

THE COMMISSIONER'S TASK FORCE
RECOMMENDATIONS ON DESIGNING
CLIENT-ORIENTED DISABILITY
SERVICE SYSTEMS

MAY 9, 1988

Submitted to:

Sandra Gardebring, Commissioner
Minnesota Department of Human Services

May 9, 1988

Sandra S. Gardebring, Commissioner
Department of Human Services
Human Services Building
444 Lafayette Road
St. Paul, MN 55155-3815

Dear Commissioner Gardebring:

It is with some relief, satisfaction, and anticipation that your Task Force on Mental Retardation and Related Conditions presents this report to you.

Changing the manner in which our system deals with people and their disability is an idea whose time has come. Many studies and recommendations have preceded ours, and many of our findings and recommendations repeat prior ones. We are indebted to those prior groups, to Task Force members who participated in the development of this report, to those members who participated in both efforts, and to you for providing our opportunity. Serious consideration has been given the issues by all who were involved. Though our focus has been on needs and overcoming deficiencies, we do not intend to distract from much that is positive about our system.

Many of the recommendations will require changes in statute as well as increases in funding. We believe, however, that with changes in the system, including training, persons currently encouraged to be dependent will increase their capabilities, and many will become economically productive; thus reducing the level of needed services and increasing individual financial contributions to remaining needed services. At first glance our recommendations may give the appearance of every advocate's wish list, but upon study you will find consistent themes and interdependence of suggested actions.

We encourage you to consider our prior reports regarding Quality Assurance and Case Management along side this report. While some overlap was necessary, we did not duplicate those prior efforts.

Also, we want you to know that we stand ready to work with you and your staff to develop any of the Task Forces recommendations further.

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Commissioner Sandra Gardebring
May 9, 1988

Our presentation format is pointed and affirmative. We focus on goals to be accomplished, illustrating barriers to achieving those goals, and recommendations designed to successfully make our goals reality. We believe that the proposals can work very well, that they are practical, and that they will be an economical approach within the spectrum of social intervention. Most importantly, --- we believe they show the kind of human concern and response that we should make in our system to those who need help.

It is with appreciation that we have all come this far together that this report is transmitted for your study and approval.

Sincerely,

A handwritten signature in dark ink, appearing to read "Duane R. Shimpach". The signature is stylized with a large, sweeping initial "D" and a trailing flourish.

Duane R. Shimpach, Chair
Commissioner's Task Force on Mental Retardation and Related
Conditions Enclosure

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GOALS, ILLUSTRATIVE BARRIERS, AND RECOMMENDATIONS

SYSTEM ENTRY GOAL

To provide information and access to appropriate services and resources that are coordinated and flexible in meeting individual needs of people with developmental disabilities.

ILLUSTRATIVE BARRIERS

- o There is inconsistency in eligibility and funding between agencies and programs due to different definitions of developmental disabilities, and different priorities. This results in gaps in services between Special Education, Department of Jobs and Training Rehabilitation Services Division, the county, SILS, etc.
- o Coordination between agencies and referral systems is often poor. There is a lack of knowledge about agencies, the services they offer, their eligibility requirements, and availability of resources between systems which hampers the referral process.
- o The U. S. Department of Health and Human Services and the U. S. Department of Education are two separate federal agencies. At the state level, however, they are three agencies. Communication and coordination can be difficult but not insurmountable.
- o Incomplete, inaccurate, or out-of-date waiting lists often exist for services. There is no uniform method by which waiting lists are developed and maintained at the county level and then used for planning and budget requests at the county and state levels. The result is that persons who inquire or formally apply for services which are not available, may not be formally acknowledged, or if they are, they are not included by the county and State in planning and development initiatives. While the goal of the system should be to have all persons served as soon as possible, the system has no idea how many people are in need, making it impossible to achieve that goal. On an individual basis, this is patently unfair as individuals can be denied services, yet they may be as needy, if not more so than persons currently receiving services.
- o The referral to, development of, access to, and use of generic

resources is an aspect of meeting a person's needs that doesn't appear to be addressed adequately.

- o Rule 185, in defining the role of case managers and county responsibilities, defines one way to enter the system and receive comprehensive services. In actual practice, there are not enough case managers, there is not appropriate training given to all case managers, and many case managers are not knowledgeable enough of other services to ensure that there is coordination of services.
- o There are different groups of people, for example, the elderly, and persons with developmental disabilities, that may need similar services such as transportation, support groups, accessible housing, etc. In looking at system entry, it may be possible to provide information and referral to services and resources to all persons who may need access to those services in a coordinated fashion based on need, not based on disability or "label".

RECOMMENDATIONS FOR SYSTEM ENTRY

- o Develop a separate information and referral system which would give information regarding all specialized services available as well as generic resources.
- o Separate the role of guardian and advocate from case management.
- o Enable and enforce case management as defined in Rule 185. Gaps in services to people that are presently involved in Social Services are largely due to inadequate case management.
- o Emphasize information gathering that goes beyond data needed for eligibility determination and funding funding.
- o Encourage an assessment and planning process which emphasizes a holistic approach to the individual client.
- o Develop statewide comprehensive community needs assessments which are accurate and functional to assist in county and state planning.
- o Support use of available generic community resources, not only for persons with developmental disabilities, but also

for other people in the community.

- o Utilize creative consultants, such as recommended in the Task Force Study on Employment, to look at available options and offer advice on how Minnesota can change its present system entry.
- o Establish early intervention as a priority for the system of services for persons with developmental disabilities.
- o Systematically monitor outcomes in Minnesota with rule changes and transition services, both for children birth to three, as well as with students 14 to 21. Apply experience gained in those areas to a wider range of persons requiring services.
- o Establish a system in which records/case files/information follow the client. Often files (comprehensive) from regional treatment centers stay at the RTC but should be with the county to ensure central record on client.
- o Improve coordination of information between Health, Human Services, Education, Corrections.
- o The Department should develop, fund, establish, and implement a clear method of determining waiting lists or unmet service needs by individual, type of service(s) needed, urgency of need, and county of residence. We recommend a comprehensive effort, such as that undertaken in Maryland ("Mentally Retarded Adults and Their Families" by Black, Smull, Crites and Sachs, May 15, 1985, University of Maryland School of Medicine), to establish an initial data base. Once a comprehensive waiting list has been developed, additional persons and changes in service needs could be added through the case management system.
- o DHS should continue developing a comprehensive MIS using current technology so that data can be aggregated and analyzed for the purpose of planning for and affording services to people:
 - a. waiting to be served, and
 - b. those currently served but requiring different or additional services now and/or in the future.

SERVICES GOAL

To serve persons with disabilities based on individual need in the least restrictive, most cost effective manner, with the intent of promoting independence, productivity, integration, opportunity, dignity, and security for service recipients.

ILLUSTRATIVE BARRIERS

- o The values that underlie improved service options do not receive enough attention or focus to enable acceptance or understanding of the human rights basis for change. Many aspects of the current system of services emphasize institutional settings, out of home placement, segregation, and unproductive activity for adults. Family supports remain the smallest part of the budget and are underfunded.
- o Regional centers continue to decrease in population but increase in cost. People moving from regional treatment centers cannot take their funding with them into the community, thus it is necessary to seek new funding for community services.
- o Community ICFs/MR are decreasing in overall number and facility size. Several ICFs/MR built for children in the 70's wish to serve adults and to serve fewer people, yet cannot make these changes under current funding constraints.
- o There are a significant but undocumented number of eligible adults waiting in their family homes for ICFs/MR, waived services, SILS, in-home supports, and supported employment. There are families with children waiting for Family Subsidy and in-home support services under the waiver.
- o State-of-the-art technology and information cannot be realized for people needing service because of inadequate training of case managers, direct care, supervisory, and professional staff and because of insufficient funds.

Although the service system is changing in several positive ways, small increases in Family Subsidy and Home and Community-Based Waivers, there are important aspects which remain unresponsive to the needs of families and individuals with developmental disabilities. Far too high a percentage of dollars spent in this area go toward institutional, segregated settings. As people move to less restrictive environments, new money must be found to

serve them, rather than allowing the funding to follow the person. The result is that two service systems must be funded and the newer, community-based, family support system is not growing fast enough to meet the demand for services.

Responsible action to change the service system in Minnesota for persons with disabilities must be based upon values. The Department's mission statement provides a basis on which to judge existing programs, services, and new proposals.

As was pointed out at the Legislature during the 1988 session, the budget impact of programs like Family Subsidy or the Title XIX Waiver are simply never documented. In seeking change, the Department should develop information and projections on the cost of not changing the service system as well as the cost of change. Although the information would be based on predictions, it would be effective in convincing policy makers that change should be funded.

RECOMMENDATIONS FOR SERVICES

- o The Department should publicly acknowledge that regional treatment centers should not be used to serve persons with developmental disabilities and continue to take action to move current regional treatment center residents into appropriate services in the community. Close all regional treatment center programs serving persons with developmental disabilities by the 1996 biennium.
- o The Department should plan for the closure of at least one regional treatment center program serving persons with developmental disabilities during the next biennium by seeking a new waiver or waivers which could have a higher average than \$64.00 per day, would fund all residents to move to community, and result in complete closure of a regional treatment center program serving persons with mental retardation. Cambridge should be the first regional treatment center to close for the following reasons: (1) Ramsey County, which has the largest number of people at Cambridge, has stated its desire to move all their residents back to Ramsey County, and (2) there are persistent and serious problems with the services as demonstrated by the Olvera report (1984), the failure to receive accreditation from ACMR/DD (1986), the ICF/MR facility correction reports (1987), the negative Department of Human Services licensing actions (1987 and

1986), the Powell and Rainforth report (1986), and incidents of serious abuse of residents by staff in 1983 and 1988.

- o In order to ensure availability of appropriate community services when regional treatment centers are closed, the Department should develop and fund an array of crisis intervention services across the state.
- o The Department should establish and publicize a method to allow Class A and Class B ICFs/MR (especially those established for children) to renovate, downsize, and upgrade services in order to serve adults with multiple disabilities. The method must allow facilities to change without jeopardizing their financial well-being. Non-profit facilities should be allowed to raise funds privately to finance aspects of a change-over plan without being penalized by a reduction in client per diems.
- o The Department should pursue new ICF/MR funding if the federal government refuses to allow increased diversions. New ICF/MR development should meet the following criteria:
 - a. Only persons who cannot be served under the current waiver should be placed in community ICF's/MR.
 - b. Only persons in the special needs category should be placed in community ICF's/MR.
 - c. Renovated existing housing should be used for new ICF's/MR whenever possible.
 - d. Property and program ownership should be separated in new ICF's/MR.
 - e. New ICF's/MR that are developed in the community should be designed to serve a maximum of six people, but preferably no more than four.
- o The Department should expand eligibility to cover all persons in need by adopting the definition of "disabilities" specified in Medicaid Reform Legislation, S. 1673 and H. 3454.
- o The Department should support legislation to provide health insurance coverage for low income persons with disabilities. And, that legislation should insure that the needs of low income persons are addressed in all planning.
- o The Department should add case management to the list of services reimbursed under Medical Assistance now that the federal Medicaid statute has been amended to allow provision

of case management by counties.

- o The Department should, in cooperation with other agencies, develop, conduct, and evaluate a comprehensive program of pre-service training for case managers.
- o The Department should, in cooperation with other agencies, study the extent to which duplication of case management duties and services exist with social workers employed by regional treatment centers, community ICFs/MR, day programs, public schools, HMOs, and public health programs.
- o The Department should review and address, in conjunction with other agencies, the recommendations contained in the final report of the Task Force on Supported Employment established by the Legislature during 1987.

In particular, the Department should work with the Division of Rehabilitation Services of the Department of Jobs and Training and the Department of Education to jointly develop by the end of the year:

1. common definitions for supported employment terms,
2. legislative proposals for increased funding and expanded eligibility for all disability groups,
3. common standards (including licensing) for supported employment,
4. evaluation measures and techniques,
5. quality assurance activities,
6. a data base and method for continued data collection.

In addition, the Department should take a leadership role in seeking additional funding for supported employment. In addition, it should develop ways in which existing funding streams and rules can be used for that purpose.

- o For persons who require full day supervision, the Department should ensure that counties offer full day services even if people have only part time jobs.
- o In order to accommodate people with disabilities whose jobs require evening, night, or weekend work but whose needs include substantial supervision, the Department should assist counties, residential, and day service providers in creating flexible options which meet individual schedules and needs for activities and supervision.

- o Establish a comprehensive system of family and individual support services, which is expanded to cover all persons with developmental disabilities, and maximizes federal financial participation where possible.
- o Change the Family Subsidy program to cover all families with sons and daughters under 22 with developmental disabilities living at home. Also, reduce paperwork for Family Subsidy recipients by eliminating the requirement of producing receipts. Need should be established annually, or more often as needed, grants should be awarded, and families should be allowed to meet their needs without verification requirements.
- o Seek an increase in SILS funding in order to cover all eligible people waiting and those projected to graduate from public school during the biennium. Funding should be at a level that requires county participation at the same rate as Medical Assistance funded programs. This reduction in the county share is sought in order to eliminate a growing financial disincentive operating at the county level against SILS. The SILS program should be flexible enough to offer all necessary community supports for people not living in 24-hour staffed settings.
- o Support and seek funding for Caregivers Support legislation; investigate, and if possible under federal requirements, seek Medicaid funding to provide respite care as recently approved for New Jersey in section 4118(o) of the 1987 amendments to the Medicaid Statute:

"Section 4118(o) of OBRA '87 makes a number of Senate-sponsored technical amendments to the New Jersey Respite Care Pilot Project. The state may submit a detailed description of the project in lieu of a formal waiver request. Persons eligible for the program are defined as those elderly and disabled whose incomes do not exceed 300% of the SSI standard and whose liquid resources do not exceed \$40,000. Respite care services are defined to include short-term and intermittent companion or sitter services, homemaker and personal care services, adult day care, and inpatient care in hospitals, SNFs, or ICFs (not to exceed a total of 14 days) and peer support and training for family caregivers. The amendment is effective as if included in OBRA of 1986."

- o Coordinate local or regional information on and training of respite caregivers. This need includes day care and latch key providers as well as respite providers.
- o Delineate the services counties should provide as part of building a comprehensive system of early intervention services to families.
- o Seek funding to establish statewide difficulty of care rates for adult foster care.
- o Require compliance with the case management rule on client/family satisfaction, MN Rules 9525.0125, Subp. 1.G. Develop client/family satisfaction interview forms and encourage case managers to use them. Develop client/family satisfaction interview forms regarding case management services to be conducted by the regional service specialist or other individual not employed by the county providing case management services to the individual or family. Collect the information from the counties and use it to improve services.
- o Support organized independent volunteer monitoring efforts by trained volunteers and encourage service providers to participate.
- o Develop a series of possible actions to be taken as a consequence of quality assurance activities, including:
 - (1) recognition of outstanding efforts by counties and providers;
 - (2) incentives for improved performance;
 - (3) offers of training and technical assistance for counties and providers;
 - (4) enforcement of standards including adverse action against agencies which do not meet the standards.

LICENSING GOALS

To create and enforce state-of-the-art licensing standards.

To establish a single independent office which could collect, disseminate, and investigate information obtained through the licensing process.

To use gathered information, along with other information generated through quality assurance, to reward successful efforts, develop action plans for improvement, provide training and other incentives for change, and impose sanctions for unacceptable performance.

ILLUSTRATIVE BARRIERS

- o Current licensing standards do not insure quality; they establish minimum guidelines.
- o The role of the human service licensor is not clearly defined to service providers. There is no separation between licensor and consultant providing technical assistance.
- o Licensing information is isolated and not a connected part of a comprehensive quality assurance system.
- o DHS licensing personnel don't have training, experience, and expertise in the area of developmental disabilities as well as in the specific area(s) which they license (day/residential services, etc.).
- o The field of developmental disabilities is changing very rapidly. Services move forward before rules are promulgated. The rule process needs to get up and going so that it is not detrimental to the development of the services.
- o No assistance is available to help providers meet standards when they are determined to be out of compliance.
- o Licensing reports have only noted discrepancies and negative sanctions offering little, if any, positive feedback to the provider.
- o There is no one place to go to find information about a service provider. (One point where all licensing data is kept including data supplied through the Department of Health, Department of Human Services, and the Ombudsman Office.)
- o Duplication and contradictory requirements exist in other Department of Human Services sections, and Health Department requirements and federal certification requirements.

It is recognized that the Department of Human Services has taken a strong position on enforcement of licensing standards. Two DHS rules, Rule 34 and Rule 42 (waivered services), are undergoing revision and Rule 38 has just recently been promulgated. A Rule 38 checklist of compliance standards is soon to be made available to providers.

Since new services and trends are emerging rapidly, they necessitate the development of new standards to help insure quality. Establishing standards can lead to better accountability and to better services for persons with mental retardation and other related conditions.

RECOMMENDATIONS FOR LICENSING

- o Develop state-of-the-art, value-based standards, which examine among other things whether programs have outcome measures with key indicators for critical areas in the development of new rules regarding residential services and waived services and the updating of other rules. Some providers have multiple surveys and reviews due to licensing, certification, and accreditation which wastes both time and money.
- o Minimize duplication and contradictory requirements contained in other Department of Human Services rules, Health Department requirements, and federal certification requirements.
- o Clarify the role of the licensor regarding the role of applying standards or providing consultant services. Establish qualification standards and ongoing training requirements for the position which parallel the services which are being licensed. Ensure uniformity in standards application.
- o Continue the enforcement of standards, including action against agencies which do not meet standards, but also develop activities which would both recognize outstanding efforts and provide incentives for improved performance.
- o Increase the number of trained case managers and systematically monitor county case management services.
- o Promulgate new Rule 34, Rule 42 (waived services), and coordinate their language.
- o DHS should support legislation which would study and recommend changes in the law which enable the coordination of rules/regulations affecting persons with mental retardation and other related conditions.

- o Increase the Department's ability to provide technical assistance to providers separate from the licensing process.
- o Ensure an identifiable, systematic licensing/monitoring approach as clients are dispersed into small, decentralized community settings.

REGULATORY REFORM GOALS

To implement a deemed status program where possible.

To develop a standard of quality that allows vendors to strive toward a program of excellence resembling those of private enterprise (hotels and restaurants).

ILLUSTRATIVE BARRIERS

- o Regulations governing day programs and residential facilities may cause as many as twelve (12) regulatory survey/reviews per year. Often these are duplication of previous surveys with citings that may contradict another agencies' regulations. This leaves the provider with the predicament of trying to satisfy opposing requirements. Surveys can be divided into content areas. Examples are:

1. Individual program planning and implementation.
2. Client rights.
3. Program support.
4. Safety and sanitation.
5. Utilization of state-of-the-art theories.

Duplication occurs when more than one regulatory body surveys the same provider for the same content. The Table below illustrates some regulatory and accrediting bodies and the content areas they would survey.

TABLE

Fire Marshal	QA	Rule 34	Rule 38	Rule 10	HCFA	SLF	ICF/MR	JCAH	ACDD	CARF
4	1	1	1	1	1	1	1	1	1	1
		3	3	2	2	2	2	2	2	2
		4	4		3	3	3	3	3	3
		5	5		4	4	4	4	4	4
					5	5	5	5	5	5

Day program and residential facility vendors are annually surveyed by a minimum of two, and as many as twelve different groups. Without exception, there is duplication in all surveys conducted. Often the citations a vendor receives from one survey may be contradictory with a second survey, thus creating an unsolvable situation for the vendor.

Much of the duplication is seen as a waste of time and money, especially when surveys may be scheduled to overlap with each other, i.e., Rule 34 survey done at the same time as the ICF review.

In addition to the redundancy of surveys, a second concern is the content of the survey tool and the process of conducting the survey. All of today's surveys and survey instruments are directed toward fault finding in programs. The final reports review only the negative issues and ignore the quality that exists. Thus, the image that is portrayed for licensing of any human service program in Minnesota is negative. Positive quality is never indicated.

RECOMMENDATIONS FOR REGULATORY REFORM

- o Develop a more intense case management system. It is felt that a strong case management system will lead to reduction in rules, regulations, and requirements. It will produce a more flexible service system with improved clinical practice.
- o We encourage the State to utilize the rule making process for major statewide policies, i.e., Residential License, Day Program License. We also discourage the use of rules to solve isolated service delivery problems.
- o Support the proposals in the 1988 bill "Coordination of Laws Governing Services for Persons with Mental Retardation", including:
 - (1) providing incentives for service to conform with laws and regulations, including extended licensing time frames, reduced surveys, or reduced licensing fees;
 - (2) requiring laws and regulations to emphasize quality assurances;
 - (3) allowing one or more national accreditation processes to accredit services in lieu of the state process under Section 245.04, subdivisions 3 to 6;

- (4) unifying into one system the licensing requirements of both the departments of health and human services for services for persons with mental retardation and other related conditions;
- (5) reducing and coordinating paperwork required to show conformance with laws and regulations;
- (6) translating laws and regulations into simple, clear language whenever possible;
- (7) setting standards and requiring ongoing training for persons involved in regulating services for persons with mental retardation and other related conditions;
- (8) analyzing the cost effectiveness of existing laws and regulations; and
- (9) establishing a procedure to determine the fiscal effect of new laws and regulations.

TRAINING GOALS

To establish training standards which are implemented consistently, are measurable, and based on performance competencies.

To develop a generic curriculum for all direct care staff which minimally covers the subjects of basic job behaviors, health, human development, philosophy and rights, behavior management and maintenance.

To prioritize training as follows: (1) direct care staff; (2) orientation for the newly hired; (3) those hired within the previous six months; (4) management; (5) ongoing training.

To ensure accessibility and equitable funding for training in all parts of Minnesota.

ILLUSTRATIVE BARRIERS

- o There is no consistency in requirements for training between programs serving clients with mental retardation and related conditions.
- o The training that is mandated does not include general information in the basic understanding of mental retardation, effects on learning, problems encountered, etc.
- o There is a lack of continuity on what training is provided and/or mandatory.

- o Appropriate training topics have not been identified or appropriately measured to assure staff competency in meeting service delivery needs.
- o There is not a clear understanding of what training is necessary or important for staff.
- o Funding is not provided to train staff and compensate them fairly for their skill level abilities. Rural settings are not provided access to training nor funding to train unskilled personnel when trained personnel are not available for hire.
- o The direct care staff person lacks the status of being recognized as a professional or even a para-professional. Lack of training and lack of adequate wage reimbursement have contributed to an overall devaluation of direct care staff.

The need for training in every area of service is absolutely clear. State-of-the-art practices, technological advances, and competent, knowledgeable staff are greatly needed in services for persons with disabilities throughout Minnesota. Retention of staff and improvement in the skill and knowledge of service providers will not occur without improved wages and establishment of career ladders.

There are several factors that have increased the need to reevaluate the status of mandatory training. The emergence of community based programs in small residential settings has placed a great deal of pressure on direct care staff. Concurrently, staff members are expected to provide increasingly more difficult types of care with clients who are more medically involved, are more vulnerable, and possibly more at risk in these environments. Small community based programs can have an isolating effect on direct care staff and clients. Lack of proper training can lead to frustration and intolerance by both staff and clients. Lack of training in conjunction with high need, difficult clients can perpetuate an already high staff turnover rate. The increase in small community based programs could expand the already existing problem of duplication of training. This results in wasted staff time and money.

As clients are served in their own communities, the services that follow them must be delivered at a high quality. Training is essential to the provider who is drawing from a local, inexperienced workforce and unable to attract the state system employee due to lower wages and benefits. Both funding for training and recognizing trained staff with appropriate compensation are essential to high quality services.

RECOMMENDATIONS FOR TRAINING

- o Establish consistent training requirements across all services. Assure training is performance and competency based and outcomes are measured. It should include on the job training as well as traditional modes of training. It should be predicated in a set of principles and be value-based.
- o Develop statewide, competency based continuing education.
- o Assure funding follows training requirements and study the fiscal impact of training, documenting its effect on performance and staff turnover.
- o Develop a system allowing providers the funding resources to be competitive in recruiting and training needed staff.
- o Develop an in-service training system which is dispersed across the state and accesses all possible resources.
- o Develop a career progression (ladder) within the industry that would retain staff by allowing for professional growth and advancement. Staff turnover greatly increases the cost of training and operations.
- o Establish training for and systematic monitoring of county case management services. Compile information county by county and use the information to resolve problems and improve services.

SALARY AND BENEFIT EQUITY GOAL

To provide compensation and benefits that will attract qualified people to community services providers, then motivate employees to stay and devote their best efforts to deliver quality services.

ILLUSTRATIVE BARRIERS

- o Minnesota has not completed a comprehensive study of the wage and benefit inequity for personnel who work in community based services for persons with mental retardation and related conditions.

- o Staff turnover appears to be a significant issue in community-based services. It appears that the wage and benefit discrepancy has a role in the turnover issue.
- o Increased regulations, and the emphasis on accountability have increased the demands on the jobs of workers in the field. The field has demonstrated a greater level of sophistication with the emphasis on active treatment and quality care.
- o Residential services and vocational programs are required to provide services during evening hours and weekends. Society is placing more emphasis on free time to recreate, making evenings and weekends valuable personal time. This further stresses the inequity of salaries and benefits.
- o As a result of deinstitutionalization, community services staff are working with higher need clients who require staff with a greater degree of training, experience, and commitment.
- o In a sample study of community services for the mentally retarded in Minnesota (ARRM, MnDACA), 74.6% of employees in these services were women. Programs have been staffed largely at the expense of women through low wages and benefit packages presenting issues of comparable worth.

The Department of Human Services, advocacy groups, and service providers have all identified the importance of competently trained staff in delivering quality services to persons with mental retardation and related conditions. Providers have been unable to recruit adequately trained personnel and/or properly train individuals when employment periods are short.

RECOMMENDATIONS FOR SALARY AND BENEFIT EQUITY

- o Implement a comparable worth study of employees working in the community serving persons with mental retardation and related conditions.
- o Develop a plan to increase wages so that they are competitive with comparable jobs in the public and private employment sectors in order to attract staff with adequate training and/or experience, and to retain employees.

- o Support legislation to phase in wage and benefit increases.
- o Initiate a feasibility study of the career ladder concept for personnel working in the service system. The North Dakota Community Staff Training Program is one approach that might be considered.
- o Improve the training and compensation of direct care staff in order to upgrade the quality of services provided to persons with developmental disabilities.

HOUSING ACCESSIBILITY GOALS

To enable accessible, safe, and comfortable housing in the community for people with disabilities.

ILLUSTRATIVE BARRIERS

- o It is costly to fully modify an existing structure that is not accessible. There are limited moneys available for the modification of existing housing to make such housing accessible.
- o Minnesota currently has no incentive for developers or investors to pursue the development of accessible housing.
- o There is no formal prioritization of how existing accessible housing funds are appropriated.
- o Clients, especially in the metropolitan area, are unable to afford housing appropriate to their needs.

RECOMMENDATIONS FOR HOUSING

- o Complete a needs assessment of housing and client needs in Minnesota. Develop a central clearing house for referrals and needs monitoring.
- o The Department of Human Services and the Minnesota Housing Finance Agency should undertake a joint accessible housing initiative to help move individuals with physical disabilities from nursing homes into the community.

- o Examine existing national projects on accessible housing and publicize available options.
- o The concept of shared housing for elderly persons should be expanded by the MN Housing Finance Agency to include persons with a disability thus allowing them to continue living in their homes or to establish a new shared home.
- o Client owned housing through MHFA should be supported.
- o When limited funds are available for accessible housing needs, a "request for proposal" system should be developed and need prioritized.
- o Develop a housing subsidy resource for clients who cannot afford existing housing.
- o Provide greater tax incentives in the private sector to pursue the development of accessible housing.
- o Provide training to case managers in regard to developing accessible housing, identifying needs and determining strategies for attaining appropriate accessible housing.
- o The Department should work jointly with the Department of Administration to enforce accessibility building code requirements.

FUNDING GOALS

To ensure an appropriate level of funding is targeted to support and effectively implement state-of-the-art community services.

ILLUSTRATIVE BARRIERS

- o Funding is not in tune with current philosophical and programmatic policies and technology. Minnesota ranks 40th in the country in the amount of state and local funds it expends on services to persons with developmental disabilities in the community relative to the amount of federal funds. However, because it has been so successful in drawing down federal Medicaid dollars (primarily for ICFs/MR), it actually ranks number two in the amount of total funds it expends for institutional and community services relative to the per capita income of its population.

- o The lack of full implementation of both the case management and the need determination provisions of Rule 185 continues to result in persons being served in inadequate and/or overly restrictive settings and situations, and frequently at a cost that is higher than necessary. The costs are higher for a number of reasons, one of which is that natural supports are grossly under-utilized or not tapped at all. We have many situations where spending less might mean more quality.
- o The major funding streams are set up so that dollars flow to unnecessarily restrictive and therefore unnecessarily costly services. While interpretations to the Title XIX ICF/MR program over the years, coupled with the adoption of the waiver, and more recently, TEFRA, have had a mollifying effect on this phenomenon, in the main, Title XIX continues to encourage the flow of dollars to unnecessarily restrictive and expensive settings and services.
- o The most stringent limitations are on the most cost effective and beneficial services. While the moratorium and 7,000 cap on ICF/MR beds may receive the most attention, a much worse situation exists in such programs as family subsidy and SILS where the number of slots is 373 and 1,037, respectively. Furthermore, a county is penalized because it can lose a SILS slot if a person graduates from the program. The waiver is capped at 1,500 slots. Given the salient characteristics of all these programs -- ICF/MR, waiver, SILS, and Family Subsidy, if one were to start out with a clean slate, the numbers or "slots" and the allocation of funding should, in all likelihood, be reversed of what they are now. There are, of course, many interests vested in the current system. These interests must be recognized but they cannot prevail over the needs of consumers.
- o In pure dollar terms, it can be readily seen that most of the money does indeed flow to the more restrictive and costly models. Approximately 40% of the 275 million dollars spent on mental retardation services goes to 15% of the population, who are residing at the regional treatment centers at a rate of approximately \$200 per person, per day. ICFs/MR, the next most costly alternative, serving 47% of the population at an average annual cost of \$18,379 per person. The waiver programs, semi-independent living services, foster care, and home care account for only 6% of the budget while serving 24% of those receiving public funds. The average cost for these programs is \$6,700 per person, per year.

- o There is no monetary incentive to alter the way people are served. In fact, on several levels, actual disincentives exist.
- o While the Legislature, through the enactment of the Day Training and Habilitation Services Act, Minnesota Statutes Section 252.40 required that the rate reimbursement scheme and methods of administration strongly favor the use of supported employment, this has not occurred sufficiently in practice for persons with developmental disabilities.
- o Minnesota's rating system is too complex and unpredictable. ICFs/MR are never really sure what their rates are at any point in time with frequent adjustments and retroactive applications of new rules and procedures. the case mix system, if put in effect, will be the fourth reimbursement system in six years. The State should move cautiously on this front. We have grave reservations about the way in which the case mix system is being designed and implemented. There are already numerous regulations that affect providers, especially small providers, and the proposed case mix system is likely to cause further difficulty.
- o Application of the Department of Human Services' audit procedures are not consistent across auditors. Moreover, fiscal audits and quality assurance reviews are not coordinated chronologically. This tends to compound problems associated with the retroactive application of reimbursement regulations and procedures.
- o The waiver has not been sufficient to meet identified needs. More waived "slots" are needed and the per capita daily average \$64.00 expenditure cap is too low.
- o There are no guidelines for waived services contracting or contract monitoring.
- o In non-Metro areas, there is insufficient competition among current or potential providers of waived services, thus driving up the price and perhaps jeopardizing quality. In the Metro area, competition may be sufficient, however, the providers with the lowest bid, but not necessarily the best potential for delivery quality services, are often the recipients of contracts.

There is an obvious relationship between services and funding. There is no getting around the need for adequate funding if we

are to have a system that meets the needs of consumers. The issues under services and funding are similar, encompassing much more than a discussion of amounts available or allocated. This interdependence requires that we put in place a quality assurance system, good need-based planning, recruitment and training of staff, adequate administrative supports and infrastructure. Finally, there is an important federal proposal to revamp the Medicaid program in the area of services for persons with disabilities (S. 1673, H. 3454) under consideration during this session of Congress. In order to take advantage of federal financial participation (54 percent of cost services), the state must offer the mandatory services, establish quality assurance measures, and develop an implementation plan with public participation.

If the federal initiative to redirect funding to community services is not passed this year, Minnesota must take its own action to accomplish the same objective: funding should follow stated policy objectives such as support of families, maximum independence and community participation. Service models exist, but lack of funding and perverse financial incentives block progress in every county in the state.

RECOMMENDATIONS FOR FUNDING

- o The Department should actively support the Medicaid Reform proposal currently before the 100th Congress, S. 1673 and H. 3454. The passage of "The Home and Community Quality Services Act" will obviate the need to pursue many of the other recommendations in this and other sections of the report, and we therefore strongly urge the Commissioner and DHS to actively support the passage of this legislation, and to that end work with our Congressional delegation.
- o The Department should prepare legislation for the next biennium which would enable Minnesota to participate fully in new services if the "Medicaid Home and Quality Services Act of 1987" becomes law before the end of the 1989 legislative session.
- o If Medicaid Reform passes during the 100th Congress, some of the recommendations made here should be examined, perhaps modified and included in legislation prepared to allow Minnesotans with disabilities to benefit from the federal changes.

- o The Department should obtain a new waiver on behalf of ICF and SNF nursing home residents with mental retardation or a related condition using the average per diem cost of ICF/MR services (\$88 in Fiscal Year 1989). This is recommended in order to remove the connection between the inappropriate nursing home placement issue and the SILS program.
- o The Department should resolve the problem of the federal government's failure to approve requested diversions under the home and community care waiver beginning in July 1990.
- o DHS should develop/modify its cost accounting and auditing procedures to guarantee that money is spent for what is specified in purchase of service contracts.
- o Technical assistance should be available to potential waived services providers to help them respond to RFP's and to develop proposals. This would most likely increase the quality of services ultimately provided.
- o DHS should develop guidelines for purchasing waived services so that only necessary, appropriate services are purchased.
- o Salaries and benefits of direct care staff in residential, day program or employment services need to be significantly increased. Rule reimbursement and contract rates must reflect this need.
- o DHS should continue to look at all of its reimbursement rules and procedures and make whatever changes are necessary to give providers a reasonable guarantee regarding what their rate is going to be and guarantee that the rates will be equitable.
- o DHS should review current application and administration procedures pertaining to special needs rates and make every effort to simplify them.
- o Future special needs rates contracts should mandate procedures for monitoring client progress pertaining to those conditions on which the special needs rates are based. They should also specify the monitoring responsibilities of the Department of Human Services.

- o Application review and contract monitoring responsibilities pertaining to special needs rates should be decentralized and placed in the hands of the DHS Regional Services Specialists. This would expedite the process and provide for greater accountability.
- o For persons with developmental disabilities or related conditions who are eligible for services, but who are falling through the cracks, better use should be made of existing generic resources such as vocational rehabilitation. As this would generally necessitate strong case management, we would further recommend:
 - a. Funding an increased number of case managers so that they have the time to do more creative linking and brokering; and
 - b. Enhanced training of case managers to better equip them with the knowledge and skills needed to better tap existing resources.
- o Funding should be increased to address the needs of persons with related conditions or other disabilities in need of service, with possible consideration given to targeting funds, e.g., to persons with epilepsy.
- o For persons who are not technically eligible under the Mental Retardation and Related Conditions programs, a case management system could certainly benefit them so that they too may better access existing services. We would therefore recommend legislation and funding to that end as well as to fund needed services directly.
- o The recommendation in our January 11, 1988 Report on case management are reiterated. A good case management system means better use of existing resources. We can ill afford to waste money. More funding is especially needed for administrative duties associated with operating a case management system, e.g., for contract development and monitoring, planning and program development, financial tracking, etc.
- o Support should continue for DHS' current efforts in providing training to case managers as well as the Waiver. However, in order to realize the goal of full implementation of Rule 185 and other laws and better use of existing resources -- we would reiterate our recommendations made in our January 11, 1988 Report to include:
 - a. more funding in order to reduce the size of caseloads to acceptable levels;

- b. more comprehensive, mandatory training based on clear values and standards, with acquisition of competence being required.
- o Continued improvement, training, and technical assistance to the counties on the strict implementation of the Need Determination Process under state statute and Rule 185.
- o Build a system of fiscal incentives --
 - a. As a fiscal incentive to counties to use the less restrictive levels of care whenever possible, the county share of the cost of waived services, SILS, family subsidies, etc. should be reduced.
 - b. As a fiscal disincentive to counties to use the more restrictive levels of care selectively, the county share of the cost of RTC care and ICF/MR care should be increased.
 - c. To insure that the restructuring of fiscal incentives/disincentives occurs in a manner that provides for optimum quality of life of clients and to the extent possible guarantees cost effectiveness, DHS should seek the advice of persons/consulting organizations knowledgeable about reimbursement methods as it develops recommendations to the Legislature regarding cost sharing.
- o The recommendations in our January 1988 Quality Assurance Report are also reiterated as we believe they too will positively impact effective expenditures.
- o Many more waiver diversions as well as conversions are needed. An amendment to our DHS contract with HCFA should be requested as well as approval from the State Legislature if needed.
- o Increase SILS to serve all eligible individuals. Innovative ways should be explored to determine whether federal reimbursement can be drawn down for SILS or SILS-type services. In lieu of or in conjunction with that, additional slots should be sought in the 1989 session. A better system of allocating SILS resources and controlling entry and exit into the program should be developed. An alternative to the current procedure might be a system that allocates slots rather than dollars to counties. Expenditures per person could be capped at \$9,000 per year with an average expenditure of \$4,500 per person. Counties could receive the allocation contingent on submission of a proposal that would specify how they would use their slots within the context of the priorities specified by the Department, e.g. what percent for nursing home residents, what percent

for ICF/MR residents, etc. This procedure would give counties use of the money while providing the Department with a solid basis for monitoring compliance.

- o Funding for family subsidy should be increased dramatically.
- o Support legislation to exempt foster care from negotiated rates and develop difficulty of care rate schedule.
- o Support legislation and increase funding for family and caregiver support services so that persons in need who are not covered adequately or at all under the waiver, or TEFRA, or CSSA dollars, may receive services.
- o All of the above recommendations should be based on actual individual and then aggregated needs. A MIS/Waiting List system is essential as recommended above. If such a system is not fully operational for the appropriate budgetary request for the 1989 legislative session, then best estimates should be made on the best sources of information that can be gathered and analyzed.
- o Funding either inside or outside of DHS should be explored for day care services for children with disabilities.
- o DHS should enhance its capacity to engage education and information dissemination to other government decision makers in the executive and legislative branches and on the county level, the general public, and interested groups in order to educate and inform them about the need and benefits of natural, individualized service arrangements truly integrated in the community.
- o Guidelines should be developed for waived service contracting and DHS should develop several model contracts to meet the varying needs of counties and the different continuum of arrangements they may enter into with providers.

RECOMMENDATIONS FOR SUNDRY INDIVIDUAL ISSUES

BILL OF RIGHTS

- o A bill of rights is needed and should be a Department of Human Services initiative in the 1989 session. The Department of Human Services should review other proposed bills of rights collected by ARC-MN and propose a bill of rights for all people with disabilities which articulates a clear set of entitlements.

PREVENTION

- o DHS should assume responsibility for creating an Office of Prevention which serves as a clearinghouse, planning, coordinating, and funding leader for prevention activities.
- o DHS should request priorities from the Early Intervention Council for 1989 legislative initiative in the area of policy, procedures, and implementation.
- o The Maternal and Child Health Advisory Committee of MDH should be asked for their recommendations on prevention.

AGING AND RETIREMENT

- o In 1989 the Department of Human Services should sponsor legislation that would fund staffing for a state task force on aging and disability. We recommend a broad base group to examine the topics and report to the Commissioner. Included should be: advocacy groups, providers (residential and day), aging experts, health care, state Board on Aging, MN State Council on Disability, Developmental Disability Council, Legal Advocacy, and Division of Rehabilitation Services county representatives.
- o Department of Human Services should further discuss the impact of Title III Older Americans Act Grant cycle change with Board on Aging and use these dollars for case management of persons who are elderly with disabilities.
- o The Department should endorse the recommendations of the consensus seminar on elderly issues, held on March 2, 1988, as part of the legislative mandated study on elderly needs.

GUARDIANSHIP

- o The Department should consider for immediate action the following changes in guardianship:
 1. Add more staff to guardianship office;
 2. Promulgate rules and standards on guardianship;
 3. Move guardianship office out of DHS;
 4. Recommend standards to cover corporate guardianship.
- o Far more study should be undertaken of all questions related to guardianship, both public and private. Perhaps a public discussion effort could be completed in the next few months to answer questions about the feasibility of continuing public guardianship and to consider the DHS guardianship Task Force report and recommendations.
- o The guardian must be separate from a case manager. Guardianship issues should be discussed as soon as a person is entering a system in order to determine whether or not they can be making their own decisions or if they need someone to be acting on their behalf.

INDIVIDUAL DISABILITY ISSUES MANAGEMENT

- o DHS should develop capacity and expertise in areas in addition to mental retardation, deaf, chemical dependency, and mentally ill. It should create new Division which would include: personal cares assistance, family support, waivers, housing, supported employment for people with traumatic brain injury, progressive degenerative neurological disorders, autism, epilepsy, and cerebral palsy.
- o DHS should target funds for other related conditions and consider expending the definition of disabilities to be consistent with the Medicaid Reform legislation, or perhaps the functional criteria definition. State match should be earmarked for providing Medical Assistance to this target group.

TECHNOLOGY INITIATIVE

- o The Department of Human Services should support a technology initiative to meet individual needs and implement the recommendations from the Governor's Task Force on Technology for People with Disabilities.
- o DHS should support Rule 17 revision to recognize rehabilitation technology services, for client evaluation, equipment selection, system design, and training.

PERSONAL CARE ATTENDANTS

- o The Department of Human Services should structure the attendant care program to ensure the greatest possible control by the recipient.
- o The Department of Human Services should communicate directly with the persons receiving Personal Attendant Care services and not just the provider of personal care attendant services, guardian, or family.
- o The Department of Human Services should work with the Minnesota Centers for Independent Living whose federal and state mandate is to do Personal Care Attendant referrals, recruitment, and training.
- o The Department should take leadership in developing guidelines/instructions for counties to assist families to use personal care attendants under the Medical Assistance TEFRA Option.

OMBUDSMAN

Seek increased funding and clear authority for the Ombudsman's Office to obtain information gathered by the Department and counties on various aspects of service provided to persons with developmental disabilities. Also, the office should seek funding to develop the capacity to conduct independent, individual evaluations of plans and outcomes (Levels 4 and 5) as described and required in the Medicaid Home and Community Quality Services Act proposal.

Provide authority for the office to obtain and compile information on services to persons with developmental disabilities provided by the Departments of Health, Education, and Jobs and Training. The purpose would be to have one office with comprehensive information on services provided or funded by various state agencies and local units of government to persons with developmental disabilities.

APPENDIX
TASK FORCE MEMBERS

TASK FORCE MEMBERS BY WORK GROUP

CHAIRMAN - Duane Shimpach

SERVICES WORK GROUP

Co-Chair - Sue Abderholden
Co-Chair - Anne L. Henry
Karen S. Pate
Barb Kaminski
LaVerne Czichotzki

QUALITY ASSURANCE WORK GROUP

Co-Chair - Dennis J. Theede
Co-Chair - Jacqueline K. Mlynarczyk
Alex Sworsky
Bill Hendrickson
Lee E. Slagter

INDIVIDUAL ISSUES WORK GROUP

Co-Chair - Mary O'Hara Anderson
Co-Chair - Colleen Wieck
William Nelson
Lee Schacht
(Vacancy)

AVAILABILITY AND FUNDING WORK GROUP

Co-Chair - David Ray Kiely
Co-Chair - Richard Cohen
Jerry Mueller
Anne Barnwell
Joan Schoepke