

83-IHM-LDW

INSTITUTIONALIZATION: HOW MANY AND WHY?

by

Lyle D. Wray, Ph.D

Court Monitor for the Welsch Consent Decree

Paper Presented to the Association of Residences
for the Retarded in Minnesota Conference -
Legal Issues: Serving the More Difficult Resident.

Roseville, Minnesota, March 24, 1983.

Revised Version

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Readmissions to the nation's state hospitals exceeded the number of admissions for the first time in 1979. As evidenced by substantial literature on predictors of community success of mentally retarded persons coming out of state hospitals, there is concern that a revolving door has developed for persons leaving state hospitals. Looking at the Minnesota context, what is the status of admissions to our seven state hospitals from community-based Intermediate Care Facilities? Is there a pattern to these admissions? Are readmissions "predictable" from discharge plans that were prepared for individuals? What steps might be taken to reduce or eliminate such admissions?

STATE HOSPITAL ADMISSIONS FROM COMMUNITY FACILITIES

From September, 1980 through March, 1983 a total of 97 people were admitted from community Intermediate Care Facilities to mental retardation programs at Minnesota's state hospitals. A total of sixty-nine community facilities demitted one or more persons who were subsequently admitted to a state hospital during this time period. Table 1 lists the community facilities and the number of demissions from each. Fifty-one (51) of the 69

facilities demitted one person during the 30-month period which resulted in a state hospital placement, 16 facilities demitted two to four persons, and 2 facilities demitted 5 or more persons to state institutions.

What reasons were given for demitting people from community facilities to state hospitals? The stated reasons for demission from community placements are shown in Table 2 for each of the state hospitals. Seventy-three (75%) of the 97 state hospital admission reports cited assaultive or aggressive behavior or the threat of these behaviors as the reason for demission from community programs. Other stated reasons varied from admission to state hospital for toilet training to being closer to the family.

Is the size of the facility related to the number of demissions to state hospitals? Table 3 shows the number of demissions by size category for all Intermediate Care Facilities. Table 4 shows demissions only for Intermediate Care Facilities for Mentally Retarded persons. Based upon a standardized measure - demissions per 100 beds - the lowest number was found in facilities with 17-32 residents and the highest number in facilities with 7-12 residents. The average number of demissions was 1.76 persons per 100 beds.

Were the behaviors cited as reasons for demissions predictable from the discharge plans prepared at the state hospital? Table 5 presents a summary of the discharges for the 97 individuals demitted from community facilities. Twenty-four of the 41 state hospital discharge reports filed from September,

1980 through March, 1983 stated the reasons for seeking institutional placement and to some degree outlined strategies for addressing those needs. An additional seven discharge reports indicated the reasons for state hospital placements but did not outline strategies for addressing these needs. Seventy-six percent of the 41 discharge plans mentioned either the behavior cited as a reason for later demission or a strategy for addressing this behavior. Despite the fact that the behaviors cited as reasons for readmissions were often stated in the discharge report as needs to be addressed and that strategies for dealing with these needs were suggested, nearly half of this number of persons subsequently entered state hospitals.

How many of the people demitted from community facilities remain in state hospitals? Sixty of the 97 people (62%) admitted from community ICF/MRs under the Welsch Decree have not been discharged since their admission. The revolving door is moving but it is moving relatively slowly for these 97 people.

CONSIDERATIONS FOR SYSTEMATICALLY ADDRESSING READMISSIONS

Working to develop a system that has the capacity to provide for all needs in the community, with the possible exceptions of a very limited number of persons involved with criminal conduct or in need of acute medical care, is a realistic goal for Minnesota in serving persons with mental retardation or other developmental disabilities. Such a system would address the needs of individuals, families and communities currently identified and provide a basis for meeting emerging needs. To arrive at this goal will require careful attention to a number of issues:

regional, economic, and service system differences; current capacities of residential and day program service providers; local social service agency capacity; funding streams and flexibility and the relationships among the many line agencies which have major impacts on the lives of persons with developmental disabilities. One of the major reasons that I believe that this has not been achieved is that our state has not set this as a goal with the consequence that no major concerted efforts are being directed to the required tasks.

In looking globally at the array of services in Minnesota, generalizations are difficult to make about the current status and future directions of the nearly 500 residential and day program facilities in the state. There are, however, a number of points that can be made. First, creating a zero-reject community service system (not necessarily implying that any given facility may not admit a person under certain limited circumstances) would address both readmissions and admissions to state hospitals. It should be recognized that some facilities may not be capable of adapting to meet the special needs of certain individuals because of physical plant barriers, staff training and management limitations, funding constraints, geographic proximity to support services, case management or service management limitations in their county, and so on. In short, we need to think in terms of a "redevelopment" initiative to reshape residential, vocational, and support services to help to move persons with developmental disabilities to ever more appropriate community living, working, and learning arrangements.

Second, there is a facility based "brick and mortar" bias in

the existing system which seems almost to preclude us from exploring more creative options in defining places to live, work and learn, or in supporting individuals in their home community. While we may have individual service plans, it is too often established before a team meeting begins that a person "needs" an intermediate care facility and a developmental achievement center program. But how many people truly need to live in a 16 bed or larger facility with a corresponding 60 person DAC? Is it not possible to serve all but a few people in 1, 2 or 3 person living arrangements in existing housing with trained staff, effective service management and coordination; with persons sharing jobs, partially participating in jobs, or experiencing job exposure or community living training without state supported "bricks and mortar" for these residential and day programs? It is likely that all but a few people can in principle be supported appropriately in such small settings, including those people with behavior shaping needs and medical-nursing needs. What then is the long term future of very large residential facilities in the community that are as big or larger in a number of cases than 3 of the 7 state hospital programs for mentally retarded persons?

Third, a new emphasis in service development is on the horizon which appears to hold great potential for serving a variety of special needs groups: namely, an expanded use of a Request for Proposal (RFP) model by counties for individuals to receive 1, 2, or 3 person living arrangements and a "day program" consisting of job sharing, partial participation in jobs, or community living experience. Such an approach relies on

components which are in place in a number of parts of the country but which have yet to be fully integrated into a service package that is developed and funded for individuals. Such an approach goes in a different direction than the current "need determination" process which is oriented largely toward a facility-centered response rather than flexible response based upon individual need, community strengths and needs, and upon a strategy tailored to fill the gap between a given individual and the demands of community living. Such a gap-filling strategy would rely upon off-budget and family and community resources to the maximum degree appropriate.

Fourth, there are good models of community-based behavior shaping and medical-nursing services in both urban and rural settings which are both cost effective and can be quick to start up. These approaches tend to fit well with the geography and human services administration system of Minnesota.

Fifth, the need for emergency out-of-home placement or emergency in-home supports is sufficiently predictable that "emergency reserve families" and "crisis spaces" in group homes should be established to provide the necessary expertise and additional manpower on a prompt, flexible, basis to address short- to intermediate-term supervision and control of individuals in exceptional circumstances. Intervention teams to provide in-home crisis assistance can realize the commitment made to averting removal from a community living arrangement by helping community members to meet exceptional needs. Relying upon the logic and effectiveness of the short term residential placement and treatment model to achieve the desired results is

perhaps a misplaced hope. The literature on learning suggests profound caution about the removal of individuals from environments to a second "treatment" environment given the difficulty of transferring any positive change back to that original environment. While there are undoubtedly a number of competent and concerned staff in the seven state hospitals, there is reason for substantial caution about the effectiveness of such a short term residential treatment model for people with developmental disabilities and grounds for concern about the effect of reliance upon state hospital resources upon families and the community's capacity to meet individual needs.

Sixth, community-based ICF/MRs are licensed and paid to provide active treatment. Consequently, they should be accountable for the efforts they make to meet individual needs in behavior shaping, skill development, and medical-nursing supports. If "failure" for a placement is to be assigned, lack of success should be tagged to the facility, to case management, and to support services and not to the individual - particularly when the potential reason for return has been described and strategies for addressing it have been addressed.

SOME POSSIBLE STEPS

My basic claim is that the development of a zero-reject community service model is 1% inspiration and 99% perspiration. That is, while there is little mystery in defining the necessary components for developing such a system, the barriers to such a

development are both obvious and formidable. Diffused accountability for making such an end result come about is one major problem and there may be significant constituencies opposed to such an outcome for a variety of reasons.

Looking at the goal of a zero-reject community service system involves a matter of perception. Everyone who has taken introductory psychology can recall the picture that looks either like a goblet or like two faces depending upon your momentary perception. Viewing community placement as part of the on-going effort to provide for community integration of mentally retarded persons presents a similar perceptual situation. Under one such view, effort is directed toward predicting who can succeed in the community system as it presently is set up assuming relatively minimal individualization of resources. In this view the person becomes the focus of the "failure" and, consequently, little pressure is exerted for remediation. In another view, that of a zero-rejection community placement model, the focus is upon identifying the factors which are responsible for difficulty with a given living arrangement and then closing that loop with remedial plans for the future. Leismer (1980) identified 17 factors supporting a zero-reject model. Table 6 lists these elements. While it is beyond the scope of this paper to review these items, it should be clear from reading this table that most items are recognized presently as important for successful community living.

If a start is to be made on a zero-reject model, the individual service planning process seems the best place to begin. Figure 1 shows a proposed framework for individual

service planning. Full team consideration of each of the elements of this matrix, given a flexible resource base, can provide a solid beginning for assuring an integrated community living arrangement for mentally retarded persons in Minnesota. A lively discussion on these elements around priorities, and strategies can be useful in setting up clear expectation of actors involved and can set the stage for accountability and remediation of discrepancies with goals identified. A major goal of such a process would be to ensure flexibility in addressing individual needs while at the same time assuring quality living arrangements that are provided in a cost effective manner. Since our quality assurance efforts to date have been directed largely at facilities rather than at processes of addressing and meeting individual needs, a reconceptualization of licensing and other mechanisms directed to program quality will be called for.

Briefly, here are a few specific suggestions for a number of key actors in the state. First, the Association of Residences for the Retarded in Minnesota should become fully familiar with and adopt a position on a zero-reject community service system for persons with mental retardation and other developmental disabilities and should encourage its members to work through their mission statements and how these relate to such a zero-reject community living posture.

Counties can take a leadership role in a number of ways: by strengthening individual service planning and case management; by using Requests For Proposals to meet individual needs and to assure accountability; examining innovative and locally

appropriate living and working arrangements for mentally retarded persons that are fiscally and programmatically responsible; by developing the capacity to meet the needs of persons requiring emergency in-home supports or out-of-home placement with standby resources in group homes or specialized shelter homes; by experimenting with providing case managers with a "block" fund with which to purchase components services of an individual service plan element by element; and by examining block funding of the county share of state hospital funds to be used to fund services on a contract for service basis.

State government could lead in several areas: policies and leadership to look at the next ten years in providing for increased community integration for persons with mental retardation or other developmental disabilities with regard to 1)places to live; 2)places to work and learn; and 3)supportive and related services. The types of state activities should include providing policy leadership, creating models, establishing guidelines, facilitating development, examining regional disparities, and offering strategies for meeting state-wide challenges in serving clients with exceptional needs.

Acknowledgements

The assistance of Debra Holtz of Legal Advocacy and David Theisen in preparing the data analysis for this paper is gratefully acknowledged.

Disclaimer

The views expressed in this paper are those of the author; no other endorsements should be inferred.

References

Leismer, G. Monitoring and maintaining quality community services. Unpublished manuscript.

Figure 1

INDIVIDUAL SERVICE PLAN AREAS

	PLACES TO LIVE	PLACES TO WORK / LEARN	SUPPORTIVE / RELATED SERVICES
ASSESSMENT			
PLANNING			
IMPLEMENTATION			
EVALUATION			

Table 1

ADMISSIONS TO STATE HOSPITALS FROM INTERMEDIATE CARE FACILITIES
BY FACILITY OF ORIGIN THROUGH FEBRUARY 1983

LEGEND - no asterisk: one admission - 51 facilities; one
asterisk: two to four admissions - 16 facilities; two asterisks:
five or more admissions - 2 facilities.

Ah-Gwah-Ching Nursing Home - one person to Willmar 1/29/81
Arrowhead House - one person to Moose Lake 3/26/81
Atwater Group Home - one person to Willmar 11/24/80
*Aurora House - three persons: one person to Brainerd 7/10/81, one
person to Cambridge 1/25/83, one person to Faribault 5/5/82

Birchwood Home - one person to Moose Lake 12/10/81
Brighter Day Residence Mora - one person to Cambridge 7/14/82

Camelia House - one person to Faribault 4/27/82
Cold Spring Group Home - one person to Brainerd 4/20/82
Colonial Manor Balaton - one person to Willmar 4/2/82
Community Living Incorporated - one person to Cambridge, 11/23/81
Crest Group Home - one person to Faribault 4/29/82

Dayton Board and Care Home - one person to Cambridge 3/31/82
Dell's Place Delano - one person to Willmar 6/8/81
Delphi Residence Shakopee - one person to Saint Peter 7/29/82

Forestview Lexington - one person to Cambridge 10/21/82

**Greenbriar - five persons to (1) Cambridge 1/18/83, (2)
Faribault 4/27/82, 9/25/82, (1) Saint Peter 5/11/81, (1) to
Willmar 11/10/82.

Haven Home - one person to Faribault on 12/31/81 and 2/1//82
*High Island Creek Residence - two persons to Saint Peter,
5/11/81, 5/15/81
Hilltop Manor - one person to Moose Lake 11/24/81
Homework Center - one person to Fergus Falls 10/31/81
*Hope Residence Belle Plaine - two persons to Faribault 7/13/81
and 9/15/81

*Kindelhope - two persons to Willmar 3/9/81 and 5/18/82

*Lake Homes - two persons to Fergus Falls 4/6/82, 9/15/82
Lake Park Wild Rice - one person to Faribault 3/31/82
Lake Owasso - one person to Cambridge 9/11/81
Lakeview Children's Home - one person to Brainerd 7/10/81
Laura Baker Residence - one person to Faribault 6/30/82

Table 1 Continued

Madden Haven Home - one person to Willmar 10/12/82
Madden Kimball Home - one person to Faribault 8/14/81
Meeker County Group Home - one person to Willmar 11/11/80
Memorial Nursing Home - one person to Fergus Falls 6/10/82
Midway Manor - one person to Cambridge 10/4/82

**Norhaven - six persons: two to Cambridge 4/1/82 and 11/23/82;
three to Faribault 12/4/81, 12/23/81, 3/22/82; one to Moose
Lake 12/19/80
Northome Group Home - one person to Cambridge 12/15/81

*Oakridge Group Home Aitkin - two persons: one to Brainerd
7/23/81, one person to Faribault 10/16/81
Orvilla Residence - one person to Faribault 4/8/82
*Osakis - two persons to Cambridge 4/12/82 and 4/16/82

Pembina Trails Home - one person to Brainerd 4/22/82
Pettit Children's Home - one person to Willmar 11/16/82
Phoenix Residence - one person to Moose Lake 3/25/82
Pillsbury Manor - one person to Faribault 12/15/80
*Portland Residence - two persons to Cambridge 8/17/81 and 6/28/82
*Project New Hope Ada - two persons to Fergus Falls 6/24/82 and
12/27/82
*Project New Hope Alexandria - two persons: one to Brainerd 7/1/81
and one to Fergus Falls 10/29/82
Project New Hope Fergus Falls - one person to Moose Lake 12/11/81

Region Park Hall - one person to Faribault 2/5/82
*REM II-Canby - three persons: one to Moose Lake 12/29/81, two
persons to Willmar 10/30/80 and 8/29/82
REM V-Tyler - one person to Cambridge 1/25/82
REM VI-Montevideo - one person to Willmar 10/6/81
REM-Bemidji - one person to Brainerd 2/3/82
REM-Bloomington - one person to Faribault 9/15/82
REM-Mankato - one person to Saint Peter 4/20/81
REM-Redwood Falls - one person to Willmar 3/3/82
*REM-Rochester - two persons: one person to Cambridge on 5/11/82,
one person to Faribault on 12/17/82
REM-Roseau - one person to Fergus Falls 5/27/82
REM-Southeast - one person to Faribault 5/5/82
Rolling Acres - one child to Willmar 8/6/82
*Roseau Children's Home - two persons: one to Brainerd 12/17/81,
one person to Fergus Falls 1/6/81

Saint Mary's Nursing Home - one person to Fergus Falls 10/8/81
Seventh Street Home - one person to Faribault 3/16/82
Shady Nursing Home - one person to Fergus Falls 2/3/82
Swift County Group Home - one person readmitted twice 11/22/82
and 12/30/82 to Willmar then transfer to Faribault 1/20/83

*Two Thousand and Two (2002) - two persons: one to Faribault
3/20/81 and one to Fergus Falls 12/28/82

Table 1 Continued

Valley Group Home - one person to Fergus Falls 12/30/82
Valley View Nursing Home - one person to Cambridge 11/3/81

*Wicklough Residence - three persons to Cambridge 9/1/81 (2) and
2/12/82

*Wilkin County Group Home - two persons to Fergus Falls 4/81,
8/4/81

Willow Nursing Home - one person to Moose Lake 5/4/81

Woodvale II Owatonna - one person to Faribault 3/17/81

Table 2

ADMISSIONS TO STATE HOSPITALS FROM INTERMEDIATE CARE FACILITIES
BY STATE HOSPITAL THROUGH FEBRUARY 1983

FACILITY	TOTAL	DESCRIPTION/COMMENTS
BRAINERD	8	7 mention assaultive, aggressive behavior, 1 mentions mood swings and cognitive disturbance
CAMBRIDGE	21	10 mention assaultive or aggressive behavior, 1 mentions running away 1 mentions pica 1 mentions being closer to family 2 do not state reason 2 mention suicide attempts 1 mentions self-injurious behavior 1 mentions failure to comply with traffic safety program 1 person refused service at DAC 1 person stealing and truancy
FARIBAULT	24	20 mention assaultive, aggressive behavior (including 1 fire setting episode) 3 mention wandering or running away 1 mentions manic depressive cycle
FERGUS FALLS	15	10 mention assaultive, aggressive behavior or threats of same (includes one fire setting episode) 1 for toileting program 1 to be closer to mother 1 for non-cooperation, more structure 1 not stated 1 for yelling and incompatibility with other residents
MOOSE LAKE	8	7 mention assaultive or aggressive behavior 1 mentions non-compliance

Table 2 Continued

SAINT PETER	6	6 mention assaultive, aggressive or acting out behaviors
WILLMAR	15	13 mention assaultive or aggressive behavior 1 mentions running away 1 mentions demission from sheltered workshop
TOTALS	97	73 75% of admissions from ICF mention assaultive or aggressive behavior or threat of same

Table 3

SUMMARY OF ADMISSIONS UNDER THE WELSCH DECREE
 ADMISSIONS FROM ICF AND ICF/MR FACILITIES*
 SEPTEMBER, 1980 THROUGH MARCH, 1983.

ICF/ICF/MR SIZE CATEGORIES	ADMISSIONS	
	NUMBER	PERCENT
6 OR FEWER RESIDENTS	12	12.9
7 TO 12 RESIDENTS	18	19.4
13 TO 16 RESIDENTS	19	20.4
17 TO 32 RESIDENTS	3	3.2
33 TO 64 RESIDENTS	14	15.1
65 TO 343 RESIDENTS	27	29.0
TOTAL	93	100.0

AVERAGE FACILITY SIZE: 51 RESIDENTS (WEIGHTED AVERAGE)
 FACILITY SIZE RANGE: 6 TO 343 BEDS (MINIMUM/MAXIMUM)

*ANALYSIS OF ADMISSIONS DOES NOT INCLUDE FOUR ADMISSIONS FROM
 SILS PROGRAMS.

Table 4

SUMMARY OF ADMISSIONS UNDER THE WELSCH DECREE
FROM ICF/MR CERTIFIED FACILITIES ONLY*
SEPTEMBER, 1980 THROUGH MARCH, 1983

SIZE CATEGORIES BY NUMBER OF RESIDENTS	TOTAL LICENSED CAPACITY: 9/82		STATE HOSPITAL ADMISSIONS:CRF		ADMISSIONS PER 100 BEDS
	TOTAL BEDS/	%	NUMBER /	%	
6 OR FEWER	641	13.3	12	14.1	1.87
7 TO 12 RESIDENTS	846	17.5	18	21.2	2.13
13 TO 16	1020	21.1	19	22.4	1.86
17 TO 32	325	6.8	3	3.5	.92
33 TO 64	938	19.4	14	16.4	1.49
65 TO 171	1058	21.9	19	19.0	1.80
TOTAL	4828	100.0	85	100.0	1.76

*ANALYSIS OF ADMISSIONS FROM ICF/MR CERTIFIED COMMUNITY FACILITIES ONLY; DOES NOT INCLUDE EIGHT ADMISSIONS FROM NURSING HOMES (AVERAGE SIZE 150 BEDS) OR FOUR ADMISSIONS FROM SEMI-INDEPENDENT LIVING SERVICES PROGRAMS.

Table 5

SUMMARY OF DISCHARGES UNDER THE WELSCH DECREE
OF PEOPLE ADMITTED FROM COMMUNITY RESIDENTIAL FACILITIES
SEPTEMBER, 1980 THROUGH MARCH 31, 1983
(TOTAL N = 97)

- SIXTY (N = 60; 62 PERCENT) OF THE 97 PEOPLE ADMITTED FROM COMMUNITY RESIDENTIAL FACILITIES HAVE NOT BEEN DISCHARGED SINCE THEIR INITIAL ADMISSION;
 - THIRTY-SEVEN (N = 37; 38 PERCENT) OF THE 97 PEOPLE ADMITTED FROM COMMUNITY RESIDENTIAL FACILITIES HAVE BEEN DISCHARGED AT LEAST ONCE - BECAUSE OF MULTIPLE ADMISSIONS/DISCHARGES, THESE 37 PEOPLE REPRESENT 41 DISCHARGES FROM STATE HOSPITALS;
 - SEVENTEEN (17) OF THE 37 CRF RESIDENTS HAVE BEEN READMITTED SUBSEQUENTLY AND HAVE NOT BEEN DISCHARGED AGAIN;
 - EIGHT (N = 8; 20 PERCENT) OF THE 41 DISCHARGE REPORTS HAD NOT RECOGNIZABLE DISCHARGE PLAN;
 - IN TWO CASES (N = 2; 5 PERCENT), THE DISCHARGE REPORT/PLAN DID NOT STATE THE REASONS WHY THE PERSON HAD BEEN ADMITTED TO THE STATE HOSPITAL;
 - IN SEVEN CASES (N = 7; 17 PERCENT), THE DISCHARGE REPORT/PLAN STATED THE REASONS FOR THE STATE HOSPITAL PLACEMENT BUT DID NOT INCLUDE STRATEGIES FOR DEALING WITH THOSE PROBLEMS OR BEHAVIORS;
 - TWENTY-FOUR (N = 24; 59 PERCENT) OF THE 41 DISCHARGE REPORTS/PLANS STATED THE REASONS FOR SEEKING INSTITUTIONAL PLACEMENT AND ALSO OUTLINED, TO SOME DEGREE, POSSIBLE STRATEGIES FOR ADDRESSING THOSE NEEDS. ACCORDING TO STATE HOSPITAL RECORDS, HALF (N = 12) OF THESE 24 DISCHARGES WERE, HOWEVER, SUBSEQUENTLY READMITTED.
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Table 6

FACTORS FOR MAINTAINING QUALITY COMMUNITY SERVICES*

1. Normalized residential settings
 2. Esthetically and programmatically appropriate sites
 3. Selective screening of good managers and providers
 4. Adequate staff-to-client ratio
 5. Coordinated service delivery system
 6. Quality Individual Program Plans
 7. Staff with adequate training, pay and benefits
 8. Adequate age-appropriate, need-appropriate day programs
 9. Adequate funding
 10. Rigorous standards for licensure
 11. Natural home support
 12. Citizen advocacy
 13. Supports for former clients living in the community
 14. Smallness of program
 15. Adequate and ample supportive services
 16. Effective Case Management
 17. Adequate transportation
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* From Leisner (1981)