986 and continued them into 1989. These interviews are the subject of this chapter. A number focus on persons who have had the good fortune to experience the community alternative and who are "doing well" in their communities. Some of our information comes from persons who asked us to help them with problems their family members were having in

¹⁰ The quotation used in this chapter title is taken from an interview in which we learned about the experiences of a person who was extremely self-abusive while in an institutional facility in Wisconsin. These self-injurious behaviors ended abruptly after she moved to a residence in her community.

state facilities. We sought additional insight from community service workers. However, a number of our interviewees were chosen simply because they were former facility residents who were willing and able to talk with us or because they provided information on current or former residents with "challenging behaviors" or particularly severe impairments.

Our interviews concerning former facility residents were, with one exception, limited to persons who have moved to the community between 1984 and 1988. To protect the privacy of all persons interviewed and of the persons whose lives are the subject of this chapter, we use pseudonyms in our presentation of excerpts from these interviews. We also avoid using job titles, references to individual facilities, or to counties of residence, and take other steps to mask identities. WCA has tape recorded the majority of these interviews to ensure that we present accurately the information shared with us.

In a report of this size, it is impossible to present more than a small sampling of the experiences of current and former facility residents. We present the following excerpts, however, as illustrations of the life experiences of a much broader group of persons with developmental disabilities in Wisconsin, both in institutions and in community settings.

B. INDIVIDUAL EXPERIENCES IN ICFs/MR, THE DD CENTERS, AND IN THE COMMUNITY

"MARY"

Mary is in her early 70's. She was placed* in an orphanage when she was three, moved to an institution for persons with mental retardation when she was ten, and remained in various institutional settings for most of the next sixty years. At the time of the WCA interview, she had been out of an ICF/MR for about a year, and was living in an adult family home.

MARY'S EXPERIENCE IN AN ICF/MR:

"I want to get out and see and do."

The person speaking is a community service worker;

"Mary has literally spent her whole life in institutions. . .She would come up to me and ask, 'How are you coming on my new home?'... 'I want to get out and see and do'...Her life wasn't horrible, but it was just dull. Endless days and nights with nothing to do...She was in an environment where other residents were lining up at 5:30 in the afternoon to take their medications and go to bed...Records at (the ICF/MR) show she was a 'behavior problem.' They said she throws things...is non-compliant...verbally abusive, argumentative. She is pretty outspoken, but I haven't seen anything that wasn't righteous.

"She is 'street smart.' Institutional living teaches you to take care of your things and keep them hidden...The fact that she was a little bit aggressive saved her in a lot of respects..."

The person speaking is Mary:

"I was put away since I lost my ma...They did bad reports about me...After I got up each day (at the ICF/MR), I didn't do nothing...I didn't go out...they had classes like crafts. We played ball-like hot potato ...I wanted to get away from there. I like it where I am.

"They stole a lot of my stuff at (the ICF/MR)... stole my watch, my purse I just sent out for...Had nobody to stick up for me. I had to stick up for myself. I felt so bad...Thank God (they) got me out of there."

(Mary asked the community service worker to help her find a family which had children) "...because I love them. Would you want to sit around all by yourself? Look at t.v.? Nobody to talk to?...I never was married. How could I?"

MARY'S EXPERIENCE IN THE COMMUNITY:

"I like everything about where I am living now."

The person speaking is a community service worker:

"She tells me she's doing things she's never done before. Had never been to a museum before, to see concerts before...The best thing has been the relationship with the family she lives with and their children. She gets so much joy out of that--just having a natural relationship with a real family...She calls the children she lives with her 'granddaughters.'"

The person speaking is a member of the family she is living with:

"Mary adjusted the first day she got here...She said (later) 'The first time I saw your face I was never leaving'...The children like her very much. She is very kind to them...they go to church with her...she helps the youngest dress each morning.

"...She is experiencing lots of food she never had in (the ICF/MR)--like chicken pot pie. She can go in the refrigerator, doesn't have to put \$.50 in a machine ...She does more now. She used to ask permission for everything. She goes to bed when she wants to. Can sleep in on weekends. The dog sleeps on her bed.

"Lots of people come to see her and take her places. She makes contacts with people who help her. We take her out to eat, to play bingo, and visit some of her friends...

"She can read and write. She tells stories to the children...She loves babies. I have a new grandson and she's always walking the floor with that baby. I could leave the house and she could change that baby...She can do a lot of things."

The person speaking is Mary:

"When I first got (to my home), I met (the youngest child). She had blue eyes and blonde hair...When I get home (from her day program), the kids ask me if I've got

candy...I bought (the youngest) a barbie doll...The girls like me. They get on my bed and jump. They're sweet. We've got a little dog. She's my bodyguard... **I like everything about where I am living now.**"

The person speaking is a community service worker:

"The improvement for Mary is in quality of life... day to day joy and stimulation. And think about it--she can look forward to a future now, for the children."

"BILL"

At the time of the interview, Bill had been out of an ICF/MR for about one year. He had been in Wisconsin institutions from infancy until he was 28.

BILL'S EXPERIENCE IN AN ICF/MR:

"Anything of value disappears."

The person speaking is Bill's guardian:

"...He spent all his time paging through telephone books...He wouldn't be separated from his telephone book...anything else he had disappeared. Even here it is still his security blanket.

"The first day I met him, he didn't talk, would turn away...The social worker took his face so he would look directly at me...I thought he couldn't talk...He did know some signs.

"I took him out at Christmas...when he saw the Christmas tree lights, he started (making noises that showed excitement)...He couldn't speak...After we finished eating, he took hold of me and whispered 'thank you'...It seemed the more we would do things together, the more single words would come out...very quietly whispered...As time went on, he started putting three or four words together.

"Life at (the ICF/MR) was very structured...they told him what to eat, when to go to bed. He didn't have

a choice of when to do this or when to do that. At (the ICF/MR) life was pretty dull and boring. He had his food and a place to sleep."

The speaker is the person with whom Bill now lives:

"At (the ICF/MR) they couldn't find his motivation ...When I came taking him for visits, the case worker really didn't know if he could talk or not, if he knew signs or not...nobody knew anything about him off the top of their head...So when I actually brought him here, I didn't know that he could say more than two words.

"When he would come here...I could never find his socks...Even after he moved in here. He came out of (the ICF/MR) with one pair of socks to his name and kept them under his pillow. He knew if he didn't hide them, he'd lose them. Whatever the residents got there that was good was gone...Once, when I took him out, I raised the roof. He had dirty rags on. **"Anything of value disappears."**

BILL'S EXPERIENCE IN THE COMMUNITY:

"It's just like watching a flower open up."

The speaker is the person with whom Bill now lives:

"I was told at (the ICF/MR) what...he was capable of. He had passed this program and passed this...but when he got home it wasn't what staff said.

"When he got here...he really could do nothing on his own. Things are now to the point where he does not even need prompts anymore...When he came here, he took 40 minutes to dress. Now he takes 20. He goes down-stairs, goes to the bathroom, washes (and does his grooming)...Now he can do his laundry, help in the kitchen...

"After he got here...day by day he'd get a new word...The first time he said a whole sentence was when I brought a ten pound bag of pretzels home...He opened them up, went right to the living room and said (to his housemate), 'Tom, come and see!'

"He got so he could do a lot of things...Mainly, it's just been that he's been treated like a human being and taken to places that human beings go and so then he developed trust...**It's just like watching a flower open up...**from the turn-away closed position that he had... Now he goes shopping, puts the groceries away, my son takes him places...he gets choices. What I think it's doing for him is giving him the status of a human being and then he opened up. Letting him make his own decisions

"He is a lot more capable than (the facility) ever gave him credit for...Life is a constant learning process for him. Now, at the progress report (at his day program) he takes a pad and pencil and, as much as the case worker writes, he is writing...He is nose to nose with them...He writes his name and lots of 'curly cues,' but it says 'I am a human being and I have the chance to make decisions.'

"If Bill weren't mentally retarded, he would be 'the boss'--and he is a lot less mentally retarded than we thought he was...We're trying to get him to the point of independent living...It's far too early to know if he can do that...It'd be nice if he could talk and do some elementary reading...

"I always thought there was a sleeping giant in Bill."

"DORIS"

Doris was 26 at the time of the interview and was living in a community residence. She had lived in institutions (a DD Center and a nursing home) for more than 15 years before moving into her group home. She has cerebral palsy and is labeled "moderately mentally retarded."

DORIS' EXPERIENCES IN A DD CENTER AND A NURSING HOME:

The speaker is Doris:

"We had school (at the Center) two hours a day... They didn't teach me much. They taught me nuts and bolts in a workshop, which I wasn't interested in because of the atmosphere I was in...The rest of the

time I just sat in the living unit in my wheelchair... I was unhappy there.

"You couldn't go into the kitchen to cook there... we got to go outside when the staff had time...They didn't have time to take us to do our own laundry.

"If I was out and taught the right way, I would have had some schooling.

"Two aides helped me leave the Center...but on the other hand, (others at the Center) told me...I was taking a risk if I moved out...They helped me move to a nursing home...if I'd stayed in a nursing home, I would've been a total bed patient...I needed total care at one time because...they wanted the staff to help me dress and bathe all the time."

DORIS' EXPERIENCES IN THE COMMUNITY:

"I've come a long way."

The WCA interviewer visited Doris in her group home.

The speaker is Doris:

"I get around better now 'cause I'm out of the institution...I have three (non-paying) jobs...I have to reassure myself I can do a good job...and stay on task...Now I can do it for ten minutes at work."

(At the group home)... "We have a van that we use...I go to the zoo...and bars...the Center would never let me do that...On Tuesday night I go swimming ...On weekends I have fun.

"We take turns cooking...There's a schedule...I'm slowly building up to taking care of myself (with an attendant)..."

The speaker is a community service worker working with Doris:

"The emphasis is that, as much as possible, everyone should participate in the everyday chores...A fairly regular thing (for Doris and the other residents) is to

go out to the store to buy personal supplies...and go shopping for food.

"She has started a reading program...She has potential in that area that's never been tapped before ...She's also just started recently to use a typewriter. It's a means for her to develop written communication skills.

"She's labeled 'retarded,' but she was never given a chance to learn...Who can say what she might have accomplished by now if she'd received an education?"

The speaker is Doris:

"I am much happier out of an institution...I have friends (come to visit) when I get motivated to call them...the difference is I'm out in the community here...

"I'm learning that it is hard, sometimes, to work out in the community...and I'm learning that from all the experience some day I might become a good worker...

"I've come a long way."

* * * * *

"LAURA AND BETH"

Laura is in her early 30's, Beth in her 40's. Both lived in institutions most of their lives. They became housemates when they were helped to move from the ICFs/MR in which they were living, about two years ago.

THE EXPERIENCES OF LAURA AND BETH IN ICFs/MR:

"Rather than having lives punctuated by interesting events, they had lives punctuated by no events."

The person speaking is a community service worker:

"Both women had what you might call 'inappropriate behaviors' when I first met them...Beth fell asleep a lot at her day program...Laura was on medications to control her behaviors. There was no day program in the

community for her when I met her. She had done a lot of 'acting out,' and they didn't particularly want her in the program...

"(In the ICFs/MR) both needed more to do...They needed more friends, more places to go...**Rather than having lives punctuated by interesting events, they had lives punctuated by no events.**...Laura was often very unhappy and frustrated...A lot of her acting out had to do with being frustrated."

THE EXPERIENCES OF LAURA AND BETH IN THE COMMUNITY:

"They've changed so dramatically by not a whole lot being done other than moving in with a regular family."

The person speaking is a member of the family with whom Laura and Beth are now living;

"When Laura moved in, she had one little box of clothing and had a box of medicine that was bigger than her clothing box...Her communication was pretty violent, at first. She'd talk about beating and breaking things ...That talk is much less frequent now...I think she must have been in a violent environment.

"Beth didn't use the steps well...hadn't developed the muscles well in her legs. I think the next step would've been a wheel chair...Her ADL¹¹ skills have improved since she got here. She needed a lot of verbal prompts to take a bath...She missed a lot of her hair with the water...They told me (at the ICF/MR Beth came from) that her ADLs were 'fine.' She wouldn't change her underwear or socks. Now she changes them daily, usually without prompts.

"When they came here, they didn't have manners... They would cough on people, cough on the food...We have changed that with verbal prompts. They used to hoard

¹¹ADL (or ADLs): "activities of daily living" -- this term sometimes refers strictly to personal hygiene and grooming, but is often expanded to include dressing, eating, and food preparation and other household tasks.

food, but now they seem a little more relaxed. Where they lived, people used to take their food...

"Beth can use the steps now without needing the railing. When she lived at (the ICF/MR), her day program staff said she slept a lot during the day. Now she doesn't sleep as much. They report she is happier and listens more to the staff...They thought she had narcolepsy. Now they don't talk about that anymore.

"Laura is also in a day program now and is doing better, although she hasn't improved as much as Beth... But she seems to be picking up a little bit. She's sitting more. She used to never sit still...used to talk constantly. Now she's quieter, does less mumbling. Her attention span is still very short.

"When they first got here, they didn't interact with each other...Now they are having conversations, they share things with each other, they interact with (his daughter)...They make their beds, dust their room, put their clothing away...Beth likes to set the table. Afterwards, they like to wash the dishes...

"We take them to exercise at the 'Y'...We take them bowling...We go out to (a relative's) farm, go on picnics. It's an active life...In the summer we go to parks, walk around the neighborhood, go to the local movie theater, walk to the donut shop...They do seem happier... some of their negative attitudes seem to be changing..."

The person speaking is a community service worker:

"The main thing about Laura and Beth is they've changed so dramatically by not a whole lot being done other than moving them in with a regular family.

"...Without the benefit of (formal) behavior programs. ..people just pointed out to Laura that what she was doing wasn't what she should be doing and she stopped doing those things...The old Laura doesn't exist anymore, as someone with 'challenging behaviors'...and the amount of activity and exercise the family has been doing with these women has made a big difference...I wish you'd met them before (they moved)...Beth was very heavy. She could barely walk upstairs...She had no polite way of interacting with people, didn't make eye

contact...Their hair was not clean, clothes were not decent. If (the interviewer) had met Laura (before she moved), you might have said, 'Very bizarre woman with a lot of problems.' But now she walks to the local theater and people don't look at her twice.

"Laura's mother didn't want her to move...She was very concerned about her living in the community. People all along have told her the best place for Laura was in an institution...She's not so worried anymore... She thinks Laura is fine in the community. Pretty independent..."

"LIZ"

Liz lived in Wisconsin institutions (including a DD Center and an ICF/MR) from early childhood until she was 36, when she moved to a community residence. She is labeled moderately retarded.

LIZ'S EXPERIENCES IN AN ICF/MR:

"There were a lot of people screaming and hollering."

The person speaking is Liz;

"They'd let me do things on my own since I wasn't like the other residents...such as get dressed and go to work on time (in a program outside the ICF/MR). (After returning from work) I went to my room...**there were a lot of people screaming and hollering.** I didn't want to get involved in their fights...My room was real small... there were two of us in it...A lot of people would steal your stuff at (the ICF/MR).

"I used to get mad at (the staff)...and throw things at them...I didn't know how to control my temper. One of the nurses would say: 'If you're not going to do (what we ask)...you'll get kicked out'...I decided to do things on my own...That's what they'd do to people when they acted bad...they'd put them back in (the Center or another institution)."

LIZ'S EXPERIENCES IN THE COMMUNITY:

'It's a freer life now...I just feel happy.'

The person speaking is Liz:

"It's **a** freer life **now**. You can go places by yourself. At (the ICF/MR) to go outside you would have to ask the nurse and you would have to stay on the grounds...Now I go to (fast food restaurants)...back to (the ICF/MR) to see my friends...I go shopping, to the drug store, to the grocery store...on weekends I go to the mall...I have more friends.

"Now I don't have to listen to fights or arguments or screaming or yelling. There's not so much noise."

Liz is currently living in a group home, but is preparing to move to a supervised apartment. "They are teaching me how to cook, how to wash dishes in a dishwasher... I bring my check home every other week and Wednesday night they budget with us...(The staff person) teaches me how to hang onto money rather than spending and spending...I'd like to get an outside job...such as being a dishwasher. I just feel **happy**."

"JACK"

Jack is in his early 40's and has lived in institutions most of his life. He continues to live in the ICF/MR in which Liz formerly lived. Liz provides this account of what life is like for her friend Jack in an ICF/MR.

JACK'S EXPERIENCES IN AN ICF/MR:

"I didn't like the way they treated Jack.
It wasn't good for him."

The person speaking is "Liz":

"I liked (the ICF/MR) because of my friends...but I **didn't like the way they treated Jack**. It **wasn't good**

for him. Every time he used to wet, they wouldn't change him. His whole room smells like urine. When the residents would get him upset, he would end up getting a shot sometimes. He's been biting his hands when they get him upset.

"It isn't good for him because he's not capable... He would mostly spend his time in the day room watching t.v....coloring in the coloring book...They don't teach him things (at the ICF/MR) because he is more retarded than I am...He goes (outside the ICF/MR) for classes... When they bring him back in the afternoon, he lays down and takes a nap 'til supper time. The staff don't take him anywhere... except circus parades, Fourth of July parades.

"When he would act up (in the cafeteria) they used to drag Jack on the floor...to the elevator and up to his room...I kept on asking them why are they abusing my friend like that...The nurses were doing that to him... but they would not do that to me.

"Every time I come there to visit him, he has a short-sleeved shirt on and some shorts and it's not even summer."

"RICHARD"

Richard is a young man with the label of "severe mental retardation with autistic-like behaviors." He lived in a DD Center from early childhood until his late teens, when he moved back to his home county.

RICHARD'S EXPERIENCE IN A DD CENTER:

"It was so...nothing."

The person speaking is Richard's guardian;

"Richard has some fine motor problems, but these problems were not worked on until (he was sent to public high school)...It was in school where he first was provided a communication book which enabled him to make real contact with others for the first time...He learned

to ride a bus, go into stores, wait his turn, open his locker, hang up his coat.

"He had problems (in school) at first, but as they figured him out and he figured out what their rules were, he had few problems...The thing they had the hardest time with was getting him back on the bus to go back to the Center. He would throw tantrums at that point.

"(During summer recess at the Center)...**it was so - nothing**...no follow-up programs of any kind...

"When he graduated (from high school), his teacher requested a meeting with Center staff to talk about how the public school teachers had worked with Richard and how we wanted that transferred to the Center...(Center staff) thought I was crazy for asking something like that...They said, 'We don't think that's going to help. What good will it do?'

"I'm afraid he will end up just sitting on his unit. That's what other people do. That's what he's doing this summer.

"He lives in a locked unit...The room is barren ...There are no carpets or curtains because people will destroy them...The television and radio are covered so the residents cannot touch the knobs...At school he liked to sit in a bean bag chair to relax, but they say he can't have it at the Center because it would be destroyed.

"Staff have always said he can't do things ('he can't ride the bus, he'll throw a tantrum')...Richard has not been violent with me because he's given things to do and...participate in...and I take him away from the Center. He runs away from the Center, but when I'm with him (in the community) he never tries to run away. He figures out how to run away a little bit quicker than the other people on his unit...It's hard to go there, it's hard to take him back. I feel like I'm taking him back to prison."

RICHARD'S EXPERIENCE IN THE COMMUNITY:

"For the first time in his life he has a tan."

WCA's interview also covered the period after Richard moved from the DD Center to a group home.

When Richard first moved from the Center, he had a difficult time adjusting. He was destructive of property and made so much noise that people in neighboring apartments complained. After he moved to a small group home, his adjustment began. He is still somewhat destructive (especially of electronic equipment), and receives close supervision, but had progressed significantly in a number of areas in the year prior to this interview.

The persons speaking are community service workers;

"When Richard was at the Center, he was in a locked unit...Here we use beepers that make noise when the door opens. There've been a couple of times when he has run across the street, normally when he hears a radio or something he likes...but he has never tried to run away at night.

"At one time, every piece of electronic equipment was in the back of the house (to keep them away from Richard). We couldn't even have a lamp out. At the Center all equipment was behind a locked door. The things we keep around here now with no problem include the stove, telephone, ceiling fan and microwave. Richard's less likely to destroy things now because he's exposed to them, they are not locked away. And we set limits.

"He participates in everything we do here...I take him grocery shopping, he pushes the cart...participates in the food selection...He wants to go out all the time ...He has learned to avoid loud music and crowds... (But) he likes walking in the park, going to the pool, eating at fast food places. A year ago at the pool we would have had to redirect him not to scream, clap, etc. Now there is no redirection needed. He is very sensitive to social cues.

"When he first came here, we had to practically dress him. Now he can get dressed by himself. I expect

Richard to do a number of things for himself...and clean up at meal time. If he makes a mess, he picks it up... We expect him to behave according to social norms... Expectations are the key to his change in behaviors ...He's a lot sharper than he lets on...He shows the ability to pick up on tasks...

"I'm optimistic because he has displayed the capacity to learn. When O.T.¹² first started working with Richard, there'd be hand clapping, biting, agitation. ..Richard came to look forward to O.T....He has worked at a single task for as long as fifteen minutes, which is pretty amazing for him...When he first got here, if you got him to sit up at the table you were doing well."

(Major continuing problems include keeping him from breaking things, inappropriate behavior in public places, difficulty in finding doctors and dentists who can work with Richard, and helping Richard make contacts with people other than staff and his guardian)... "But he's happy here...he doesn't try to run away."

The person speaking is Richard's guardian:

"The most exciting thing is that we know Richard can make it (in the community)...He's not in jeopardy ...He won't be going back to the Center.

"He's eating a wide variety of food...has put on weight. He eats fruit, chicken, hamburgers, hot dogs, french fries. He's getting out to do things.

"For the first time in his life he has a tan."

"CYNTHIA"

Cynthia is in her 20's and has lived in a DD Center since childhood. She is labeled as "severely mentally retarded with challenging behaviors." She has been on medications for many years, but recently they have been successfully reduced. Her guardian is working on finding a community placement for her.

¹²O.T. refers to "occupational therapy" or "occupational therapist."

CYNTHIA'S EXPERIENCE IN A DD CENTER:

"No, it's unlikely that her behavior will ever change."

The person speaking is Cynthia's guardian:

"What (the Center staff) say is the best way for Cynthia to get out (of the Center) is for her to move through the Center's progression which is from 'cottage X' to 'cottage Y' and from 'cottage Y' to the next step up. So I asked them what Cynthia would have to do in order to move to 'cottage Y.' They told me she'd have to be less self-injurious...but that even if that behavior goes down she won't be able to move because of (other behavior problems)...I asked, 'Is that behavior likely to change?' and they said, '**No, it's unlikely that her behavior would ever change.**'"

"I said, 'You're telling me, in order for her to get out of (the Center), the next step is to go to "cottage Y," but she'll never be able to move to "cottage Y"?'...and it was like they didn't get it.

"Then one staff member launched into this discussion of this new behavior program they have for her... She gets stickers when she does certain things right and gets 'smiley faces' when there's a mistake...I went home and called a friend and said, '*I understand why the residents of (the Center) pound their heads into the wall, because if the wall had been a little closer during that meeting, that's what I would have been doing...'"

"LEE"

Lee is a former DD Center resident around 30 years old. He is labeled "severely mentally retarded with challenging behaviors." He spent several years at a DD Center before receiving a community placement.

LEE'S EXPERIENCE IN A DD CENTER:

"He was never even taught to button his shirt."

The person speaking is Lee's parent:

"Lee spent long hours on his unit with nothing to do...He slept a great deal...The aides just sat and smoked while residents acted out. I never had a sense of formal programming...There was no structure to what they did with him...No one helped him go through a book.

"Lee lived in a cell-like room...He could not protect his personal possessions from being destroyed... People around him were yelling and screaming...He had no privacy...He is very fussy...not suited to that environment... He is very protective of what is his.

"He wants me to sit and listen to him. He will be quiet then...No one sat and listened to him at the Center...**He was never even taught to button his shirt...** He put his underwear on backwards...He received no bathroom training...Dressing and bathing were done for him to speed things up. Now he pours his own cereal. He never had a chance to at the Center.

"When he first went to the Center, he spent some time in the infirmary where he did well. After moving to his living unit (for persons with challenging behaviors), he began scratching and hitting at himself more. He never got any behavior programming...Time out was his program. They'd give him medications to keep him quiet.

"Lee...wasn't loud until he went there...He is experiencing all the emotions that were around him (on his living unit at the Center). When they moved him out, I said, 'This is the answer to my prayers'...I pray and hope that he never has to go back to an institution."

LEE'S EXPERIENCE IN THE COMMUNITY:

"I can't believe it's the same Lee."

The WCA interviewer spoke with Lee's parents and one of his foster sponsors about Lee's programs and experiences since leaving the Center. What follows is the interviewer's summary of those conversations. The persons quoted are Lee's parents and a foster sponsor.

Lee lives with his foster sponsors, their young daughter, and another roommate in a four bedroom house. His community program for the first two years emphasized independent living skills, behavioral change, keeping a schedule and staying on task. Shortly after moving, Lee got a three day a week job at a local bakery. Twice a week he would jog at the Y and spend afternoons with a county staff person in the community. It was difficult at first to get him up and to work. His major behavioral problems occurred in the first few months while he was making his adjustments. Once he became used to keeping a daily schedule, these problems began decreasing.

He goes to softball games with his foster sponsor, and carries the team's equipment. The team members enjoy him and "see him as a functioning human being. One of the best things is getting to know people in everyday life..."

Lee is now much less self-abusive than he was at the Center. He has had his medications reduced. He "keeps busy with his weekly program and stays on schedule." Lee can now dress himself, shave, brush his teeth, brush his own hair, and "is learning manners." He is making progress with independent toileting. He uses eating utensils properly and knows how to put away his clothing. The next programming phase is learning to help with the household chores and do his own laundry.

Lee is "less frustrated" now that he has personal care skills. According to both his foster sponsor and his natural parent, he is much happier than he was at the Center and enjoys his daily activities. "The environment had a lot to do with his unhappiness." Now that he has learned to keep schedules and care for himself, he is "much closer to being ready for structured employment. "

At a softball game, Lee met someone who knew him before he returned to the community. His friend's reaction: **"I can't believe it's the same Lee."**

"RAY"

Ray is in his mid-60's. He was placed in a children's home when he was one. When he was five, he moved to a DD Center, where he lived for 53 years. For the five years prior to his move to a community residence, he lived in an ICF/MR.

RAY'S EXPERIENCE IN AN ICF/MR:

"He was sitting in a room by himself eating pureed food."

The persons speaking are two community service workers:

"When I met him, he was just working on puzzles and watching t.v. He had a roommate but they always had a curtain pulled between them...He didn't socialize...he just stared at the t.v. which he couldn't hear (because of profound hearing loss)...When I tried to talk to him, he wouldn't look at me.

"He was supposed to be working on various art activities and things of that sort, but he wasn't very interested...None of what the staff planned involved leaving the place.

"He knows basic signs...Since none of the (ICF/MR) staff could sign, it didn't matter to him. He was virtually completely isolated and there was no communication with him at all.

"We were told he needed all his food pureed. That's what (the ICF/MR) was doing...**He was sitting in a room by himself eating pureed food...**

"Think about that for yourself...think about being put in there as a little kid. No wonder the records talk about him having a 'flat affect.' He was downright depressed, was just so very disconnected..."

RAY'S EXPERIENCE IN THE COMMUNITY:

"In the short time he's been here,
there are many more expressions of joy."

The persons speaking are two community service workers:

"After he got the idea he was going to move (from the ICF/MR), he was just going crazy to talk to me and be around me...

"When he first got (to his day program), he didn't smile, didn't look around...he was shy, non-communicative, a little confused...the facility's records say, 'He can't speak, he doesn't speak, etc' Since he's moved, he talks a little bit...When we had a meeting with him...he was trying to communicate with us about something...He went through this elaborate charade. We couldn't tell what he meant. And he finally said, 'Flowers and plants.' He wanted flowers and plants in his room.

"In the short time he's been here, there are many more expressions of joy...He gets very excited about going places. We were going downtown on the bus. He'd keep looking and pointing with wonder on his face...I've seen him realize that he's part of a group and that he can interact...(Now) he really notices what's going on around him. He will make (visual) jokes, then turn to the group for approval.

"He is labeled 'moderately mentally retarded,' but that is probably wrong. He does puzzles very well...He shows problem-solving ability...He figures out how to get what he wants.

"We tried cutting food up in small pieces, at first ...We haven't seen any problems (with regular food). Today he had meat loaf, mashed potatoes, vegetables. We have him referred to O.T. to get him to cut up his own food.

"The family he lives with lets him have a lot of say in how he has his own things, something he didn't have before...At (the ICF/MR) many of his things were stored away. He has his things in his room now. He can

arrange where he wants them. He really enjoys pictures of pretty things like flowers, plants, trees...The fact that he can have space for his pictures is a big thing for him."

C. SUMMARY

These experiences speak for themselves, sometimes eloquently, regarding the impact on residents of life in Wisconsin institutions. The interviews also give us some sense of the dramatic effect on people's lives of leaving these facilities to move into the community. We summarize here some of the major recurring themes in these interviews, emphasizing those which correspond with the patterns of violations identified in official surveys (Chapter IV):

1. The most frequent complaint about life in the institutions described here is that nothing is going on in the residents' lives. That appears to be related, at least in part, to facility staff's low expectations concerning residents' capabilities in the institution as well as potential for living in the community.
2. These interviews also add insight on how isolating and grim life can often be in institutions. The interviews provide convincing evidence that residents are aware of the negative aspects of these environments and that some residents have a burning desire to leave these places.
3. When people are given a chance to leave the institution and move to adequately supported community arrangements, the move can literally be life-transforming. Some of the interviews convey a feeling of liberation, of leaving the custody and confines of "the closed place" to return to the freedom of open society. This feeling is not simply due to an increase in personal liberties. It also relates to the transition from an environment in which people often define you in terms of "what you can't do" to one in which people have positive and challenging expectations of what you can learn and who you could become.

The characterization in one of the interviews of what is happening in the life of a person who had recently

moved out of an institution seems quite apt: "It's like watching a flower open up."

4. The life experiences of persons confined to institutions stand in stark contrast to the vision for people with developmental disabilities which is embodied in the five goals derived from Wisconsin statutes and policies:

"Integration into the community's mainstream"

"A valued home in the community"

Emphasizing "skills, behaviors, and service settings which foster maximum feasible participation in community life"

Enabling people to be "part of a network of personal relationships with valued people"

Achieving "maximum feasible control over their own lives"

On the other hand, when we learn about the life experiences of persons who have moved to the community from institutions, we see the powerful, positive impact on people's lives of a service system approach which is based on these goals. These success stories validate these five goals and point to the urgency of putting them back at the center of the state's planning process.

Although a sampling of stories about formerly institutionalized people with developmental disabilities who are adjusting to community life does not "prove" that community integration "works" for all persons with developmental disabilities, these stories: (a) demonstrate that community integration can work for people with a wide range of impairments; and (b) provide some of the explanations for these successful adjustments. The lessons we learn from stories like these have implications for developing community support for many other people with developmental disabilities currently living both in and out of institutions in Wisconsin.

CHAPTER IV: OFFICIAL EVIDENCE OF STATEWIDE ACTIVE TREATMENT
VIOLATIONS IN WISCONSIN

INTRODUCTION

In this chapter we present findings by federal and state survey teams of ongoing, statewide violations of federal Medicaid program regulations related to active treatment. This evidence covers the period January, 1986, through February, 1989, and is taken from official reports on the DD Centers and on eight of the 22 free-standing ICFs/MR in Wisconsin. Our focus includes both public and private facilities. However, all the facilities are regulated by the state and federal government, and all the reports we have relied on are available to the public.

We have included the findings of federal and state surveys in this report:

- (a) to show that there are ongoing and pervasive violations of Medicaid regulations in Wisconsin, 17 years after the start of the ICF/MR program and four years after increased enforcement of active treatment requirements began; and
- (b) to add detail to and show the universality of the picture we get from the interviews in Chapter III of what life is like in Wisconsin institutions.

Even though full compliance with active treatment regulations still falls far short (or misses the point) of the state's major goals for people with developmental disabilities (see Chapter II), it is instructive to examine the pattern of violations of these regulations. One striking aspect is the extent to which these patterns correspond with some of the major themes which run through the life experiences of a number of the persons we interviewed. These common themes include: isolation; nothing going on in residents' lives; inaccurate assessments of residents' capabilities; violation of privacy and loss of dignity; the negative impact of institutional environments on behavior and functional abilities; and failure to develop even the most rudimentary of daily living skills.

As we see the glimpses of life in these facilities which these violations provide, we are reminded of an important fact: these places are institutions—they have the feel, the atmosphere, the unmistakable and indelible air of institutional life. No set of standards, no matter how well-intentioned the drafters and how vigilant the enforcers, will change that basic reality.

The findings presented in this chapter are not the subjective impressions of advocacy groups or other opponents of the use of ICFs/MR and nursing homes. They are the official, objective records of state and federal government survey teams. We have organized these findings of violations of active treatment-related standards into the following sections:

- A. EVIDENCE OF RESIDENTS RECEIVING NO PROGRAMS AND SERVICES OR MINIMAL LEVELS OF PROGRAMS AND SERVICES
- B. EVIDENCE OF RESIDENTS RECEIVING PROGRAMS AND SERVICES WHICH ARE NOT INDIVIDUALIZED OR ARE POORLY IMPLEMENTED
- C. FAILURE TO PROVIDE RESIDENTS WITH SPECIALIZED PROFESSIONAL PROGRAMS AND SERVICES
- D. FAILURE TO USE APPROPRIATE RESIDENT EVALUATIONS AND REASSESSMENTS IN DEVELOPING PROGRAMS AND SERVICES
- E. USE OF CHEMICAL AND PHYSICAL RESTRAINTS AND AVERSIVE PROCEDURES IN THE ABSENCE OF APPROPRIATE PROGRAMMING
- F. OBSTACLES TO ACTIVE TREATMENT RELATED TO RESIDENTS' LIVING ENVIRONMENT AND STAFF TREATMENT OF RESIDENTS

We present here evidence of active treatment violations for the three DD Centers and eight free-standing ICFs/MR. To determine which ICFs/MR to include in this report, we reviewed Nursing Home Profiles compiled by the State Division of Health for each of the 22 free-standing ICFs/MR in Wisconsin for 1986, 1987, and 1988. These profiles provide overviews of surveyors' findings of violations of applicable federal program regulations, and of Chapters HSS 132 and 134 of the state's Administrative Code (which define conditions of licensure for nursing homes and ICFs/MR).

In selecting the free-standing ICFs/MR to include in this report, we focused on facilities which house a substantial proportion of the total number of ICF/MR residents in Wisconsin, and which have a significant number of violations. Thus, we have included in this report those facilities with populations of 50 or more which have been cited for the most violations of federal and state regulations for 1986-1988, according to the Division of Health Nursing Home Profiles. The combined population of these facilities exceeds one-half of the total population residing in free-standing ICFs/MR in Wisconsin.

We have included those surveyors' findings which, in our opinion, demonstrate most clearly the consequences for residents of life in these facilities. This report includes surveys from January, 1986, through February, 1989, because of the importance of examining patterns of problems not only across facilities, but also across time.

Please keep in mind:

These violations are only a fraction of those cited between 1986 and February, 1989, for the facilities included in this report.

The facilities included in this chapter house approximately 2700 of the 3546 people who live in the DD Centers and free-standing ICFs/MR.

In March of 1986 HCFA informed the Secretary of Wisconsin's Department of Health and Social Services that federal surveyors had found that "...active treatment was not being provided to large segments of the resident population..." in the DD Centers and ICFs/MR.¹³

To avoid decertification actions by HCFA, in late 1986 the state approved for Southern Wisconsin Center 115.25 new and re-allocated positions and a funding increase that totalled \$4,656,989 for fiscal years 1987 and 1988. The state also approved for Northern Wisconsin Center a funding increase that totalled \$1,265,748 for fiscal years 1987 and 1988 to cover 31.2 new and re-allocated positions and additional psychological services. In spite of these emergency staffing and funding increases, active treatment violations for these facilities have continued, as demonstrated by the evidence presented in this report for 1987 and 1988. In January, 1988, Central Wisconsin Center received state approval to hire 16.35 additional staff, resulting in a funding increase for fiscal years 1987 and 1988 that

Letter from Barbara J. Gagel, Regional Administrator, Health Care Financing Administration, to Linda Reivitz, Secretary, Wisconsin Department of Health and Social Services, March 3, 1986.

totalled \$456,700.¹⁴ Nevertheless, the state 1988 survey of Central Wisconsin Center shows continuing serious active treatment problems.

Wisconsin is in the process of converting over 1700 nursing home beds to ICF/MR status, on the theory that active treatment can be delivered in an institutional setting and will benefit the residents of these facilities. We think this theory is not valid. We encourage readers, as they review this evidence, to consider the validity of this theory for themselves.

Information on these staffing and funding increases at the three DD Centers was provided in an April 17, 1989, letter to WCA by the Director, Office of Program Support, Division of Care and Treatment Facilities, DHSS.

KEY TO FACILITY ABBREVIATIONS USED IN THE CHARTS

DD Centers

SWC	Southern Wisconsin Center for the Developmentally Disabled, Union Grove
CWC	Central Wisconsin Center for the Developmentally Disabled, Madison
NWC	Northern Wisconsin Center for the Developmentally Disabled, Chippewa Falls

ICFs/MR

Cottonwood (cited as "Demes" in 1986-87 surveys)	Cottonwood Center, Green Bay (53 beds) (formerly Demes Rehabilitation Center)
Hearthside	Hearthside Rehabilitation Center, Brown Deer (247 beds)
Horizons Unlimited	Horizons Unlimited, Rhinelander (248 beds)
Jackson Center	Jackson Center Nursing Home, Milwaukee (126 beds)
Milwaukee County South*	Milwaukee County Mental Health Center Rehabilitation South (125 beds)
Orchard Hill	Orchard Hill, Madison (96 beds)
St. Coletta	St. Coletta/Alverno Cottage, Jefferson (76 beds)
Van Buren	Van Buren Hall, Green Bay (50 beds)

* Milwaukee County South received approval to work toward ICF/MR status in August, 1987, and was certified in April, 1989. It is included here because people with developmental disabilities comprised a substantial part of its total population prior to 1989, and because it meets our other selection criteria.

A. EVIDENCE OF RESIDENTS RECEIVING NO PROGRAMS AND SERVICES OR MINIMAL LEVELS OF PROGRAMS AND SERVICES

The evidence in this section demonstrates that many residents of facilities in Wisconsin are receiving no programs or services at all, or virtually none. The findings point to long hours of idleness, wasted days, and residents left unattended -- in some instances while residents engage in ongoing, self-injurious behavior.

This section also includes evidence of major service gaps which must negate, or severely reduce, the benefits from the services residents do receive. The findings include residents going through entire summers without structured activities, receiving only one training session in self-help over a two-day period, and receiving a total of four to ten minutes a day of programming.

1. Evidence of residents receiving no programs or services at all

Facility	Source/ Date	Summary/Description
Hearthside	DOH 423994 2/22/89	Each client has not received an active...(treatment) program which is ongoing and includes (a) consistent individualized...program application...On 2/8/89 on the p.m. shift, the surveyor...(observed) 10 residents...with TV on and no one watching...Res. #0948 with short verbal outburst once per minute for 10 minutes. Res. #1027 whining and striking self with force - counted 17 times in two minutes. No programming observed - only staff interventions were directive to sit or come...Nineteen residents with one direct care staff on the p.m. shift in the 2N solarium. Staff interventions were verbal and solely focused on keeping residents in the area. There were no...(activities) - no materials... (On a.m. shift) resident #1100 hit...himself in head nine times without intervention. Five minutes later hit head three times. Only staff interaction was...to direct resident to sit down or stay in solarium. On 2/9/89, day shift...(a resident) with program for self abusive (behavior)...struck self repeatedly without staff intervention... [Violates 42 CFR 483.440]
	DOH 433379 2/22/89	The facility has failed to provide sufficient direct care staff to manage and supervise clients in accordance with their individual program plans. Examples:

Facility	Source/ Date	Summary/Description
		<p>...Between 9:30 a.m. and 9:45 a.m. on 2/10/89...twenty-three residents were on the unit with one RA who was in a room making a bed. At least six of the residents were in the solarium alone engaged in no purposeful activity. Resident #275 was in the hallway alone rocking in a chair...Between 9:45 and 9:50 on 2/10/89 on the 2 NW unit one RA was in the solarium with 20 residents. The RA was folding linen...while one resident was rocking on the floor, one resident was removing his pants. Resident #1077 was in Rm. 263 sitting in the corner making loud noises and pounding on the closet walls. [Violates 42 CFR 483.430]</p>
Hearthside	DOH 295191 5/21/86	<p>...For extended periods of time residents have been observed (often unattended) in solariums without any programming... [Violates 42 CFR 440.150 and 435.1009]</p>
	DOH 295132 5/21/86	<p>...On 5/8/86, 6 residents were unattended in the lounge adjacent to rm. 293. Nine residents were unattended in the lounge adjacent to rm. 249; the lounge was being mopped and one resident was restrained. On 5/7/86 11 residents were in the lounge adjacent to rm. 253 unattended; one R/A entered the room, turned on a TV and told the residents to watch it. On 5/12/86 8 residents were unattended in the lounge adjacent to rm. 173... [Violates 42 CFR 442.433]</p>
Horizons Unlimited	DOH 426386 10/5/88	<p>...Residents were observed for extended periods...without any activity program...body rocking, playing with strings, socks, shoes, underwear, engaged in stereotypical movements... staff did not have the time to spend training residents in these required areas and often were unaware of where the resident was. [Violates 42 CFR 442.433]</p>
	DOH 417696 9/29/87	<p>...Throughout the survey... survey staff observed...residents who were poorly dressed, engaged in...aggressive behavior, repetitive behaviors, screaming, crawling on the floor, stealing others' food, and staff were unable to intervene in an appropriate manner.</p> <p>Examples include but are not limited to...9/15/87, 10:20 AM Resident #6198 was...(moving a) chair around the day room area, bumping into other residents who were lying and crawling about on the floor...During this time the staff member in the immediate area was sitting...in the doorway, to prevent residents from leaving... [Violates 42 CFR 442.432]</p>

Facility	Source/ Date	Summary/Description
Jackson Center	DOH 405006 11/24/86	...Residents #0263-0198-0153-0116-0110-0080-0226-0077...do not attend outside programming and were observed for hours lying on their beds or sitting at the ends of hallways or roaming aimlessly about the facility. [Violates 42 CFR 442.411]
	DOH 403421 11/24/86	...Many residents were observed sitting in their rooms, standing in the hallways during scheduled class times. No attempt was made to involve these residents in programs... On 11/20/86...16 residents were attending the adaptive education class in the dining room on first floor. Only two residents were actively participating...The other residents were observed sitting at tables and wandering in and out of the dining room... [Violates 42 CFR 442.435]
NWC	DOH 408657 3/27/87	...Residents remaining on the unit (during the day) were observed engaging in maladaptive behaviors including climbing on furniture, assaulting peers, lying on the floor, self-isolation/withdrawal, and a variety of self-stimulatory behaviors... [Violates 42 CFR 442.433]
St. Coletta	FED 6/10 - 6/13/86	...Residents were observed wandering about the facility, lying in bed and sitting alone...At any time, except meals, surveyors counted in excess of 10-12 residents on the sleeping wings, pacing, lying in bed; and there were no direct care staff available in the area...A resident record...contained the entry "sleeps in bed most of the day, chooses not to attend most activities." [Violates 42 CFR 442.435]
SWC	FED 5/19 - 5/23/86	...Direct care staff in Cottages such as 18 and 11 were observed making beds and other chores while their eight clients were unsupervised and observed stripping, rocking, roaming and exhibiting other maladaptive behaviors... [Violates 42 CFR 442.433]

2. Evidence of residents receiving programs and services at minimal levels and/or with major gaps

Facility	Source/ Date	Summary/Description
Van Buren	FED W210 W211 5/9 - 5/11/88	...Over two plus days of surveying, two surveyors observed only one training session (in daily living, self-help, or social skills)... [Violates 42 CFR 442.433]
NWC	DOH 426018 3/11/88	...Three residents in Highview 4C were observed to be alone in the second dayroom with the lights out for a 30-minute period of time and they didn't receive any staff interaction/observation during this time. Interactions observed on this P.M. shift were reactive in nature, rather than proactive/teaching (e.g., "no stealing")... [Violates 42 CFR 442.411]
Jackson Center	DOH 424239 10/7/88	Observations and interviews with direct care staff revealed that they did not have training adequate to implement IPPs... Interviews and observations on 9/27/88 and 9/28/1988 with direct care staff regarding unit based activities they were assigned to do with residents demonstrated the only activity noted was coloring... [Violates 42 CFR 442.432]
SWC	FED 5/19 - 5/23/86	...in Cottages 10 and 11 activity schedules reflected gross and fine motor activities for approximately one hour period in the morning and the afternoon, constituting all programming for these clients...however...each client's portion of the program lasted for only 4-10 minutes... [Violates 42 CFR 442.433]
	FED W219 1/26 - 1/29/87	...clients were observed for extended periods without the provision of training, leisure activities or needed staff intervention...As a result, down time was observed to be "dead time," not resulting in or promoting the individual's growth or development...Clients were observed to be pushing each other, pushing staff, eating inedibles and ripping clothing. [Violates 42 CFR 442.435]
CWC	DOH 419391 7/17/87	The suspension of the regularly scheduled program and services that are held September through May for the summer months results in numbers of residents whose training and habilitation needs are not met... [Violates 42 CFR 442.463]
	DOH 414707 7/28/88	There is not an active treatment process in evidence... [Violates 42 CFR 440.150]

Facility	Source/ Date	Summary/Description
Cottonwood	DOH 430051 9/29/88	Active treatment for all residents is not provided by the facility...(Areas not addressed include) feeding, communication, and behavior... [Violates 42 CFR 440.150]
Milwaukee County South	DOH 410472 5/28/87	All residents who are developmentally disabled are not receiving active treatment. The active treatment does not include the resident's regular participation in professionally developed and supervised activities, experiences and therapies which are directed toward acquiring...(the) skills necessary for the client's maximum possible...independence. [No federal regulation number cited]
St. Coletta	DOH 435227 11/29/88	The facility residents are not always in an active treatment program throughout the day. Residents ignore programs or wander throughout facility... [No federal regulation number cited]
Orchard Hill	DOH 404698 3/4/ - 3/10/87	The activity schedules allow periods of unscheduled activity to extend longer than three hours for some individuals. These schedules are not implemented daily... [Violates 42 CFR 442.435]

B. EVIDENCE OF RESIDENTS RECEIVING PROGRAMS AND SERVICES WHICH ARE NOT INDIVIDUALIZED OR ARE POORLY IMPLEMENTED

Surveyors' reports indicate that active treatment for large numbers of residents of facilities in Wisconsin is destined to fail, regardless of the duration or intensity of programs, or the competence of staff, because much of the programming is not designed to fit the needs and skills of the individual resident. We find instances of written orders and plans which are alike for large groups of residents, even though the residents do not need the same services, and of activities which have no relationship to the individual plan objectives or to the skills the residents need to learn. We also find evidence of failure to help residents learn basic activities of daily living, which reduces the likelihood that these residents will be recommended for discharge, and promotes the kinds of dehumanizing circumstances which we explore further in Section F.

Facility	Source/ Date	Summary/Description
Horizons Unlimited	DOH 417949 9/29/87	Living unit staff do not adequately and consistently train residents in ADLs and the development of self-help and social skills...(Examples) On 9/17/87 this surveyor observed ...resident #6218 again on the floor "scooting" about, playing his game of getting staff attention by trying to get past the staff in the doorway. The staff person jumped at him, making a loud noise, and landed right at his side. She then proceeded to maneuver him off down the hall, using her feet and lower legs in a shoving motion...Staff responses and lack of response only serve to reinforce residents' dependency and aberrant behavior. [Violates 42 CFR 442.433]
	DOH 417954 417953 9/29/87	...Residents were observed throughout the survey process appearing disheveled, wearing unsuitable clothing, stained with food, wet with saliva and other substances. Residents' hair is messy and presents an uncombed appearance. Residents exude odors which strongly suggest bodies and undergarments with urine/soiling not well cleaned up. Many residents have bad breath...Clothing was often too long, too short, too big, too small. Colors were inappropriately mixed as were patterns and materials... [Violates 42 CFR 442.443 and 442.442]
Hearthside	DOH 405086 2/23/87	...Residents were observed attempting to eat a thin soup from soup bowls using teaspoons, as no tablespoons, soup spoons, or soup mugs were provided. The frustration caused many of the residents to drink the soup from the soup bowls. When this was attempted by the residents, the staff would direct the residents to eat with the teaspoons... [Violates 42 CFR 442.467]
CWC	DOH 414828 7/28/88	Facility staff failed to provide adequate supervision for self-help eating programs in dining room areas...(Example) at the evening meal on 3B on 7/13/88...resident #5-019...was upset, and smeared food everywhere...He was given little assistance or supervision as staff was busy with other residents. . .Resident #5-2501 attempted to eat his pie by holding small dish in hand, dropped pie onto his bib, then ate the pie off his bib without redirection... [No federal regulation number cited]
SWC	DOH 436773 11/11/88	(The IPP must include)...training in personal skills essential for privacy and independence...Toilet paper, soap, and paper towels were not readily accessible for any of the resident bathrooms in Cottage 3 on 11/8/88 from 6:30 a.m. to 7:56 a.m. Also during this same period, three residents... walked naked to the bathroom across the hall...and then through the dayroom. No attempts...to teach the residents to

Facility	Source/ Date	Summary/Description
		use a bathrobe or to dress in the area where they undress, etc. [Violates 42 CFR 483.440]
Orchard Hill	DOH 405576 3/11/87	The program schedules... for the use of...staff do not reflect resident training in activities of daily living or development of self-help and social skills...Schedules were general and non-specific... [Violates 42 CFR 442.456]
Van Buren 5/11/88	FED W214 5/9 -	...Program plans were frequently not specific (nor developed to meet clients' needs)...For example, one man had an objective to alert staff of any soreness of gums. The program which was developed addressed cleaning of dentures...Another...program plan...required...(a) woman to trace certain information. However, the woman was able to write the information without tracing... [Violates 42 CFR 442.434]
St. Coletta	DOH 414412 11/20/87	...Training and habilitation objectives for residents are not always stated in...terms that allow progress to be assessed ... [Violates 42 CFR 442.463]
SWC	DOH 436775 11/11/88	...Many instances were found throughout the facility where the (IPP) objectives are not written in measurable terms... [Violates 42 CFR 483.440]
NWC	DOH A 281200 3/18/86	...There are areas in which WAF* program tasks have no relationship to the stated objectives: i.e., money to buy a can of pop equals development of social skills, walks equal ADL skill development... [Violates 42 CFR 442.433] [*WAF refers to the "Ward Activity File" which..."is a file of activities (developed by NWC for each resident) that facilitates the provision of active treatment in an organized yet flexible format..." (From explanatory material developed by Northern Wisconsin Center)]
	DOH A 281191 3/18/86	...Despite the WAF Program, each resident is not receiving adequate training designed to encourage maximum independence in health, hygiene, and grooming practices, including bathing, brushing teeth, shampooing, combing and brushing hair, shaving, etc. [Violates 42 CFR 442.486]
Jackson Center	DOH 424240 10/7/88	The facility's direct care staff have not consistently demonstrated the implementation of programming in activities of daily living and development of self help and social services... [Violates 42 CFR 442.433]

Facility	Source/ Date	Summary/Description
Jackson Center	DOH 405685 11/24/86	...Residents weren't trained in activities of daily living. Early morning cares and bedtime cares were provided in groups without individual skills being taught/strengths ad... [Violates 42 CFR 442.433]
	DOH 402155 11/24/86	...Many...(individual) plans were repetitious with goals for residents very similar for the entire populati on... [Violates 42 CFR 442.475 and 442.434]
CWC	FED W215 1/27 - 1/31/86	The program plans available to direct care staff are not specific, for 48 of 50 randomly selected residents... [Violates 42 CFR 442.434]

C. FAILURE TO PROVIDE RESIDENTS WITH SPECIALIZED PROFESSIONAL PROGRAMS AND SERVICES

In this section, we present evidence of the denial of residents' rights to specialized professional programs and services, such as physical therapy and speech therapy. At times, the lack of these specialized programs and services not only limits residents' opportunities to progress, but also leads to regression and loss of ability to function, e.g., deteriorating eating skills and ambulation.

Facility	Source/ Date	Summary/Description
Van Buren	FED W504 W505-W511 5/9 - 5/11/88	<p>Although the facility had a contract for occupational and physical therapy services, these services were not being provided to clients...(For example):</p> <p>One client who was severely stooped over and had a shuffling gait. One client (who) used a wheelchair and had a shuffling gait. There were at least three clients with cerebral palsy that had difficulty eating, but there were no feeding evaluations done on these clients.</p> <p>One client with cerebral palsy had his last physical therapy evaluation March 16, 1983 (five years prior to this survey). It said "has good range of motion and strength at extremities. Ambulates well with good balance and gait." Now the interdisciplinary care plan has identified problems of</p>

Facility	Source/ Date	Summary/Description
		"impaired gait and to be free of any falls due to unstable gait..."
		One client who now uses a wheelchair had a physical therapy evaluation December 19, 1986. At that time it said "his gait was independent with walker. Needs work on endurance and stair climbing..." [Violates 42 CFR 442.486]
Horizons Unlimited	DOH 416151 9/29/87	The PT* & OT staff do not provide treatment and training programs...to preserve and improve abilities for independent function...and prevent insofar as possible, irreducible or progressive disabilities through means such as appliances, assistive and adaptive devices, positioning, behavior adaptations and sensory stimulation to all of the residents in need of these services.
		...#6051 has an unsteady gait and has fallen many times...He was checked by PT for injury after one fall but there is no program component designed to reduce the number of falls. [Violates 42 CFR 442.486] [*P.T. refers to "physical therapy" or "physical therapist."]
Milwaukee County South	DOH 422571 5/12/88	...MD ordered P.T. 3/30/88 for gait training related to a fractured ankle. PT (done by contracted service) declined providing service without a guardian's signature. Guardian expired 8/87. No evidence of the multi-disciplinary team planning/managing to obtain this needed service. No evidence that the MD who ordered PT was alerted of the delay of weeks since order written... [Violates 42 CFR 405.1124]
SWC	DOH 436782	Resident #5429 was reportedly ambulative in Wallace prior to 11/11/88 her transfer to Cottage 16...(where) she was not ambulating. She was transferred back to Wallace when she again was able to ambulate and then was transferred back to Cottage 16 where she is...unable to walk (now) and is in a wheel chair all day. A physical therapist has been working with her to decelerate the regression... [Violates 42 CFR 483.440]
	FED 5/19 - 5/23/86	...physician certifications and interdisciplinary team recommendations consistently listed behavior problems as the overriding reason that clients must remain institutionalized; yet, programs to deal with these behaviors have not been developed. [Violates 42 CFR 442.463]

Facility	Source/ Date	Summary/Description
Hearthside	DOH 433377 2/22/89	...The professional staff...has identified in excess of fifty residents who require behavior treatment programs and do not have such a program established. (Examples)...#1027 - head banging; body twisting; hair twirling. #6449 - pulling out her hair and picking her scalp. #0698 - self-abusive rubbing body fluids into face, causing redness and irritation. #1248 - clothes chewing. #760 - hitting peers and throwing objects. #1064 - breaking windows. #1295 - Name calling and striking out. #1119 - fecal smearing. #875 - grabbing staff and peers. [Violates 42 CFR 483.430]
Cottonwood	DOH 430045 9/29/88	...behavior program development has not yet begun at the facility... [Violates 42 CFR 442.489]
Jackson Center	DOH 424111 10/7/88	...Res. #059 observed 9/27/88 at 2 p.m. in unit dayroom. Resident biting tops of hands to point of drawing blood. Direct care staff attempting to follow guidelines provided without success. The three direct care staff in dayroom clearly related their frustrations with approaches and lack of revision, noting an increase in self abusive behavior since approximately 8/17/88 since resident was held from workshop. Direct care staff state "every morning she says can I go to work today?"... Res. #180 has demonstrated numerous agitated episodes with physical striking out behavior without evidence of revision in guideline for "agitated behavior." Direct care staff later viewed 9/28/88 re: #180 stated "she used to love to go to workshop" "Now she hasn't gone for about a month" "She hits people, gets shot, quiet for a day or two and then hits somebody again." [Violates 42 CFR 442.490]
SWC	DOH 431870 11/11/88	The facility did not provide... speech therapy as identified in residents' IPP's. Programs and related goals were...on hold for up to three to four months... [Violates 42 CFR 483.480]
NWC	DOH 409252 3/27/87	...(Blind) Individuals...on various living units...are not provided with programming for trailing skills/mobility training. [Violates 42 CFR 442.454]
Cottonwood	DOH 425041 5/13/88	Comprehensive audiological exams were not all carried out based on results of screening...(For example)...(Resident) #229. Last audio exam 6/13/86. Slight loss found. No further testing. Res. #224. Hearing eval. 1985 - "Severe conductive...(hearing) loss..." (Recommended) annual evaluation. None found since 6/2/86...Res. #A213 - Hearing eval.

Facility	Source/ Date	Summary/Description
		10/21/87 showed mild to profound loss bilaterally. . .no evidence of the assessment of the use of amplification... [Violates 42 CFR 442.496]
Cottonwood	DOH 425043 5/13/88	Comprehensive speech and language evaluations were not done based on individual... needs. (Examples)...Res. #267 screening of 8/9/83 ...(recommends) "full speech/language (evaluation) .. .Able to imitate variety of words...(Evaluation) was never performed...(Resident) frequently screams out loudly." Res. #A275. No speech/communication...(evaluation) in record. Res. uses only gestures to communicate. Res. #262 ...(diagnosis) of expressive language disorder. No speech/...(communication) eval. in record. [Violates 42 CFR 442.496]
Demes	DOH 296039 5/2/86	...There was no documented evidence of direct contact between (the speech) therapist and residents, and no evidence of written recommendations for programming/treatment by the therapist...The facility has many residents with mild to severe communication disorders. [Violates 42 CFR 442.496]
Orchard Hill	DOH 414263 1/11/88	...The facility has been without speech services since mid-Oct. 1987 and has not employed an audiologist at least since last survey (ten months prior to this survey). [Violates 42 CFR 442.498]
CWC	DOH 419397 7/17/87	There are numerous residents throughout the facility who could benefit from but who are not receiving communication services... [Violates 42 CFR 442.496]
Horizons Unlimited	DOH 416153 9/29/87	...(There are no specialized programs) for developing EACH resident's communication skills in...speech, reading, auditory training, and hearing aid utilization... [Violates 42 CFR 442.496]
NWC	DOH A 281189 3/18/86	...There is a lack of adequate program plans to maximize each resident's development and acquisition of perceptual skills, sensorimotor skills, self-help skills, communication skills, social skills, self direction and emotional stability and effective use of time, including leisure time... [Violates 42 CFR 442.454 and 442.463]

D. FAILURE TO USE APPROPRIATE RESIDENT EVALUATIONS AND RE-ASSESSMENTS IN DEVELOPING PROGRAMS AND SERVICES

The progress of residents is often hindered or prevented by initial and ongoing evaluations which are inaccurate, and which often embody extremely low expectations for people's future development. In this section, we present evidence of reliance on "informal perceptions" of residents' capabilities which limit their opportunities to progress. The findings include evaluation processes which consider no alternative for the residents other than continued institutionalization, and re-assessments which do not lead to changes in program goals, even though the goals are no longer appropriate.

There are also examples of individuals who were admitted to an ICFs/MR although they did not have a developmental disability. The evidence shows that they were retained in the ICFs/MR even after assessments verified that their placements were inappropriate.

Facility	Source/ Date	Summary/Description
Jackson Center	FED W330-W331 3/23 - 3/25/87	A...resident had no verification in her chart that she is in fact mentally retarded...and staff felt that she is not retarded and she demonstrated highly developed cognitive skills in direct interviews with surveyors. A...resident, who moves freely in the community without supervision and recently had herself referred to a mental health center for counseling...has no test scores in her psychological report to verify that she is in fact mentally retarded... [Violates 42 CFR 442.456]
	DOH 423985 5/23/88	The facility admitted and retained resident #0281 who required services which the facility did not provide or make available. A comprehensive pre-admission evaluation was not conducted that covered resident #0281's cognitive level of functioning. There was no admitting diagnosis of mental retardation. According to the physician's progress note of 10/7/87, "...Patient may not be appropriate for facility..." (An evaluation) on 12/14/87 stated that #0281 "is functioning intellectually and adaptively in the borderline range of normal intelligence" and that "there is little he could learn regarding adaptive skills at Jackson Center." [Violates 42 CFR 442.418]

Facility	Source/ Date	Summary/Description
Van Buren	FED W330 5/9 - 5/11/88	...(Evaluations were) not always accurate. For example, one man's most recent psychological evaluation placed him in the severely retarded range in contrast with past psychological evaluations which place him functioning in the borderline range of intelligence. Following an interview with this man the surveyors questioned the diagnosis of severely mentally retarded and asked staff to explain the discrepancy between the two tests. Staff commented that they believed the man's functioning level was in fact closer to the borderline score rather than the score which placed him in the severely retarded range. [Violates 42 CFR 442.456]
Milwaukee County South	DOH 423425 5/12/88	...Res. #108799 re-admission assessment did not address resident's accelerated behaviors on readmission resulting (in) use of full leather restraints for 26 hours in 3 days ...In spite of the interdisciplinary team's decision to refer resident #115916 for community placement on 2/22/88, referrals were not made until 5/11/88. [Violates 42 CFR 405.1130]
Orchard Hill	DOH 414265 1/11/88	Records in general show a lack of annual reviews...(and of) preadmission...(and) readmission evaluations... [Violates 42 CFR 442.499]
Demes	DOH 408431 6/2/87	...annual reviews... lack documentation of consideration of advisability of continued residence and alternative programs ... [Violates 42 CFR 442.422]
Hearthside	DOH 422290 3/3/88	...The evaluation process does not include alternative services for residents. Throughout the (review)... individual program plans contained (an old)...statement that reads... "continued placement in this...facility due to need for structured and supervised environment." [Violates 42 CFR 442.495]
CWC	DOH 414721 7/28/88	...The only evidence of an interdisciplinary team discussion (of the advisability of continued residence and alternative programs)...is a recommendation to "refer to the placement committee for community placement" or "continued residence on _____," as examples. This is not adequate discussion of this matter... [Violates 42 CFR 442.422]
Van Buren	DOH 425506 3/29/88	There is no documentation that the facility conducted a comprehensive evaluation of social, emotional, cognitive factors on or before admission of (15) residents... [Violates 42 CFR 442.500]

Facility	Source/ Date	Summary/Description
SWC	FED W579 1/26 - 1/29/87	...At least 100 clients need evaluations. Two of eleven records reviewed had no screening or evaluation, and one record had an evaluation eight years old. There are no policies and procedures specifying the length of time before evaluations must be done, but eight years is far too long... [Violates 42 CFR 442.496]
Cottonwood	DOH 419083 5/13/88	...(IPPs) do not provide indices of resident performance based on data collected during evaluation and intervention ... [Violates 42 CFR 442.434]
NWC	FED W163 12/8 - 12/12/86	Although representatives from the direct care and professional staff annually reviewed the clients' status, the goals and objectives at times remained unchanged from year to year... [Violates 42 CFR 442.422]
	FED W333 12/8 - 12/12/86	Although programs were periodically reviewed, changes were not made when the individual's progress was consistently poor. For example, one client displayed no progress on a food identification program for 4 months. The program was not revised. One client displayed limited or no progress on her clothing program for at least 5 months. The program was not revised... [Violates 42 CFR 442.456]
	FED W259 W262 12/8 - 12/12/86	...Time out was to be used for a woman who was aggressive towards staff and peers. The program which was written for this client was almost five years old and was no longer current... [Violates 42 CFR 442.441]
	DOH A 281189 3/18/86	...Training and habilitation services are influenced by informal staff perceptions of the resident's ability, which deny many residents the opportunity to maximize their development... [Violates 42 CFR 442.454 and 442.463]

E. USE OF CHEMICAL AND PHYSICAL RESTRAINTS AND AVERSIVE PROCEDURES IN THE ABSENCE OF APPROPRIATE PROGRAMMING

In this section, we focus on evidence of practices resorted to by facilities when they fail to provide residents with appropriate programs and professional services. The surveyor findings pertain to the unauthorized and inappropriate control of residents by institution staff. This evidence relates primarily to the use of medications and physical restraints, but also includes

the inappropriate use of "time-out"¹ and "aversive stimuli"¹⁶, such as electric shock.

Facility	Source/ Date	Summary/Description
Horizons Unlimited	DOH 416093 9/29/87	...Control and disciplinary measures are not promoting resident skills in the area of self-control and good judgment. .. (They) are abusive...counter-productive...(and) substitutes for appropriate programs. [Violates 42 CFR 442.437]
	DOH 416147 9/29/87	Each resident is not free from mental and physical abuse. Res. examples include, but are not limited to:...Res. No. 6370 was restrained on the floor in the activity room...by four staff for a period of one hour. The resident was physically restrained...(with) a physical crisis intervention hold on a tile-over-concrete floor. ...Resident No. 6326's record documents the following: "8/30/87...(the resident) was very upset so writer went to ask her what was wrong. She said her throat was sore then she said a staff on AM's choked her...(The resident) stated that day staff held her by the throat and forced liquid down her at meal time (lunch)...Although the above incident was investigated and disciplinary measures were taken (staff suspension) the above incident should not have occurred if the dining room was appropriately supervised, staff were adequately trained and sufficient in number, and adequate training and habilitation programs were in place. [Violates 42 CFR 442.404]
	DOH 416138 9/29/87	Restraints have become a convenient alternative to staff intervention, activity, and treatment. This is particularly true of helmets, masks, mitts, and elbow splints. Residents wear them for the most part of the day and only have them removed when staff can closely supervise them...There is no evidence that splints are removed and the residents' arms exercised for at least 10 minutes per 2 hours of restraint... [Violates 42 CFR 442.438]
Milwaukee County South	DOH 409791 5/28/87	Not all residents receive adequate and appropriate care within...the facility...(Examples): Locked seclusion with five point leather restraints for up to eight hours or until calm for 1 to 1/2 hour are ordered and frequently used for (9) residents...The type, duration and frequency of restraint

"Time-out" refers to physical isolation of residents.

¹⁶"Aversive stimuli" refers to the use of unpleasant and/or painful stimuli to control or alter residents' behaviors.

Facility	Source/ Date	Summary/Description
		usage exceeds what is necessary to protect residents from themselves, others, or property. [No federal regulation number cited]
SWC	FED - 5/23/86	...the facility houses numerous clients with maladaptive behaviors including self-injurious behaviors, physical aggression toward others, pica behaviors (ingestion of inedibles), etc. In spite of this fact, client-specific behavior modification programs have not been developed...for these clients. Instead, PRN (as needed) physical and chemical restraint orders are written by the physician... [Violates 42 CFR 442.441]
Van Buren	FED W35 5/9 - 5/11/88	The facility had 26 of 47 clients on psychotropic medications...ten (of whom) were... neither chronically mentally ill nor dually diagnosed. These medications were not used in conjunction with a program to decrease behaviors, if indeed they existed. [Violates 42 CFR 442.404]
St. Coletta	DOH 414409 11/20/87	There is not a behavior program for each resident who is on psychotropic medications.* [Violates 42 CFR 442.404] [*"Psychotropic medications" refers to medications which directly affect the central nervous system. They are commonly used in the treatment of mental illnesses or disorders. These drugs are also used to modify the behaviors of persons with developmental disabilities, as in the instances cited in these charts.]
	FED 6/10 - 6/13/86	...Fourteen residents were receiving psychotropic medications at the time of the survey... Some of the residents... had objectives in their program plan related to behaviors but it was not clear that these were the reason for the use of the psychotropics...None of...(these) residents...had specific programs written such that staff could correctly and consistently intervene when behaviors occurred...(and evaluate) progress or lack of progress in dealing with the behavior. [Violates 42 CFR 442.404]
CWC	DOH 431510 7/28/88	In general, the facility's physicians are not indicating... why they are prescribing medications and restraints...There are residents who have orders for medications or restraints, but who do not have behavior programs. For example, resident #5-845 has a helmet prescribed as needed for self-injurious behavior, but no program describing when and how to use the helmet... [Violates 42 CFR 442.404]

Facility	Source/ Date	Summary/Description
CWC	DOH 419399 7/17/87	Twenty percent (20%) of the residents are receiving psychotropic medications for behavior control. Many of these lack formal behavior programs. Some...programs (do not reduce)...medications...as targeted behaviors are reduced or extinguished... [Violates 42 CFR 442.440]
NWC	FED W259 W262 12/8 - 12/12/86	...Twenty-one of...thirty-seven clients received behavior modifying medications in the absence of a behavior modification program designed to lead towards the increase of adaptive behaviors... [Violates 42 CFR 442.441]
Jackson Center	FED 6/9 - 6/11/86	...The facility had 53 of 122 residents (43%) on psychotropic medications. Twenty-six residents had PRN*...psychotropic medication orders. There was only one behavior modification program... [Violates 42 CFR 442.440] [* "PRN" refers to "as needed".]
	DOH 433680 10/7/88	...Res. #0185 is receiving psychotropics for behavior management against the 8/10/88 written refusal of the resident's mother/guardian for daughter to receive Mellaril and Tegretol. Res. #0005 was physically restrained by staff 7/13/88, 7/28/88, and 9/18/88 without evidence of physician order, not part of a consented behavioral program... [Violates 42 CFR 442.404]
Horizons Unlimited	DOH 416139 9/29/87	Chemical restraint is being used as a substitute for activities and treatment... [Violates 42 CFR 442.440]
CWC	DOH 414592 7/28/88	The Bureau has not reviewed and approved any programs from Central Wisconsin Center which use time out...forced compliance. . .physical restraints, aversive stimuli...there are approximately 200 programs (at the Center) which utilize one or more of these techniques or procedures. [Violates HSS 134.60 - state requirement]
Hearthside	DOH 422465 5/15/88	There are individuals whose behavior programs include the use of behavioral controlling medications, time out, specialized clothing and restraining devices which are not (1) Reviewed and approved by the facility's APR committee or QMRP; (2) Conducted only with the consent of the affected residents) parent or legal guardian; and (3) Described in written plans that are kept on file in the facility... [Violates 42 CFR 442.441]

Facility	Source/ Date	Summary/Description
Hearthsides	DOH 295128 5/21/86	Resident #755 has been restrained instead of receiving treatment to alleviate her water intoxication problem...she spends most of her day restrained in a geri-chair... [Violates 42 CFR 442.438]
SWC	DOH 436779 11/11/88	(A behavior program has not been developed for)...resident #5046 who picks at her skin, resulting in open sores... (Three) residents...who receive medication to promote sleep because of inappropriate behavior at and after bedtime...do not have an active treatment goal and approach or behavior program... [Violates 42 CFR 483.440]
	FED W252 W253 W255 W256 1/26 -1/29/87	Although there is evidence of reduction in the use of psychotropics, the overall use is still high. Sixty-three percent of the clients were on psychotropics in May, 1986. Sixty-one percent of the clients were on them in January, 1987... [Violates 42 CFR 442.440]
	FED W239 W240 1/26 -1/29/87	In the absence of the prescribed staffing pattern (i.e., a 1:1 ratio) clients were observed to be restrained...As a result, these restraints were viewed as being used for the convenience of staff and as a substitute for activities. [Violates 42 CFR 442.438]
Orchard Hill	DOH 414214 1/11/88	Consents for...behavior treatment programs with medications are not being completed when major changes take place. Residents/guardians are not always...notified. [Violates 42 CFR 442.501]
NWC	DOH 426027 3/11/88	The facility may not use physical restraint as a substitute for activities or treatment...residents...have had a jacket/bed belt restraint used without an informed consent... [Violates 42 CFR 442.438]
	FED W237 12/8 - 12/12/86	...(One) individual's approach... required that a baskethold be used until calm and if necessary authorized the use of a straight jacket. There were no objectives, no positive component nor consent for the use of these techniques. [Violates 42 CFR 442.438]
	FED W116 12/8 - 12/12/86	...One client with an aversive faradic stimulation program (electric shock) had had the program implemented for approximately two years. The use of this program was not reviewed ...until more than a year and a half after its initiation. The review...was a review of a checklist rather than the program itself. By the time of the review the objectives contained in the program were outdated and the targeted

Facility	Source/ Date	Summary/Description
		behaviors had changed. Nonetheless, based upon the check - list, the program was recommended for continuation without any changes. [Violates 42 CFR 442.413]

F. OBSTACLES TO ACTIVE TREATMENT RELATED TO RESIDENTS' LIVING ENVIRONMENT AND STAFF TREATMENT OF RESIDENTS

State and federal surveys document widespread violations of facility residents' rights to privacy, personal possessions, dignity, and life in humane environments. Included in this evidence of mistreatment of residents are examples of residents of an ICF/MR working for the facility without proper compensation and the failure to provide residents with clothing, soap, toilet paper, blankets, and pillows.

It is important to note here that HCFA's procedures for survey teams emphasize the relationship of environment and staff behavior to active treatment outcomes (Survey Procedures, October, 1988, pp. 11-12). We include the following evidence for this reason and because it adds an important dimension to our understanding of the overall quality of life for persons in the DD Centers and ICFs/MR in Wisconsin. Also, this evidence relates to the examples in Section A of residents receiving no programming at all, in that the types of abuses described below often take place because there is nothing positive going on in the facility.

Facility	Source/ Date	Summary/Description
Horizons Unlimited	DOH 417947 9/29/87	...(In Moffett Hall) A staff member sits on a chair in the open side of the double doors and holds the other door closed with their foot or leg. 12 to 15 residents are huddled in mass about the doorway area. Some attempt to crawl out, some try to scoot out on their bottoms, and others are pushing and crowding the area. Other residents in the day room area are body rocking, flipping their hands and arms, engaging in self-abusive slapping, crawling on the floor, etc. The noise levels are intolerable with loud TVs, stereos, and radios. Residents are yelling and screaming also. All of this

Facility	Source/ Date	Summary/Description
		presents a totally chaotic environment... [Violates 42 CFR 442.404]
Horizons Unlimited	DOH 416095 9/29/87	...There are no privacy curtains in the 500, 600, and 700 units. The facility air is often humid, heavy, and malodor laden...Resident living areas are crowded and chaotic... [Violates 42 CFR 442.446]
	DOH 421272 10/5/88	...Rooms were barren except for an occasional small picture screwed to the wall or a floral arrangement or stuffed toy hanging...out of reach. [Violates 42 CFR 442.436]
CWC	DOH 432213 7/15/88	Adult residents (18+) live on Units 3 and 4 North, 4 South. All toilets are child size, about 12 inches high...Toilet and bath facilities are not of the size and design to meet resident needs... [Violates 42 CFR 442.450]
SWC	DOH 431868 11/11/88	...(in one Cottage) there (were)...no soap dispensers, paper towels, or toilet paper available..." [Violates 42 CFR 483.470]
	FED W312 1/26 - 1/29/87	The toilet facilities in Tramburg Hall are not equipped with toilet seats. [Violates 42 CFR 442.450]
	FED W398 W399 1/26 -1/29/87	In Wallace 2 East...fourteen clients were fed without benefit of a table, and in the smaller living area twelve clients were fed without being placed at tables. The space in the two areas was generally crowded. There was no specific dining area...One table for 35 clients is insufficient. [Violates 42 CFR 442.471]
	FED 5/19 -5/23/86	Staff...were overheard referring to clients as "kids," "boys," "girls," even though the clients were adults... [Violates 42 CFR 442.404]
NWC	FED W227 12/8 - 12/12/86	Clients were not allowed to have access to items such as pillows, clothing, toilet paper, soap, towels, etc., in Highview 3 and 4. [Violates 42 CFR 442.404]
	DOH A 297721 3/18/86	...Interview of staff throughout facility revealed use of resident smoking materials, scheduled treats, and personal possessions to control, modify, and condition behavior without care plan approaches or programs in place... [Violates 42 CFR 442.404]

Facility	Source/ Date	Summary/Description
Hearthside	DOH 422457 4/17/88	...On 2/4/88 between 7:35 and 7:45 p.m....(on the) NW wing... residents #672, #1102, #745, #263, #947, #1003, #996, #1215, and #1064 were in bed... [Violates 42 CFR 442.435]
St. Coletta 6/13/86	FED 6/10 - Residents must	All resident records reviewed contained a form indicating that they had volunteered to perform work activities. Residents must be compensated for all work that is not designed to promote greater independent functioning...and is not part of the resident's plan of care with behavioral and measurable objectives...Numerous residents were observed assisting in the kitchen, washing tables, dusting stairs and handrails, sorting and folding clothes for the whole unit... [Violates 42 CFR 442.404]
Hearthside	DOH 433650 2/22/89	The facility failed to ensure that clients' rights to retain and use appropriate personal clothing is maintained...(Examples) #1317 - no underpants on 2/10/89 at 11 a.m...(staff) said she has none, was wearing slacks. Wearing another resident's slippers as she had no shoes. #1283 was wearing soiled blouse...on 2/6/89 in a.m. Slacks were too long, rolled up approximately 6". #0669 - p.m. shift on 2/6/89, pants too long, dragging on the floor. #1307 - white stains on dark colored slacks and dirty glasses on 2/6/89 a.m. [Violates 42 CFR 483.420]
Horizons Unlimited	DOH 421272 10/5/88	...The majority of residents in the 600 wing have no personal possessions except clothing. Many residents on the 500 and 700 wings have no personal possessions or a very limited number... [Violates 42 CFR 442.436]
Jackson Center	DOH 424227 10/7/88	During evening programming observations on 9/28/88, at 6:30 p.m., several residents approached the RN surveyor complaining they were cold and did not have blankets. Direct care staff interviewed stated "we're out of blankets." Direct care staff were unable on the second or third floor to state where they could find any. On the 2nd and 3rd floor units, 55 beds were found with sheets only on the bed and the units were chilly... [Violates 42 CFR 442.448]
	FED W264- W267 3/23 - 3/25/'87	Each resident does not have enough neat, clean, suitable and seasonable clothing...(Examples): one female resident (J.V.) had no underwear, hat, gloves, or boots. Only one pair of shoes was seen in her closet and they had no laces. J.T. had one sock in her drawer and few, if any, underwear or dresses ...A Wednesday observation of residents on one floor revealed

Facility	Source/ Date	Summary/Description
		<p>pants too long and dragging on the floor...blouse sleeves too long, soiled pants...shoe laces too long, a resident wearing no shoes, a dress too short with an uneven hem and a sweater with holes and buttons missing... [Violates 42 CFR 442.442]</p>
	<p>DOH 403415 11/24/86</p>	<p>...On 11/17/86, three residents were unable to attend outside programming as sufficient clothing was not available... Several staff members admitted to using other residents' clothing to properly dress residents lacking adequate clothing. Residents' rights to retain and use their own personal clothing has not been maintained by this facility. [Violates 42 CFR 442.404]</p>

A Closing Note: The 1988 state survey reports on Southern Wisconsin Center and St. Coletta/Alverno Cottage included favorable active treatment-related comments. The survey for Southern Wisconsin Center included a statement that indicates the "facility is generally providing continuous active treatment." However, other 1988 survey findings presented in this chapter indicate that in fact there are significant active treatment problems at Southern Center, e.g., failure to provide behavior management programs for certain residents, failure to develop measurable individual plan objectives, and failure to provide training in personal skills related to independence. Surveyors' notes in the 1988 St. Coletta survey indicate "no federal deficiencies identified." However, the report also indicates that residents of St. Coletta are not always in an active treatment program.

CHAPTER V: CONCLUSIONS AND RECOMMENDATIONS FOR THE FUTURE

A. NEW PERSPECTIVES ON ACTIVE TREATMENT

This report has examined active treatment from several angles:

a close analysis of the pertinent federal regulations;

a comparison between the federal requirements and Wisconsin statutes and human service principles;

a look at the life experiences of current and former residents of facilities required to provide active treatment; and

a review of federal and state surveys of state DD Centers and free-standing ICFs/MR housing 2700 of the total 3546 people residing in such facilities.

This analysis sheds new light on the concept of active treatment and its implications for people with developmental disabilities in Wisconsin. Taking all the above perspectives together, several important conclusions about active treatment emerge:

1. Active treatment is largely an empty goal. Compliance with active treatment requirements falls far short of Wisconsin's goals for people with developmental disabilities, and furthermore, it is not responsive to the greatest desire of many residents of nursing homes, ICFs/MR, and DD Centers: to get out of the facility and have a chance to live in the community before their lives run out. Regardless of how much money is spent on these facilities to meet active treatment requirements, there is no assurance that this investment of resources will move people any closer to community life.

Ironically, the federal government is essentially neutral on the policy question of whether Wisconsin should move people out of Medicaid-funded institutions and into the community. HCFA is not promoting the creation of new distinct-part ICFs/MR, nor is HCFA discouraging the use of CIP-Ib. HCFA is only saying that if Wisconsin keeps people in ICFs/MR, those facilities must meet active treatment requirements. It is Wisconsin, not HCFA, which has decided to promote the continued use of institutions, and to keep the CIP-Ib per diem rate well below what the federal government would allow.

ICFs/MR and DD Centers are not nice places to live. Both the interviews and surveys remind us of an important fact about the places where active treatment is supposed to be provided in Wisconsin: the quality of life in these facilities is poor. Regardless of how substantial the federal regulations are, how vigilant the government's enforcement of them is, and how much money future state budgets keep adding to the per diem rates of DD Centers, ICFs/MR, and nursing homes, these places will still be institutions.

Compliance with the programmatic and paperwork requirements of active treatment, no matter how well-intentioned, cannot make these facilities into something they are incapable of becoming -- nice places to live. These facilities will continue to fall prey to the universal tendencies of institutions: depersonalization, lack of true individualization, tendency toward group activities and group responses, isolation from community life, and an overall living atmosphere which few people in Wisconsin would want to call "home."

Most, if not all, institution residents could "make it" in the community. It is becoming increasingly evident in Wisconsin that large numbers of people with developmental disabilities living in nursing homes, DD Centers, and ICFs/MR can live successfully in the community. In fact, almost 800 people with developmental disabilities are already being served through the CIP 1a and CIP 1b programs in Wisconsin. Also, the "before and after" stories in this report of people who moved out of institutions further illustrate the capacity of residents to live successfully in the community.

At the time of this report, several counties in Wisconsin (e.g., Milwaukee, Washington, Waukesha, Dane, Oneida, Outagamie) have already invested the time and energy to assess the community service needs of many of their nursing home and ICF/MR residents with developmental disabilities. The picture which emerges from these assessments is clear: these counties believe that a substantial number (their estimates generally ranged between 30% - 50%) of the people could and should live in the community.

WCA's view is that virtually all of the people with developmental disabilities living in ICFs/MR and the DD Centers could live successfully in the community. The views of state government appear to coincide with those of WCA: in Central Wisconsin Center's formal "Plan of Correction,"

submitted in response to the most recent (July, 1988) survey of Central Center by the state Division of Health, the state made a strong proclamation of its views of the potential for community living of Central Center's 600+ residents:

"All residents are deemed placeable, providing adequate services are available in the community." (Signed by Gerald E. Dymond, Deputy Administrator, Division of Care and Treatment Facilities)

4. Active treatment is full of contradictions. As acknowledged in this report, active treatment does have some merit. It does provide certain protections for people and it is likely to improve conditions in some facilities. At the same time, however, when one examines closely the entire body of active treatment requirements, some major internal contradictions appear:

- (a) Although active treatment principles stress the importance of residents' "independence," "self-determination," and "dignity," they do not require that residents move out of institutional settings, where independence and self-determination are restricted the most.
- (b) Active treatment promotes the idea of attempting to build skills and change behaviors in settings which, as we learn from the interviews, inevitably inhibit motivation and learning. The interviews also remind us that the active treatment approach to behavior management overlooks a key factor behind many residents' "inappropriate" behaviors: those behaviors are often caused by or directly related to their lives of isolation in Wisconsin's institutions.
- (c) Active treatment is a process focused, in large part, on teaching persons skills needed in the community – but it attempts to teach these skills in isolation from the community. Unfortunately, for many people this does not work because they are only capable of learning these skills in the place where they can actually use them: in the community. Compounding this absurdity is the implicit, underlying premise of a person's stay in these facilities: that until people learn the skills needed in community life (i.e., the skills they are unlikely to learn in the institution), they will not be "ready" for discharge.

- (d) Medicaid regulations do specify certain rights to which residents are entitled, but when one steps back to reflect on the context in which this list of rights is presented, it becomes apparent that something is wrong: once you take away a person's basic rights to choose where to live, with whom, in what type of living arrangement, and how to spend the day, you have created a second class of citizenship. After that, whatever "rights" you afford an individual can only have a marginal importance in that person's life.
5. "The clock is ticking" for the people whose lives we are talking about. Many of these people have already been the victims of one or more of Wisconsin's state policy "wrong turns": some people moved from DD Centers to nursing homes in the early 1970's under the banner of "deinstitutionalization"; some people moved from their natural families into nursing homes because Wisconsin did not have an adequately funded "diversion" program to cover the costs of a less expensive community arrangement; and, recently, people have been involuntarily transferred great distances away from their families and home communities because the nursing home they have been living in did not choose to provide active treatment.

If Wisconsin continues to promote the current delusion that ICFs/MR meeting active treatment standards are acceptable places for people with developmental disabilities to live long-term, then many of Wisconsin's citizens who want to live in the community, and are capable of it, may miss their last chance to leave the institution. That is a sobering thought, and one we should not lose sight of in the current policy and funding debates which will shape the future for institutionalized people with developmental disabilities in Wisconsin.

B. A REVIEW OF THE CENTRAL MESSAGE OF THIS REPORT

At this point, we believe that we have demonstrated (through various methods) the validity of Points 1. and 2. in the central message of this report, which was spelled out in Chapter I. We assert that Point 3. logically follows. These points are shown again on the following page.

THE CENTRAL MESSAGE OF THIS REPORT

1. THERE IS SOME MERIT TO ACTIVE TREATMENT: IF INSTITUTIONS COMPLY WITH THESE STANDARDS, EACH RESIDENT WILL HAVE AN INDIVIDUAL PROGRAM PLAN AND RESIDENTS MAY HAVE LESS "DEAD TIME" THAN WHEN THEY WERE LIVING IN FACILITIES NOT PROVIDING ACTIVE TREATMENT.
2. HOWEVER:
 - FOCUSING OUR PRIMARY ATTENTION ON ACTIVE TREATMENT COMPLIANCE DOES NOT FIT WITH -- AND DIVERTS US FROM -- OUR STATE'S OFFICIALLY-ADOPTED GOALS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES: ADEQUATE AND APPROPRIATE SUPPORT FOR PEOPLE TO LIVE IN THE COMMUNITY, AS VALUED CITIZENS IN THEIR OWN HOMES AND NEIGHBORHOODS.
 - ADDING FUNDING TO PROVIDE ACTIVE TREATMENT CANNOT CHANGE THE FACT THAT DD CENTERS, NURSING HOMES, AND LARGE ICFs/MR ARE STILL INSTITUTIONS, NOR CAN IT CHANGE THE FUNDAMENTAL REALITY OF LIFE FOR INSTITUTIONALIZED PERSONS WITH DEVELOPMENTAL DISABILITIES: INSTITUTIONS ARE AND WILL REMAIN INAPPROPRIATE AND OFTEN INHUMANE ENVIRONMENTS, REGARDLESS OF THE TIME AND MONEY WE POUR INTO THEM; AND
 - ACTIVE TREATMENT IS INTERNALLY INCONSISTENT -- IT AIMS TO TEACH SKILLS FOR COMMUNITY LIFE IN ISOLATION FROM THE COMMUNITY, CONSEQUENTLY ELIMINATING MOST OR ALL OPPORTUNITIES FOR NATURAL USE OF THESE SKILLS; AND IT ATTEMPTS TO CHANGE "INAPPROPRIATE BEHAVIOR" IN AN INSTITUTIONAL ENVIRONMENT WHICH MAY ITSELF BE A MAJOR CAUSE OF THIS BEHAVIOR.
3. CONSEQUENTLY:
 - WE MUST RENEW OUR COMMITMENT TO THE INTEGRATION OF INSTITUTIONALIZED PERSONS WITH DEVELOPMENTAL DISABILITIES INTO THEIR HOME COMMUNITIES, A GOAL WHICH HAS ALREADY BEEN SHOWN TO BE ATTAINABLE IN WISCONSIN;
 - WE MUST FINALLY TRANSLATE THIS COMMITMENT INTO CONCRETE POLICY AND FISCAL ACTIONS WHICH MOVE LARGE NUMBERS OF PEOPLE OUT OF INSTITUTIONS AND ENSURE ADEQUATE SUPPORT FOR THEM IN THE COMMUNITY; AND LASTLY
 - WE MUST FIND WAYS TO MEET ACTIVE TREATMENT REQUIREMENTS WITHOUT EXPANDING AND LEGITIMIZING INSTITUTIONS IN WISCONSIN.

C. RECOMMENDATIONS FOR ACTION BY THE GOVERNOR, THE WISCONSIN LEGISLATURE, AND THE WISCONSIN DEPARTMENT OF HEALTH AND SOCIAL SERVICES

In the "central message" of this report, it is proposed that we "renew our commitment to the integration of persons with developmental disabilities into their home communities" in Wisconsin. In the final segment of the report below, we will spell out specifically what it would take to do that.

In proposing that large numbers of currently institutionalized people return to the community, we suffer under no illusions regarding the quality of community services in Wisconsin. As a statewide advocacy agency, we often receive calls from people with disabilities and their families who are dissatisfied with the quality or appropriateness of the community services they are receiving. We are well aware that:

many recipients of community services are not receiving all the support they need;

people often are not experiencing as much integration in their home or work life as they would like;

some people lack meaningful work to engage in during the day;

many people do not have adequate case management; and

there are frequently not enough choices of services available.

However, it is clear that these characteristics of community services in Wisconsin are a direct outgrowth of inadequate funding and support for these services. As long as institutional services continue to be a higher priority use of limited human services dollars than community services in our state, we should continue to expect these shortcomings in our community services.

Changing the current excessive preoccupation with active treatment compliance and with creating new distinct-part ICFs/MR will require leadership on the part of the Governor, the State Legislature, and the Department of Health and Social Services (DHSS). Below are action recommendations which require joint effort among more than one of these parties:

1. First, it is essential that both the Governor and DHSS reaffirm the principles of service delivery for persons with developmental disabilities which the state has officially adopted, but which have been eclipsed by the recent concerns

about compliance with federal requirements and potential loss of federal funds. It is important that counties, providers, families, and people with developmental disabilities waiting in institutions know that leaders in state government still believe in the goal of community living, and that this goal has not been displaced by the goal of meeting active treatment standards and keeping people inside ICFs/MR.

Specifically, we recommend that the Governor send a communication to counties, to the Legislature, and to interested groups making clear his personal commitment and the commitment of DHSS to the goal that:

Every person with a developmental disability living in an institution in Wisconsin or at risk of entering an institution will be offered a genuine opportunity to choose to live and receive necessary supports and services in community settings. To this end, the state will make at least the same level of resources available to counties for development of community services as are made available for provision of institutional care.

In the process of creating new distinct-part ICFs/MR in Wisconsin and increasing the investment of public monies to enable such facilities to meet active treatment standards, it is essential to avoid making these facilities a permanent feature of the human services landscape. We strongly recommend that the state use its powers under the sunset provision to promote plans for down-sizing ICFs/MR. The most important thing that the state can do in this regard is to make the community alternative feasible for counties (see below). The availability of alternatives to ICFs/MR can become a real factor in the review of ICF/MR need. In addition, the door should be kept open for easy reconversion to nursing home status. As counties increase their capacity to provide community services for people in ICFs/MR, it would be unfortunate indeed if the major obstacle was that counties and facilities felt "locked in" to ICF/MR status, and thus felt compelled to "hold on" to residents to keep their ICF/MR beds filled.

We understand the hard reality that Wisconsin cannot afford decertifications of Medicaid-funded facilities or major disallowances of federal funds. We are not suggesting "under-funding" ICFs/MR or attempting to avoid compliance

with federal regulations. On the other hand, we must remember that no other state has chosen to plunge into the creation of distinct-part ICFs/MR in the way that Wisconsin has. Furthermore, when the state began moving in this direction it was viewed by the Legislature as a temporary measure to deal with an immediate crisis, not as a long-term service model. That is why a "sunset" provision was adopted by the Legislature: to review the ongoing need for these facilities every four years in light of available community alternatives, keeping open an easy option of reconverting ICF/MR beds to regular nursing home beds.

3. Strengthen the Community Integration Program 1b (CIP-Ib) to make it a viable community alternative for people with developmental disabilities who are currently residing in nursing homes, free-standing ICFs/MR, and "distinct-part" ICFs/MR, or who are likely to be newly admitted to such facilities in the near future. This would require action by the Legislature and the Governor in the current biennial budget session:

- (a) Increase the per diem rate for CIP-Ib to the maximum allowable level under the terms of the state's Medicaid waiver agreement with the federal government. The formula used for determining this level ensures that the state's share of the Medicaid cost of CIP-Ib could never exceed the state's share of the cost if the person resided in an ICF/MR. By the end of the 1989-91 biennium (based on the Governor's proposed distinct-part ICF/MR rates), the CIP-Ib rate could rise to approximately \$60/day. After that time, the CIP-Ib rate could be increased only if there was an ICF/MR rate increase first.

- (b) Require COP or CIP-Ib assessments prior to any admissions to ICFs/MR. People who are admitted to ICFs/MR because funding is unavailable would be placed on COP or CIP-Ib waiting lists and be discharged as soon as funding is available. A COP or CIP-Ib services plan would thus become a required part of the ICF/MR admission information.

4. We recommend that the legislature request DHSS to develop a long-range plan (with timelines) by September 1, 1989, which spells out how the state will:

ensure against certifying too many ICF/MR beds during the current crisis;

prepare for and carry out its "review of need" at the end of the initial four-year "sunset" period for distinct-part ICFs/MR;

prevent inappropriate new admissions to ICFs/MR; and

promote maximum possible utilization of the CIP-Ib program to enable people to move out of ICFs/MR if their right to the least restrictive environment is being violated.

We also recommend that the legislature require annual reports from DHSS on the progress in implementing this plan.

5. We recommend that the legislature and the governor work together to pass legislation to reduce existing zoning obstacles to the development of small, community-based residential arrangements for people with developmental disabilities. The existing rule places limits on the development of residences for three or more people via a "minimum distance between programs" requirement. In some parts of Wisconsin (where several community programs have already been established), the available sites for creating new homes for people are in short supply because of this requirement.

A simple alteration in existing law would allow the same flexibility in site selection to homes of 3-4 persons as presently exist for homes of 1-2 persons. This legislation would change the minimum size of homes subject to the "minimum distance" rule from three persons to five persons.

D. RECOMMENDATIONS FOR ACTION WHICH CAN BE IMPLEMENTED IMMEDIATELY BY DHSS

1. We recommend that DHSS Secretary Goodrich send a letter to all Wisconsin counties and to all distinct-part ICFs/MR, reminding them that the current utilization of distinct-part ICFs/MR is a short-term solution. This letter should also discourage future admissions to ICFs/MR, encourage cooperation between facilities and counties in developing individual service plans for community services, and remind counties and facilities of the "easy-in/easy-out" aspect of distinct-part ICFs/MR (the flexibility to reduce beds over time). This letter should also be a reminder that DHSS expects to see reductions in bed size for any facilities which have not totally closed their distinct-part unit by the end of their four year certification period.

2. Wisconsin is currently in the process of certifying many more ICF/MR beds than would be needed if we had an adequately funded CIP-Ib program. We recommend that DHSS undertake (and complete by August 31, 1989) a study of how much existing nursing home and ICF/MR capacity (i.e., how many places or "beds") would be "freed up" if individuals already assessed as "ready for community placement" (and placeable at or below the maximum allowable CIP-Ib per diem rates) actually left these facilities. This would be a particularly important piece of information to add to the current analysis of the "nursing home bed squeeze" some Wisconsin counties are experiencing. It is also an important factor to consider in the face of increasing pressure in some parts of Wisconsin to raise the state's nursing home bed capacity. The results of the study should be distributed to counties, facilities, and interested advocacy groups.

3. We recommend that DHSS develop a policy paper on the "choice requirement" (related to a resident's or guardian's choice of where the resident will live in the future) in OBRA (the federal Omnibus Budget Reconciliation Act of 1987). This law requires that every person with a developmental disability living in a nursing home must be offered "an appropriate institutional or noninstitutional alternative" (emphasis added). This paper should specifically address these questions:
 - (a) How will Wisconsin define the term "appropriate" for application of the choice requirement in Wisconsin in a manner which is consistent with our state statute and policy?
 - (b) What would actually have to be in place (e.g., in the per diem rates and capacity of the CIP-Ib program, in counties' individual assessment and service planning processes, in provision of information and community service visits for residents and guardians, and in the state's enforcement of the "choice requirement") for people to have truly informed and meaningful choices for their future living arrangements?
 - (c) If a person with a developmental disability lives in a nursing home which is converting part of the facility to a distinct-part ICF/MR, has that person's right to "choice" been violated unless the person is presented
 - with the alternative of moving to the community at that time? (This analysis may indicate that Wisconsin is in violation of OBRA already.)

As in Recommendation D.2. above, we recommend that this paper be completed by August 31, 1989, and disseminated to counties, facilities, and interested advocacy groups.

4. We recommend that DHSS play much more of an active leadership role in addressing the funding and policy questions related to the whole arena of: ICFs/MR, active treatment, OBRA, and CIP-Ib. Many counties, facilities, families, and advocates have complained that "we're not sure where the state's headed," "we don't know how the state will interpret/enforce the OBRA requirements," and "we're not sure if the state will really support us if we move in the direction of the community alternative."

Consequently, DHSS must resolve the apparent conflicts between the rhetoric and policies the Department has espoused over the years and its recent actions regarding persons with developmental disabilities in nursing homes and ICFs/MR. This recommendation is related to the earlier recommendation for DHSS to develop a clear long-range plan in this area. There is also an opportunity here for DHSS to "set a tone," and act in a "convener" role for the events in the next 2-3 years which will determine the destiny of people with developmental disabilities currently living in nursing homes and ICFs/MR.

5. We recommend that DHSS greatly improve its support to counties in the areas of:

"resource development," i.e., helping counties develop strategies for improving/expanding the capacities of community service providers already in their counties, and to attract new qualified providers into their counties in order to expand "community capacity" for people who should leave, or who are at risk of being admitted to, Medicaid facilities; and

maximizing the positive aspects of the OBRA screening and assessment requirements, e.g., performing these federally-required functions in a way which
(a) directly connects the required assessment to a person's eventual movement to a community setting, and
(b) "captures" federal revenue for the assessment activity, thereby addressing one difficulty all counties face: "we don't have enough staff time or resources to go into the facilities and figure out what services it would take for the person to be able to live in the community."

6.

Notwithstanding the limitations in the active treatment standards on the issue of "least restrictive environment," we recommend that the Bureau of Quality Compliance (inside DHSS) raise more penetrating questions around this issue in its survey activities. For example, surveyors should hold facilities more accountable regarding:

whether or not all new admissions to facilities genuinely meet the required criteria for admission (i.e., use of currently valid assessments to make the admission decision; determining whether the prospective resident is "likely to benefit from" placement in the facility);

whether or not programs are in place which actually are helping residents "function with as much self-determination and independence as possible";

- whether or not a resident for whom the facility has had little success in addressing his/her "challenging behaviors" over time may be someone whom the facility is incapable of ever serving appropriately, and/or someone who could not possibly develop more appropriate behaviors in such a large residential setting. (How many years of unsuccessful intervention must go by before someone, perhaps the Bureau of Quality Compliance if no one else, questions the facility's ability to ever respond to the person's needs appropriately?) ;

whether or not the facility is taking seriously people's rights to participate in "social, religious, and community group activities," and promoting "frequent and informal leaves from the facility for trips, visits, or vacations"; and

whether or not the facility (and/or the person's county of origin) are violating the "right to least restrictive environment" as provided in Chapter 51.

APPENDIX A

SUMMARY OF THE ACTIVE TREATMENT REQUIREMENTS
ESTABLISHED UNDER FEDERAL MEDICAID PROGRAM
REGULATIONS AND GUIDELINES GOVERNING ICFs/MR

WISCONSIN COALITION FOR ADVOCACY

ay, 1989

SUMMARY OF THE ACTIVE TREATMENT REQUIREMENTS ESTABLISHED UNDER FEDERAL MEDICAID PROGRAM REGULATIONS AND GUIDELINES GOVERNING ICFs/MR

This summary of the basic principles of active treatment for residents of intermediate care facilities for persons with mental retardation and related conditions (ICFs/MR) was prepared by the staff of the Wisconsin Coalition for Advocacy from three official federal source documents. After the citation of each source (below), the abbreviation for that source is indicated. This is the abbreviation which will be used in the left margin of the summary each time that source is cited.

"Medicaid Program Conditions of Participation for Long-Term Care Facilities" (42 Code of Federal Regulations, Part 483, Subpart D, published June 3, 1988, effective October 3, 1988) Abbreviation in summary = 42 CFR + specific standard -- e.g., **42 CFR 483.440(a)**

"Discussion of Comments," preceding the "Conditions of Participation," Federal Register, Volume 53, No. 107, Rules and Regulations, page 20449, June 3, 1988; provides clarification by HCFA of policy reflected in the regulations. Abbreviation in summary = Discuss. + page number -- e.g., **Discuss P. 20460**

"Survey Procedures and Interpretive Guidelines for ICFs/MR" (Appendix J of the Provider Certification Section of HCFA's State Operations Manual), issued in October of 1988 to clarify policy reflected in the regulations and to assist surveyors to determine facility compliance with the law and regulations. Abbreviation in summary = App. J + page number -- e.g., **App. J P. 80**

All major elements of active treatment are covered in this summary. Residents' rights and some related areas of programming which bear directly on learning, skill development, and the management of challenging behaviors are also included. It is these programming areas in which persons with developmental disabilities generally require the most unique and intensified services. Please note that we have paraphrased much of the source material used here, and have omitted considerable detail, in order to make this summary as compact as possible. We have gone to some length, however, to cover the essential elements of active treatment and related areas, and have included more detail -where it was most important to do so (e.g., in the subsection on the Individual Program Plan).

1. The definition of active treatment

42 CFR 483.440 For a facility to meet the federal condition of participation requiring active treatment services, each (a) resident of an ICF/MR "...must receive a continuous active treatment program, which includes aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services. . .directed toward:

- (1) the acquisition of the behaviors necessary for the client to function with as much self determination and independence as possible; and
- (2) the prevention or deceleration of regression or loss of current optimal functional status."

App. J P. 61 "Continuous" (as used in 42 CFR 483.440) means "...the competent interaction of staff with (residents) at all times, in formal and informal settings..."

Discuss. P. 20460 Active treatment "... specifically encompasses those services that clients must require and receive in order to be certified as needing ICF/MR care under the Medicaid benefit."

2. Key elements of the active treatment process

42 CFR 483.440 (a) Admissions, Transfers and Discharge

(b) Persons admitted to ICFs/MR "...must be in need of and receiving active treatment services...Admission decisions must be based on a preliminary evaluation of the client...(which contains) background information (and) currently valid assessments...to determine if the facility can provide for the client's needs and if the client is likely to benefit from placement in the **App. J** facility." No admission should be regarded as p. **64** permanent. The same requirements apply to readmission. **42 CFR** At the time of transfer or discharge, the facility must **483.440** document that the decision was made for good cause and (b) must provide reasonable time for it to take place. At the time of discharge, the facility must develop a final summary of the resident's status and provide a post-discharge plan of care.

(b) Individual Program Plan (IPP)

42 CFR 483.430 The active treatment program for each person must be integrated, coordinated, and monitored by a Qualified Mental Retardation Professional (QMRP). The program must be based on an individual program plan which identifies the resident's needs and the services that meet these needs without regard to whether these services are available. Within 30 days after admission, an interdisciplinary team must do a functional assessment of a new resident which must cover: physical development and health; nutritional status; sensorimotor development; affective development; speech and language development and auditory functioning; cognitive development; social development; skills or behaviors necessary for the client to be able to function in the community; and (as applicable) vocational skills. Meetings should be scheduled and conducted to assure participation by all team members, especially the resident.

42 CFR 483.440 The program plan must be based on the assessment and specify prioritized objectives expressed in measurable behavioral terms. There must be a written training program for each objective. "'Measurable indices of performance' are the quantifiable criteria (for determining) achievement of the objective...For example, 'M. will walk 10 feet with her...walker for 5 consecutive days... George will grasp spoon 8/10 trials per meal for 6 consecutive meals.'"

42 CFR 483.440 Residents' programs must specify the methods for achieving each objective, determining progress, and (c) replacing "...inappropriate behavior, if applicable, with behavior that is adaptive or appropriate." The plan must "describe relevant interventions to support the individual toward independence... and include training in personal skills essential for privacy and independence until it has been determined that the individual is developmentally incapable of acquiring them. (These skills include) toilet training, personal hygiene, dental hygiene, self-feeding, bathing, dressing, grooming, and communication of basic needs."

42 CFR 483.440 The plans for persons with multiple disabling conditions must provide that these persons spend most of (c) each day out of their beds and bedroom areas and in App. J proper body alignment at all times "to prevent regression, contractures, deformities, and to provide sensory stimulation..." The IPP must identify the mechanical supports needed and the situations, reasons, and schedules for their use. The resident "...should not be in

the supports all the time or as a substitute for pro-42
CFR grams or therapy..." **483.440**

(d) "Plans must include opportunities for client choice and self management."

(c) Implementing, Monitoring, and Changing the Individual Program Plan

42 CFR The interventions and services called for in the IPP
483.440 must be implemented by all staff who work with the (c) client (except where licensed personnel are required) in a manner which supports the achievement of plan objectives.

App. J The resident should be given "...a broad range of
P. 80 options...and be able to engage in...(program activities) as independently...as possible." "...The
42 CFR facility must document significant events" relating to
483.440 (e) the client's skill level and progress, and the IPP must
42 CFR be revised accordingly. It must be reviewed and
483.440 revised at least annually.
(f)

(d) Ensuring Client Rights

42 CFR The following rights are to be guaranteed residents of
483.420 ICFs/MR throughout the active treatment process. (a)
(These rights are found, primarily, in the "Client Protections" Condition of Participation, not in the Active Treatment Services Condition of Participation.)

right to be informed of "...the client's rights and the rules of the facility"

right to be informed of "...medical condition, developmental and behavioral status...risks of treatment, and...the right to refuse treatment"

right to "...exercise their rights as clients of the facility, and as citizens of the United States..." including the right to due process and to file complaints

right to "...manage their financial affairs..." and to be taught to do so "...to the extent of their capabilities..." and to be afforded various protections regarding clients' personal funds entrusted to the facility.

- freedom "...from unnecessary drugs and physical restraints..." and the right to receive active

treatment to "...reduce dependency on drugs and physical restraints"

freedom from "...physical, verbal, sexual or psychological abuse or punishment" ..

right to "...personal privacy and...privacy during treatment and care of personal needs"

- right to "...communicate, associate and meet privately with individuals of their choice..."

right to participate in "...social, religious and community group activities"

right to compensation for any work performed for the facility "...at prevailing wages and commensurate with (residents') abilities"

right to "...retain and use...personal possessions ..." and to dress in one's own clothing each day

right of "...husband and wife...in the (same) facility to share a room"

42 CFR
48 .44
(c

right to "...opportunities for client choice and self-management" ("choosing housing or roommates ...clothing...what to eat...")

Ap . J
P. 78
42 CFR
48 .45
(a

right to participate "...to the extent possible... in the formulation of...policies and procedures... for the management of conduct between staff and clients..."

42 CFR
48 .42
(c

- (e) Communications with Clients, Parents, and Guardians

The facility must promote:

"...participation of parents...and legal guardians ..." in the active treatment process "...unless their participation is unobtainable or inappropriate"

"...visits by individuals with a relationship to the client" (including close friends and advocates)

"...frequent and informal leaves from the facility for trips, visits, or vacations"

-
3. Policies related to the delivery of active treatment related services (These requirements are found outside of the Active Treatment Services Condition of Participation)
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- (a) Placement of residents in the least restrictive alternative is not an active treatment requirement

Discuss. Requiring the placement of residents in the least P. 20459 restrictive alternative available "...is an important principle in the field of mental retardation and developmental disabilities...Requiring (placement in the least restrictive alternative)...as a part of the active treatment program...would go beyond the intent of Congress in authorizing ICF/MR services. There is nothing in (the Social Security Act)...that suggests that the size or location of a facility, or whether a facility is the least restrictive alternative, should determine whether or not a facility qualifies for (funding). The only statutory requirement is that a client receive active treatment at the facility." [Emphasis added]

- (b) Medicaid program regulations do not require that ICF/MR residents benefit from active treatment

Discuss. The active treatment outcomes to which HCFA holds P. 20460 facilities accountable in determining eligibility for continued funding do not include actual outcomes or benefits for residents. "We believe the state-of-the-art is such that we can hold providers accountable (only) to implement, review, and continually modify the strategies they use to improve client functional abilities..." Rather than focusing on outcomes, "active treatment is measured more in terms of how aggressively, competently and consistently the ICF/MR pursues objectives on behalf of clients."

- (c) Management of inappropriate client behavior

42 CFR "The facility must develop and implement written 483.450 policies and procedures (on managing) inappropriate (b) client behavior." The procedures must specify all approved interventions, establish a priority order for using them, ranging from least to most intrusive, and document that less intrusive techniques have been tried App. J before more restrictive interventions are used. The P. 90 interdisciplinary team is to consider trying to change

a resident's environment before taking more intrusive steps.

42 CFR Behavior management procedures must cover the use of time-
48 .45 out rooms, physical restraints, drugs, and "...the
(b application of painful or noxious stimuli." These
App. J stimuli are to be used "...as a last resort and only
P. 91 when...positive reinforcement methods have failed (and
where not using these stimuli would cause) irreparable
42 CFR harm..." Any use of behavior management techniques must
be incorporated into the IPP, and must include safeguards
48 .45 to protect client safety and rights. These techniques
(b must never be used for disciplinary purposes, staff
convenience, or as a substitute for active treatment.
"...Standing or as needed (PRN) programs to control
inappropriate behavior are not permitted..."

42 CFR A resident may be put in a time-out room only under a
48 .45 limited, directly supervised time-out program, and not in
(c an emergency situation. Physical restraints may be used
42 CFR only: as part of an IPP which is to lead to less
48 .45 restrictive means of behavior control; in an emergency,
(d but "...only if absolutely necessary..." to protect
) residents' safety; or as a health-related protection.

42 CFR Drug dosages may not be used which interfere with daily
48 .45 living activities. The use of drugs for behavior control
(e must be included in the part of the IPP aimed at reducing
) and eliminating the behaviors for which the drugs are
used.

42 CFR Drugs used for behavior control "must not be used until it
48 .45 can be justified that the harmful effects of the behavior
(e clearly outweigh the potentially harmful effects of the
drugs." These drugs must be monitored closely and
gradually withdrawn at least annually, unless clinical
evidence indicates otherwise.

42 CFR The facility must designate a special committee (or
483.440 committees) consisting of persons experienced or (f)
trained in managing challenging behaviors and persons with no
ownership or controlling interest in the facility to review,
approve and monitor individual behavior management programs and
other programs involving risks or potential abridgement of
residents' rights.

App. J (d) Resident Grouping

P. 116

42 CFR The grouping of facility residents should be "...in
483.470 keeping with their level of functioning..." Residents
(a) must not be segregated "solely on the basis of their

physical disabilities." Priority consideration in grouping should be given to social and intellectual development, friendships and interests.

(e) Access to professional program services - ,

42 CFR "Each client must receive the professional program
483.430 services needed to implement (his or her) active treat-
(b) ment program..."

(f) Requirements for staff

42 CFR "The facility must provide sufficient direct care staff
483.430 to manage and supervise clients in accordance with
(d) their individual program plans...(They) must be
provided by the facility in the following minimum
ratios of...staff to clients..."

- 1 (staff) : 3.2 (residents) -- for living units serving children under 12, residents with severe impairments, residents with very challenging behaviors
- 1 : 4 - - for units serving residents with moderate retardation
- 1 : 6 . 4 -- for units serving residents with mild retardation

42 CFR All staff who work with the residents must have the
48 .43 training they need to manage challenging behaviors and
(e implement IPPs.
)

App. J (g) Requirements for dining areas and service

P. 135 "To the maximum extent possible, individuals should... eat
42 CFR routine meals...in dining areas (like) those afforded to
48 .48 their peers without disabilities." Table service should
(d be provided for all residents able to eat at a table.
Residents are to be given "the social experience of dining
' with their dining companions." Tables, chairs, eating
Ap . J utensils and dishes should be designed for the
P. 135 developmental needs of each resident. Residents should
42 CFR receive direction in self-help eating procedures. "To the
48 .48 maximum extent possible, staff should model appropriate
(d mealtime behavior...by sitting at the table" and eating
' with residents when possible. "Mastery of the social
Ap . J skills involved in eating...is another step to...
P. 137 independence..."

(h) Services provided by outside sources

42 CFR 483.410 (d) App. J p. 25 "The facility must assure that outside services meet the needs of each client." Staff must "work closely with the outside program to ensure (that the program is) suited to each individual's needs..."

4. There are some individuals with disabilities:

(a) for whom active treatment is not required; and

(b) who are not appropriately placed in ICFs/MR.

42 CFR 483.440 Active treatment is not meant to apply to "generally independent clients who are able to function with (a) little supervision or in the absence of a continuous... program."

App. J P. 62-63 "Individuals displaying some or all of the (following) characteristics...do not need 'active treatment services ' and are not appropriately placed" in an ICF/MR...:

...independent without aggressive and consistent training;

...usually able to apply skills learned in training situations to other settings and environments;

...generally able to take care of most of their personal care needs, make known to others their basic needs and wants, and understand simple commands;

...capable of working at a competitive wage level without support and to some extent...able to engage appropriately in social interactions;

...able, usually, to conduct themselves appropriately when...away from the facility's premises; and

do not require the range of professional services or interventions (needed by persons with more severe impairments) in order to make progress."