POLICY ANALYSIS SERIES

ISSUES RELATED TO WELSCH v. NOOT / NO.

ADMISSIONS/READMISSIONS TO STATE HOSPITALS SEPTEMBER 1, 1980 to MAY 31, 1981: THE BEHAVIOR PROBLEM ISSUE

I. INTRODUCTION Under the provisions of the Welsch v. Noot Consent Decree, the State is required to reduce the number of mentally retarded persons residing in state hospitals to no more than 1,850 by mid-1987; 2,375 by July 1983.

There are approximately 2,500 individuals with mental retardation currently

residing in Minnesota's eight state hospitals.

While setting specific goals for deinstitutionalization may hasten the relocation of many individuals, it also highlights critical issues. Among these is the need to develop appropriate community residences, services and programs for persons with severe or profound retardation, individuals with behavior problems or residents in need of health and medical care. The further success of deinstitutionalization efforts will depend greatly upon the State's ability to develop and maintain alternative community living arrangements for persons most in need of prolonged and intensive residential programs.

"Deinstitutionalization does not simply involve the placement of mentally retarded persons into the community, it also involves the establishment of those programs intended to reduce the need for initial admission and readmission."

(Scheerenberger, 1981, p. 6)

The literature indicates that behavior problems are a major reason for admi sions/readmissions to public institutions. Similarly, an analysis of state hospital admission reports indicates that behavior-related problems are a primary reason for admissions in Minnesota. Therefore, if admissions to state hospitals are to be avoided, the behavior management skills of families and community service providers must be further developed.

The purpose of this paper is to:

--briefly review literature related to behavior problems and movement trends;

The state hospital at Anoka does not have a mental retardation program. During a special session of the 1981 Legislature, a bill was passed which calls for the closing of Rochester State Hospital by June 30, 1982. Administrators of that hospital anticipate that all residents will be transferred or relocated and the facility closed by January 1982. There are approximately 80 mentally retarded persons currently residing at the hospital.

- --present a summary analysis of admission/readmission reports from the eight state hospitals; and
- --identify implications for state policy and planning relating to the development of community residential services.

II. REVIEW OF THE LITERATURE

Several studies have identified maladaptive behaviors and health problems as the major reasons for readmissions and community placement failures (Mayeda & Sutter, 1981; Pagel & Whitling, 1978; Sutter, Mayeda, Call, Yanagi & Yee, 1980; Keys, Boroskin & Ross, 1973). Other research indicates that individuals' abilities in self-help and social skills are <u>not always</u> predictive of placement potential. Sutter et al (1980) found that the relative sophistication of the unsuccessful persons in self-help and social skills could not, in many cases, overcome the negative impacts of maladaptive behavior; and in fact, individuals who failed in community placements "were significantly more proficient than were successful clients in personal and community self-sufficiency and in social responsibility" (p. 264). In another study, Pagel and Whitling (1978) concluded that failures were not typically attributed to deficits in self-help skills.

The problem then is how to control and/or effectively manage behavior problems in community settings. Part of the answer may lie in the placement process itself. Mayeda and Sutter (1981) suggested that the compatibility between an individual's behavioral characteristics and the caregiver's expectations regarding the management of behavior problems may be of some consequence. The findings from their study suggested that "...even clients with a large number of behavior problems (five or more per client) could be successful in community care if placed with care providers who indicated a willingness to manage the behavior they exhibited" (p. 380). In an earlier study (Sutter et al, 1980), researchers concluded that caregiver-client pairs that were unsuccessful were notably more mismatched for maladaptive behavior than were the successful caregiver-client pairs.

Lakin, Bruininks and Sigford (1981) stated similar conclusions. They suggested that policy-makers consider developing a system whereby clients' characteristics are matched with caretakers' "tolerances" for those characteristics. Moreover, "...researchers need to address the effectiveness of training programs...in enhancing caretakers', and potential caretakers', tolerance of and effectiveness in dealing with specific client behaviors" (p. 400).

The current review of the literature indicates that level of retardation is not consistently indicative of failure or success. For instance, one study (Sutter et al, 1980) found that 63 percent of the successfully placed individuals were classified as severely or profoundly mentally retarded, while 71 percent of those who "failed" in community placements were borderline, mild or moderately mentally retarded. It is true nonetheless that persons with severe or profound mental retardation are less likely to be placed in community settings; that they are more likely to "fail" because of

health-related problems than for maladaptive behaviors (Eyman & Call, 1978; Pagel & Whitling, 1978; Landesman-Dwyer & Sulzbacher, 1981).

In 1979 Scheerenberger (1981) surveyed 278 public residential facilities in the United States. He estimated that 77.4 percent of the residents of those facilities were severely or profoundly retarded. Although the total population of institutionalized persons is gradually declining (on a national basis, the average daily population decreased approximately four percent annually during the years 1972 to 1979), barriers to community placement remain formidable. Scheerenberger described these barriers in terms of seven factors:

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--availability of alternative living facilities;
--quality of available community living facilities;
--availability of community support services;
--quality of community support services;
--funding;
--number of community program personnel;
--adequacy of training.
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While medical services, the availability of community support services and educational programs were generally rated as being adequate for mildly and moderately retarded students, the same services for severely and profoundly retarded persons were considered to be less than adequate (at the time of the national survey, Public Law 94-142 was relatively new). Scheerenberger noted that "adult programming and behavior management, regardless of retardation, were basic services uniformly judged inadequate throughout the country" (p. 8).

Scheerenberger's study indicated further that the training of professional personnel (in medicine, education and adult programming) was considered to be inadequate to meet the needs of more severely handicapped individuals; and behavior management personnel generally lacked "sufficient training to deal effectively with mentally retarded individuals regardless of their level of intelligence" (p. 10).

All of this suggests that, unless substantial changes are made in the focus and delivery of community services, public institutions will continue to be the primary treatment sites for persons with severe/profound mental retardation and individuals with behavioral or medical problems (Scheerenberger, 1981; Landesman-Dwyer & Sulzbacher, 1981); hence the rate of deinstitutionalization will decrease.

Successful deinstitutionalization implies more than placement in community settings. How individuals adapt to those environments is equally important—"adaptation" is not necessarily synonymous with "normal" behavior. Seltzer, Sherwood, Seltzer and Sherwood (1981) suggested that persons should be assessed on an individual basis. This concept has particular relevance for persons who are severely or profoundly retarded since they may not, in many respects, be able to measure up to "normal" standards. Instead, success should be measured in relative terms: how well or how much an individual improves and adapts to a particular environment.

This concept of community adaptation is important for two reasons: (1) it lifts much of the "blame" for community failure from the shoulders of the retarded person because he/she need no longer measure up to unrealistic standards of "normalization"; and (2) it may help encourage persons in the community to recognize relative improvement as genuine achievements rather than as failures to reach absolute levels of performance.

"As the population being released from institutions increasingly consists of the "hard to place" (including retarded persons who are medically fragile, multiply handicapped or elderly, those with severe behavior problems, and the more severely and profoundly retarded), an analysis of the effects of deinstitutionalization on these types of individuals becomes more and more important. Because the needs presented by these types of persons are very complex, it cannot be casually assumed that deinstitutionalization will produce the uniformly positive effects hoped for..."

(Seltzer et al, 1981, p. 86)

A study of deinstitutionalization must necessarily include a review of state hospital admissions and readmissions. It seems logical that before problems can be ameliorated and institutional admissions avoided, program planners and policy-makers must first know what kinds of behavioral problems exist, and then, why persons are being referred to state hospitals. The following analysis is an initial step toward identifying these two important policy variables.

III. METHODOLOGY

This analysis of admissions/readmissions is based upon a review of state hospital reports on file in the Department of Public Welfare, Mental Retardation Program Division. Inasmuch as admission reports from the individual hospitals vary greatly in content, quality and format, this is a summary analysis of admissions and readmissions and the circumstances leading to placement in a state hospital.

This analysis covers the nine-month period from September 1, 1980 to May 31, 1981. The Welsch Decree--which restricts admissions to state institutions--went into effect September 15, 1980.

Much of the summary data contained herein does not include admissions to Cambridge State Hospital. Admission files from that hospital report only aggregate data; information on individuals and the circumstances surrounding admissions was not available. Cambridge, which entered into a separate consent decree in December of 1977, became subject to the provisions of the Welsch Decree on July 1, 1981.

For the purposes of this analysis, an admission was classified as "behavior related" if maladaptive behavior or behavior problems were cited within the report. Although admission reports varied greatly in content and quality, at least an indirect relationship between behavior and state hospital placement could be inferred when behavior was mentioned.

An example of a behavior-related admission might be an individual in need of health or medical care services; community facilities were unable to provide the necessary services because they could not, at the same time, deal with the person's behavior problems. In many cases behavior-related admissions were more obvious, e.g., individuals admitted to a hospital for evaluation or programming following incidents of aggression or property destruction.

IV. RESULTS

During the nine-month period from September 1, 1980 to May 31, 1981, there were approximately 120 admissions/readmissions to Minnesota's eight state hospitals. The admissions ranged from a low of two at Rochester State Hospital to a high of 34 at Cambridge. Admission reports indicated that, where specified (N=78), 41 percent were "new" admissions (i.e., the report classified an admission as being "new"; in almost all cases it was not possible to determine if an individual had been institutionalized in the past at another hospital), while 59 percent were "readmissions" (i.e., the report indicated that the individual had resided at the hospital at least once before--includes prior short-term, respite care admissions). In 42 instances the reports did not specify whether the individual had been released from the hospital before or if it was a first-time admission.

Table 1

Admissions to Minnesota's Eight State Hospitals
September 1, 1980 to May 31, 1981
(total admissions = 120)

Admission Status	N	%
New Admission Readmission Unspecified	32 46 <u>42</u>	41.0 59.0
Tota1	120	

Personal Characteristics

Most reports did not identify the MR characteristics of the individuals being admitted. No psychometric data were indicated in the 34 admission reports from Cambridge; and of the remaining 86 reports from the other seven hospitals, only 17 indicated an individual's level of mental retardation. State hospital social work representatives (MR Admissions Evaluation, 1981) estimated that 63 percent of all persons admitted during calendar year 1980 were severely/profoundly mentally retarded; 23 percent moderately retarded; and 14 percent mild/borderline. They also estimated that nearly 80 percent of respite care admissions were readmissions; one-third of all other admissions were readmission; and one-third of all court commitments were readmissions.

Table 2

MR Characteristics of Persons Admitted to Minnesota State Hospitals
September 1, 1980 to May 31, 1981
(total N=86; respondents=17)

Degree of Mental Retardation	N	%	
Profound (19 and below) Severe (20-35) Moderate (36-51) Mild (52-68) Borderline (69-84)	1 5 4 6 <u>1</u>	5.9 29.4 23.5 35.3 5.9	
Total	17	100.0	

Reports from Cambridge did not identify any individual characteristics of persons admitted to that hospital during this nine-month period. Admission reports from the other hospitals (total N=86) indicated the following resident characteristics:

Age: N=60 Sex: N=86

Range=2 to 59 years Female=25 (29.1%) Mean=26.1 years Male=61 (70.9%)

Twenty-three (23) out of 86 reports indicated that an individual had an additional disability; several were multiply handicapped (mean=1.3 disabilities --in addition to MR).

Place of Prior Residence

While some reports indicated the type of most recent residential placement (i.e., the community placement from which the individual was admitted), many did not specify how long the person had been living in that residence. Where it was specified (N=30), the range was from three months to 16 years; the mean was 3.8 years.

Table 3 shows admissions to each state hospital during the nine-month period ending May 31, 1981. The table indicates admissions by type and the setting from which individuals were admitted. Respite care—an informal admission—constituted 42.5 percent of all admissions. Thirty-nine percent (39.2%) of all admissions (N=120) came from an ICF/MR.

Disregarding the ten admissions to Cambridge (for which no detailed information is available), 21 (81%) of the 26 admissions from natural or adoptive homes were classified as respite care/parental relief admissions.

Examples of "other public institutions" in Table 3 would include the Braille and Sight Saving School at Faribault or another state hospital (most likely a transfer).

Table 3

Admissions to State Hospitals by Facility, Type and Prior Residence September 1, 1980 to May 31, 1981 (total admissions = 120)

	BRAINERD	CAMBRIDGE	FARIBAULT	FERGUS FALLS	MOOSE LAKE	ROCHESTER	ST. PETER	WILLMAR		TOTAL
Type of Admission									N	0/ /2
Informal Court Committed Transfer In Respite 2 Return from P.D. Emergency Hold	2 5 0 9 1 6	5 5 1 19 4 0	11 1 5 2	6 0 1 8 0	3 0 0 0 1	0 0 1 0	3 0 0 3 0 2	3 0 1 6 0 2	34 11 4 51 8 12	28.3 9.2 3.3 42.5 6.7 10.0
Total	23	34	21	15	5	2	8	12	120	100.0
Type of Admission									N	o/ 次
New Admission Readmission Unspecified	4 8 <u>11</u>	16 18 <u>0</u>	4 14 <u>3</u>	7 3 <u>5</u>	0 1 <u>4</u>	0 0 2	0 1 7	1 1 <u>10</u>	32 46 <u>42</u>	26.7 38.3 35.0
Total	23	34	21	15	5	2	3	12	120	100.0
Admitted From									N	0/ //
Parents/Relatives Foster Home Board/Group Home Nursing Home Other Pub. Inst. Community Hosp. Out-of-State Fac. Unspecified Total	8 1 10 0 0 0 1 3 23	10 6 9 0 5 3 1 0 34	3 2 10 0 3 2 1 0 21	8 0 5 0 2 0 0 0 0	0 1 3 1 0 0 0 0	0 0 2 0 0 0 0 0	1 4 0 1 0 1 0 1 8	6 0 4 1 0 0 0 0	36 11 47 2 12 5 3 4 120	30.0 9.2 39.2 1.6 10.0 4.2 2.5 3.3 100.0

²Provisional Discharge

Behavior Problems

Table 4 is an analysis of admissions and behavior problems. The table does not include admissions to Cambridge State Hospital. The remaining admission reports (N = 86) specify behavior or behavior-related problems in almost two-thirds of the cases (64.0%); 33.7 percent made no mention of behavior-related problems; and in two instances, no reason for admission was stated.

Table 4

State Hospital Admissions: Behavior Problems
September 1, 1980 to May 31, 1981
(total N = 86)

All Admissions	N	%	
Behavior-related Not Behavior-related	55 29	64.0 33.7	
No Reason Specified	2	2.3	
Total	86	100.0	

Table 5 is an analysis of "readmissions"--but does not include the 18 individuals readmitted to the hospital at Cambridge. Nineteen (19) out of 28 reports classified as readmissions cited behavior problems (67.9%); four of those 19 were respite care admissions. Nine "readmissions" were not specifically attributed to behavior problems; seven of those nine were classified as respite care admissions.

Table 5

State Hospital Readmissions: Behavior Problems
September 1, 1980 to May 31, 1981
(total N = 28)

Readmissions	N	%	Classified as Respite Care	N	%
Behavior-related Not Behavior-related	19 9	67.9 32.1		4 7	21.1 77.8
Total	28	100.0		11	39.3

Admissions from ICF/MRs

The following summary analysis of ICF/MR admissions does not include Cambridge State Hospital. Reports from that hospital give only total admission figures and do not specify licensed capacity or months of residence in a group home. Of the 34 persons admitted to Cambridge during this nine-month period, nine (26.5%) came from an ICF/MR.

ICF/MR Characteristics

Admission/readmission reports from the other seven hospitals (N = 86) indicate that an ICF/MR was the most recent place of residence for 38 individuals (44.2%). In seven (7) instances, no descriptive characteristics of the ICF/MR were identified.

Table 6

Admissions from ICF/MRs: Size Characteristics September 1, 1980 to May 31, 1981 (total N = 38; respondents = 31)

Licensed Capacity	Mean	SD	N	%	
1 - 6 Residents	6.0	0.0	3	9.7	
7 - 16 Residents	12.7	2.7	17	54.8	
17 - 32 Residents	30.0	0.0	2	6.5	
33+ Residents	69.5	41.9	9	29.0	
Total	29.7	34.4	31	100.0	

The licensed capacity (size) of the 31 ICF/MRs ranged from six to 171; the mean was 29.7. Sixty-six percent (20 individuals) lived in facilities with licensed capacities of 15 or less; nearly one-third (9 persons) had resided in a group home licensed to serve 15 persons.

Only 19 of the 38 admission reports indicated how long an individual had been living in a group home prior to admission. Where specified (N = 19), the length of residency in an ICF/MR ranged from three months to eight years; the mean was 25.0 months. Sixty-three percent (12 persons) had resided in those placements for 14 or fewer months.

Behavior Problems

Of the 38 admission reports on individuals coming from an ICF/MR placement, 30 (78.9%) specifically mentioned behavior problems. Thirteen (13) reports identified an individual as having been a resident of a hospital at least once before; 92.3 percent of these readmissions were behavior-related--only one of the 13 readmissions was for respite care purposes.

Twenty-two (22) reports did not specify if an individual had been released from the hospital before or if it was a first-time admission. Sixteen of the 22 (72.7%) were behavior-related; six reports made no mention of behavior problems. Three of the 16 behavior-related admissions (18.8%) in the unspecified category were classified as respite care.

Table 7

State Hospital Admissions from ICF/MRs
September 1, 1980 to May 31, 1981
(total N = 38)

Admissions	N	%	Classified as Respite Care	N	%	
New Admissions			,			
Behavior-related	2	66.7		. 0	0.0	
Not behavior-related	1	33.3		Ö	0.0	
Readmissions						
Behavior-related	12	92.3		1	8.0	
Not Behavior-related	- 1	7.7		0	0.0	
Unspecified			•			
Behavior-related	16	72.7		3	18.8	
Not Behavior-related	6	27.3		1	16.7	
All ICF/MR Admissions						
Behavior-related	30	78.9		4	13.3	
Not Behavior-related	8	21.1		i	12.5	
Total	38	100.0			72.2	
10001	. 30	100.0		5	13.2	

Reasons for Admissions

The following is a synopsis of the statements most often cited as reasons for seeking an admission to a state hospital. The narrative is neither definitive nor exhaustive, rather it attempts to convey a sense of the circumstances and pressures which compel a family, a group home or a community facility to place an individual in a state hospital.

In many cases there appears to be no single reason for admission, but a combination of factors. Though there is much overlap and ambiguity in admission reports, one thing seems apparent: to many families or community facilities, the state hospital is (or is perceived to be) the only available resource.

Respite Care Admissions

Admissions classified as respite care/parental relief accounted for the largest number of admissions during the nine-month period from September 1, 1980 to May 31, 1981. The reasons for those temporary placements were numerous and varied. Quite often, respite care admissions were more than simple, short-term relief from care responsibilities—they were coupled with requests for evaluation, intensive training or medical and health care services.

In many instances, reports indicated that <u>appropriate respite care services</u> could not be located in or near the community; behavior problems made continued

residence in the home difficult and very often precluded the use of community services—if those services existed. The inference is that "appropriate" meant either a sitter capable or willing to care for a retarded child, or a respite care program with staff proficient in behavior management skills.

In three instances an admission report stated that <u>medical care</u> was the primary reason for seeking state hospital/respite care placement. Either the group home or family could not provide the necessary medical care—and alternative community services were not available—or behavior problems complicated attempts to provide those services.

In nine cases a family or group home sought respite care because they could not control an individual. Seven of the nine admissions seeking <u>evaluation</u> were associated with behavior problems. In two instances an individual had struck out at or otherwise threatened the staff or other residents. Other reports indicated a need for respite care with intensive training in personal care skills. Two reports indicated that respite care admissions were sought because there were no vacancies in other community facilities, e.g., group homes.

Family emergencies were the most frequently cited reason for requesting a respite care admission—all of these admissions (N = 11) were from family settings; only one specifically mentioned behavior problems. Reasons included: family trips or activities, recent or prolonged hospitalization of a parent, illnesses in the family, unavailability of community respite care services.

Other Informal Admissions

Nearly all reports which identified an admission as informal (N = 29; does not include informal respite care admissions) indicated that an individual had exhibited behavior problems. Generally, the behavior problems were of a more severe nature. Examples include: self-abusive/injurious behaviors, tantrums, incidents of aggression/assault against staff or other residents, property destruction. In some cases behavior problems were exacerbated by an individual's lack of self-care skills or by multiple handicaps.

The reason most frequently cited in an informal admission report was the family or group home staff's <u>inability to control an individual</u>. Either the individual's behavior was disruptive to the environment or the behavior presented a risk to other residents, the individual him/herself, the staff, or property-e.g., knife-throwing, physical aggression, suicide attempt, or destruction of furniture.

Seventeen out of 29 (59%) informal admission reports specifically mentioned a lack of appropriate alternative community placements. (Again, the implication is that "appropriate" means capable of managing behavior-related problems.) Among the reasons for referring an individual to a state nospital were: the inability of family or staff to place an individual elsewhere in the community; the need for services or programming not available in the community (e.g., SNF care); the need for care and supervision while community placements were located.

Medical or specialized supervision was a major reason for several informal admissions. Reports indicated that local facilities were either unwilling or unable to provide services to persons with medical and health care needs. In most cases continuing care in a particular setting was deemed inappropriate because an individual exhibited behavior problems. For example, a hospital or nursing home might be unwilling to provide post-surgical medical care on a long-term basis because they could not, at the same time, provide the necessary supervision. In other instances, individuals (because of recent surgery, suicide attempt, or deteriorating physical conditions) were referred to a state hospital for an evaluation of care needs. Generally, admissions in this category came from a nursing home, a community hospital or a group home.

Committed

All six of the admissions identified as "committed" indicated that the individual had come from a group home. In four cases, the admission report stated that the group home had closed--only one of those four reports mentioned any behavior problems. In the remaining two cases, both reports indicated behavior problems as well as the unavailability of alternative community placements or services.

In these three instances, behavior problems were characterized as being severe. Additionally, the individuals required considerable attention with regard to personal care.

Returns from Provisional Discharge

Four persons were readmitted following a return from provisional discharge. Three were admitted from group homes; the other placement was unspecified. Three of the four were identified as having severe behavior problems: disorderly conduct, assault, aggressive behavior, criminal damage to property, temper tantrums, threats of suicide. One report indicated only that placement in an out-of-state group home had not worked out. One report stated that there had been a lack of day programming.

Hold Orders

Twelve individuals were admitted on hold orders. Nine reports indicated that the individuals had been admitted from an ICF/MR--two reports did not specify the most recent placement; one was admitted from the family home.

Eleven of the twelve reports indicated that behavior problems were severe; that other residents, staff or property were threatened by an individual's behaviors: physical threats, acts of aggression/assaultive behaviors, firesetting, physical abuse, property destruction.

Among the reasons stated for seeking admission to a state hospital were the staff's inability to control an individual's behaviors, the need to avert more serious episodes of physical aggression or property destruction, lack of existing community facilities which were capable of providing the necessary services and supervision.

Transfers

Admissions classified as "transfers" indicated that the individuals were being moved in order that they might be closer to their family or, in the case of a transfer from Anoka State Hospital, to obtain more appropriate programming.

V. DISCUSSION

Although this analysis of admission reports is not totally conclusive, it does give some indication of the nature of admissions; it also raises some important issues.

It is apparent that many families and community care providers rely upon state hospitals for respite care services. Approximately 80 percent of the admissions from family homes were for parental relief. The admission reports suggest that had those services been available in the community, many of these short-term informal admissions might have been avoided. Social work representatives from the mental retardation programs of the state hospitals (MR Admissions Evaluation Report, 1981) estimate that one-half of all admissions during 1980 were for respite care purposes.

Nearly 60 percent of the informal admissions (other than respite care) specifically mentioned a lack of appropriate community services. Additionally, several reports indicated that community support services (e.g., nursing homes, community hospitals) could not manage or would not accept persons with behavior problems. This is similar to Scheerenberger's findings (1981) which indicate that behavior management skills are generally lacking in community settings.

A significant proportion of the admissions (39%) came from group homes. The literature suggests that smaller facility size is more indicative of personalized attention, and yet data from the admission reports suggest that perhaps as many as two-thirds of these admissions came from relatively small ICFs, i.e., 15 or fewer residents.

It is likely that some characteristics of the service delivery system contribute to the failure of some of the community placements. For instance, a national survey of community residential facilities in 1977 identified personnel issues--recruitment, retraining and development of staff--as major management problems (Bruininks, Kudla, Wieck & Hauber, 1980). Discontinuity in staffing patterns and inadequately trained personnel will have some impact upon the success or failure of many community placements.

The distinction between providing services and meeting individuals' needs must be recognized. As Lakin, Bruininks and Sigford (1981) suggest, "care" and "services" are not necessarily synonymous terms:

"It is essential to assess what services are needed by clients, regardless of whether or not they are available in the area in order to measure "need." (Assumptions about who can benefit from what kinds of services must be made explicit.) (p. 407)."

The Welsch Decree formally acknowledges this concept. By the terms of the agreement, the annual, required assessment of hospital residents is to be made "in terms of actual needs of the resident rather than in terms of services presently available." Furthermore, individual counties and the Commissioner of Public Welfare are to use these "assessments in planning for and implementing the reduction in institution population...and in developing plans for new residential and non-residential county based services" (Welsch v. Noot Consent Decree, 1980, p. 6, paragraph 21).

VI. IMPLICATIONS FOR PLANNING

Planning for community programs and services must consider, among other things, the relative needs of two particular populations residing within public institutions: (1) mildly and moderately mentally retarded persons who have behavior problems; and (2) persons who are severely or profoundly retarded.

Eyman and Call (1978), among others, have shown that a significantly larger number of mildly and moderately retarded persons in institutions have severe behavior problems than do mildly and moderately retarded individuals living in the communities. Because they function at relatively higher levels than do other persons in institutions, they are considered more likely candidates for community placement. Their successful placement, however, will depend upon the behavior management capabilities of individual service providers in the community.

Severely and profoundly retarded persons have traditionally been difficult to place into community residences. Although persons who are severely or profoundly mentally retarded may represent a relatively small proportion of the total MR population, they constitute a significant proportion of those in need of lifelong services; and an increasing percentage of individuals in public residential facilities (Landesman-Dwyer & Sulzbacher, 1981; Scheerenberger, 1981). And yet if deinstitutionalization is to be considered successful communities must develop services and residences geared toward serving these individuals. While the challenges presented by these two groups of persons may be formidable, they are not insurmountable.

Minnesota is heavily reliant upon ICF-certified programs but other models do exist. These alternatives merit consideration for two reasons: (1) in addition to being sound programmatically, they may be cost effective relative to institutional care; and (2) they may inject more variability into a system which is being asked to accommodate a very heterogeneous population of individuals. Some possible alternatives for addressing the needs of behavior problem clients might include:

-Building capacity within existing programs (Bruininks, et al, 1980; Scheerenberger, 1981).

An example might be an increase in the use of specially trained foster care homes. To date, Minnesota has not made extensive use of foster care models. Another example might be use of existing group homes with specially trained staff persons.

- -Developing specialized services and using existing resources to better advantage, e.g., community mental health centers and state hospitals. A report by the Chesterfield (VA) Mental Health and Mental Retardation Services (1979) cites several behavior modification programs which work concurrently with clients and family. One approach is to link respite care at state hospitals (which includes evaluation and behavior modification programming) with parental visits and training in behavioral techniques.
- -The same report, and many others (e.g., Wray, Browne & Koster, 1978), suggests the efficacy of <u>crisis/home intervention teams</u>. Again, the emphasis is upon parent training in conjunction with behavioral modification programming. Problem resolution in the home is an essential component of these models.
- -Several authors suggest greater attention be given to <u>placement strategies</u>. Potential for success is much greater where facility staff are more willing and able to deal with disruptive behavior problems (Mayeda & Sutter, 1981; Sutter et al, 1980). Pre-service and in-service training for residential staff persons is a primary consideration.
- -Adoption of a <u>zero rejection model</u> will facilitate community placement and the development of alternative services. Implicit in this model is the concept that no one will be rejected simply because they manifest difficult placement problems. Instead, counties, communities and caregivers adopt a positive attitude about providing necessary services. Institutionalization is considered only after all other alternatives have been rigorously explored and thoroughly exhausted. The major advantage of this model is that counties and communities "learn" not to rely upon state institutions, but rather upon their own initiatives and resources.

Finally, the following excerpts are from a paper on behavior problems and institutionalization. They summarize a variety of programmatic and philosophical approaches to behavior management and the reduction of institutional admissions:

"PHILOSOPHICAL ORIENTATION. To assure the availability of a comprehensive array of community based residential and habilitative services for persons in need of supportive residential living, good leadership and a dogged commitment to successfully creating such a system is required. Staff have to be resolved to keep the "IN" door to the institution barred but to not deny services for persons in need. This means that

3The excerpts are from an unpublished paper written by Jerry Leismer entitled Prevention of Institutional Admissions and Returns: Especially Those Due to Client Behavioral Difficulties (July 29, 1981). Mr. Leismer is the courtappointed master in the Michigan "Plymouth Case."

By order of the U.S. District Court, the Michigan Department of Mental Health, and others, are to develop and implement "a comprehensive system of appropriate, less restrictive habilitative training, and support services" for all residents of the Plymouth Center for Human Development by January 1, 1984.

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staff are going to have to be tenaciously solution-oriented rather than problem-oriented. Instead of regretfully accepting someone in the front door to the institution "because of a problem," staff must aggressively pursue alternative means for addressing the client's, family's, or provider's particular needs which resulted in a knock on the door. This also means that state or county agencies will have to increase their awareness of and sensitivity toward responding realistically to the major needs perceived by community providers...

AN ONGOING RATE OF DEVELOPING COMPONENTS FOR THE COMPREHENSIVE ARRAY OF COMMUNITY SERVICES must be established to accommodate both current needs (deinstitutionalization) and future needs (requests for new admissions or returns). This entails generating an adequate continuum of supervised to relatively independent residential alternatives to be able to address the varied needs of persons seeking assistance. To do so would contraindicate complete reliance on only foster care or group homes or apartment programs. A combination of options will help prevent the incidence of persons who "wouldn't fit" into a more limited number of established molds.

There is significant value in knowing the needs of the persons awaiting the opportunity for community living and then proactively developing/recruiting/training providers specifically expected (and expecting) to work with these persons...Proactive development of particular types of residences based on the particular needs of the clients is the only way to assure community living opportunities for all persons in wheelchairs or with adaptive needs. Various types of supports for natural families should not be overlooked as one of the tools for precluding the need for an alternative residence. It should be noted that the larger the number of community living alternatives that evolve, the greater the capacity of that system to absorb new persons with residential needs into existing vacancies and to accommodate more intense (i.e., behavioral) needs...

ADEQUATE FUNDING is required to assure adequate opportunities and support for persons who are community-placed. So often there is a very large gap between what persons consider a reasonable amount to spend for institutional care and what they consider acceptable for community based homes...To the extent that community living can be developed to provide a more normalized, personal, and appropriate quality of life, greater parity in funding between the institution and the community is warranted...

There needs to be a sensitivity toward providing varied costs based on the degree of needs of respective clients. There is no better way to assure that more challenging clients will not have the opportunity to successfully leave an institution than by providing a flat rate or a rate with limited flexibility to buy services for a very heterogeneous group of individual clients...

<u>SIZE OF THE RESIDENTIAL SETTING</u> may be a factor influencing interpersonal relations, the hominess of the setting, and how acceptable the neighbors find the home...

...there is greater potential for clients to identify (and emulate) significant role models in the smaller adequately staffed homes than in larger residential settings. Staff activities tend to be more client-oriented and the potential for consistency in implementing techniques for behavioral programs (teaching new behaviors or ameliorating other behaviors) is increased with smaller numbers of staff and residents interacting. Also, the smaller the number of clients in a setting with adequate staffing, the smaller the apparent diffusion of responsibility for dealing with individual client needs...

ADEQUATE STAFFING AND STAFF TRAINING are essential to allow especially those clients with larger repertoires of challenging behaviors to successfully live in normalized home environments.

...to preclude some persons from being forced to leave the home established, it will be necessary for all staff to go through pre-service training and for some to receive specialized training in behavior modification and behavior management...Training should be geared toward client-specific needs and challenges...

... Tied to the provision of adequate staffing is the provision of adequate pay and benefits for staff in the community settings... Again, the issue of parity needs to be considered here to assure the ability to attract and retain an adequate number and quality of trained staff to run good programs.

ADEQUATE SUPPORT SERVICES are essential for a viable community service system. Predominant among such supports is a good case management, follow-along system...

[Other support services might include]...a crisis center hotline with on-call staff available to "trouble-shoot" problems which arise when the provider can't reach the case manager...[or] Peer groups for providers can be established either with foster care families or with group homes and apartment program administrators...

An additional type of support...is the "trainer-in-the-home" program. This program can provide...for a staff member to go into a natural family's home if a behavioral crisis arises with which they need assistance. The "trainer" would work both with the client and the family...

AMPLE AGE-APPROPRIATE/NEED-APPROPRIATE DAY PROGRAMS (geared toward the individual needs of clients) can enhance social, emotional, and adaptive development. Whether good school programs, good activity programs, good pre-vocational (or vocational) programs, or competitive employment, a meaningful day program is important to foster

growth, to enhance clients' self-image, and to provide appropriate means for spending time...

MEANINGFUL INVOLVEMENT WITH COMMUNITY ACTIVITIES is important. Much of the inappropriate behavior which occurs happens because of a lack of appropriate ways for clients to spend time or to address quite normal needs. If there isn't something appropriate, interesting, or meaningful to be involved with or to expend...energy on or to satisfy... curiosity, some persons may seek another way to stimulate or to entertain themselves or to expend their energy...

<u>APPROPRIATE HOME PROVIDERS...</u> The quality of the providers will determine the capacity of the community to appropriately address the needs of all of its residents...

Providers need to be clearly geared toward client-specific needs. Staff assisting clients who are blind, deaf, non-ambulatory, not toilet trained, self-abusive, aggressive, etc., will need special training and additional support...If caretaker preference is related to client success, then caretakers need to be developed who are desirous of and capable of addressing more intense client characteristics.

...For the community system to work, community providers must also have a commitment that they are "going to make it work for all clients!"

EFFECTIVE INDIVIDUAL PROGRAM PLANS...To the extent that any setting aspires to be growth-enhancing rather than merely custodial or incidentally developmental, it is helpful to have (and to assure some program accountability through) individualized methodologies with which to deal with prioritized client-specific needs. The more limited in adaptive abilities or more difficult the behaviors presented by a particular client, the more essential an Individual Program Plan is as a supportive guide for staff (and support service staff) in assuring that such clients can be absorbed into community systems...

Linked to the quality of the Individual Program Plans is the availability of the interdisciplinary team and/or consultant support staff to respond to a crisis or to a difficult situation which may arise in a community home.

RESPITE. One of the most critical factors which can impact on requests for new institutional admissions or returns is the ready availability of respite services. It has been stated that "temporary help at the right time" can prevent a situation from deteriorating to such a point that long-term care is sought out by natural families. Similarly, some form of relief or respite is extremely valuable in preventing some foster providers...or group home providers from "burning out"...

It has been estimated that six respite slots may prevent from 6-20 admissions or returns a year. Given these potential advantages, efforts should be vigorously pursued to eliminate the financial and other disincentives that prevent ample development of respite care options.

> INSTITUTIONAL PROGRAMS TO AID CLIENT TRANSITION INTO COMMUNITY PROGRAMS There are a large number of activities which an institution can engage in to foster the eventual assimilation of clients into community programs and to reduce any potential for transfer anxiety. Such activities include, but are not limited to: (1) the holding of small group meetings of residents on campus where the same six-to-eight persons meet regularly to discuss common interests...(2) a Life Book can be put together which consists of a client's scrap book with photos and/ or pictures of the client and his/her family, friends, and roommates at various points in his/her life and at various places where he or she has lived...which provides a sense of being part of a continuum... (3) toileting programs are always good for clients to be involved with because staff are always more willing to assume responsibility for a client with toileting skills than one without. (4) Increasing exposure to the community with field trips and other community outings makes the community appear more appealing and less foreign...(5) A realistic and responsible placement review process is necessary to assure the appropriate match of clients to providers, clients to homes (or sites), and clients to clients...(6) pre-placement visits to proposed home placements and weekend visits can help reduce the stress of transition...(7) involving ward roommates and institutional staff in the actual moving of a client to a new home also aids in reducing trasitional stress...and, (8) [sending] institutional staff who [are] close to clients...into the homes for a week or two to work with the client and with the home's staff to help orient each to the other...

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