

**Assuring the Quality of Services
to Persons with Developmental
Disabilities in Colorado:**

System Design Recommendations

FINAL REPORT

ASSURING THE QUALITY OF SERVICES TO
PERSONS WITH DEVELOPMENTAL DISABILITIES
IN COLORADO: SYSTEM DESIGN RECOMMENDATIONS

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Preface

The size of the community residential network in Colorado has tripled over the last five years. In 1976-77 an estimated 400 adult clients with developmental disabilities were residing in community living arrangements. By 1981-82 the number had grown to nearly 1,200 adults and this does not include residents in the thirty-five 8-bed satellite program facilities constructed over the last few years. Under Colorado's Title XIX community waiver the number of residential programs, day programs, and case management services should grow even faster. Colorado Officials are justifiably proud of their ability to develop a continuum of programs for persons with developmental disabilities (DD) in Colorado in such rapid fashion.

However, there has been a growing realization that the accelerated growth of the developmental disabilities service delivery system may have outpaced the ability of state and county officials to manage it as effectively as they might like, that is (1) to decide just where the system should go and to assure that it proceeds in that direction, and (2) to establish a developmental disabilities quality assurance system (DDQAS) for assuring that the providers are capable of providing good service and that the services provided are appropriate to client need, efficient, and effective.

The Human Services Research Institute (HSRI) contracted with the Developmental Disabilities Council to assess the existing DDQAS, and to recommend ways in which it might be improved. In reviewing the existing DDQAS as documented and as seen through

the eyes of knowledgeable and concerned individuals, HSRI has indeed found system weaknesses, limitations and duplications, most quite apparent to those interviewed. This takes nothing away from Colorado's achievements, and is, one would expect, an almost certain concomitant of marked system growth. Colorado is probably better positioned to develop an efficacious quality assurance system today than it would have been had it moved to develop and institutionalize quality standards, monitoring, evaluation and control mechanisms piecemeal. All this is to say that while this report necessarily concentrates on system shortfalls, we are not mindless of the many strengths of Colorado's system of care for persons with developmental disabilities, nor should the reader be.

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I. INTRODUCTION

A. What is a Developmental Disabilities Quality Assurance System?

Any system developed to ensure the quality of services for persons with developmental disabilities should be composed of a number of interconnected quality assurance mechanisms. These mechanisms include four elements:

- o standard setting
 - This element involves establishing the dimensions of program quality of concern, and the level of performance expected for each.
- o performance measurement
 - This element involves measuring actual performance against an expected or (standard) level of performance.
- o feedback
 - This element involves relaying the performance measures to the quality assurance agency or decision makers. This information may be obtained and transmitted through direct inquiry, written reports, telephone, or direct observation.
- o control
 - This element involves deciding whether action is warranted to maintain or improve service quality based on the feedback obtained, and if so, initiating that action. The decisions may be ad hoc or pre-set. The controlling actions may be coercive or persuasive in nature.

These elements address one or more of a state's developmental disabilities quality assurance responsibilities:

- (1) to assure that providers of services have the capability to provide an acceptable level of service;
- (2) to assure that services are provided consistent with accepted beliefs about what constitutes good practice;
- (3) to assure that a given commitment of resources produces reasonable levels of services;

- (4) to assure that the services provided have the intended outcomes; and
- (5) to assure that the limited supply of DD services is provided to the most needy clients as defined by the legislative and administrative agency(ies) funding developmental disability services.

As the principal sponsor of these services the state assures these quality assurance responsibilities at two levels: (1) the policy or systems level, and (2) the operational or provider-specific level. At the policy level, quality assurance decisions are strategic and complex in nature, encompassing a relatively broad program scope and geared to a long versus short term purpose. Decisions at this level apply to the overall delivery system, and are primarily concerned with the relative cost effectiveness of alternative service designs (i.e., programs).

At the operational level, the quality assurance decisions are tactical and less complex in nature, more focused on present rather than future concerns, and less concerned with service design alternatives than with the provider's efficient implementation of a given service design.

B. Purpose and Scope of the Study

Most of the persons with developmental disabilities requiring public support are multiply-handicapped and require a mix of services appropriate to their ever-changing developmental levels and behaviors during the course of their lifetimes. Assuring the appropriateness and quality of these services amidst the growing size and complexity of the network of caregiving agencies is a particularly challenging task. The vulnerability of the population with developmental disabilities makes the task

especially important. Recognizing the need for a sound quality assurance system serving the interests of persons with developmental disabilities in Colorado, the Developmental Disabilities Council initiated this study.

The objectives of the study were:

- (1) To review and document the state-of-the-art and related trends in the design of quality assurance mechanisms applied to services for persons with developmental disabilities based on a review of the literature, interviews of knowledgeable individuals, and a survey of the quality assurance activities in 20 states.
- (2) To identify the administrative and economic quality assurance system requirements and constraints, and to identify system overlaps, duplications, and gaps based on an analysis of Colorado's existing quality assurance procedures.
- (3) To recommend a developmental disabilities quality assurance system design for Colorado consistent with the design requirements and constraints uncovered in the state-of-the-art review and Colorado System Analysis -- recommendations incorporating the best features of the quality assurance systems and methods found operating in other parts of the country.

Not so many years ago, most state authorities took a narrow view of their quality assurance responsibilities and related procedures. Their responsibilities, as they perceived them, were largely concerned with assuring the capability of providers to offer an acceptable level of service through the periodic on-site reviews of programs prerequisite to facility licensing and funding. Today, not only has the sense of responsibility increased, but so have the variety of monitoring and control mechanisms available to assure the quality of services provided to persons with developmental disabilities.

While a few of the states have had the wisdom and vision to take advantage of these mechanisms, many have not. Many of these

mechanisms exist for other purposes but may be tapped for the purposes of quality assurance as well.

The challenge is to breath life into these mechanisms using them to fulfill the states quality assurance obligations. The challenge is to fashion a cost/effective developmental disabilities quality assurance system through creative planning and active coordination. This study marks the beginning of Colorado's in-house planning and coordination efforts.

The scope of the study has been circumscribed by the Request for Proposal and Steering Committee to exclude:

- o day programs for children ages five to 21 in recognition of the quality assurance procedures established by the Colorado Department of Education.
- o those eligibility determination mechanisms designed to assure that the limited supply of developmental disabilities services are provided to the most needy clients in deference to the work of the target population committee established by the Division for Developmental Disabilities, Department of Institutions.

With respect to the first exclusion, although HSRI made no effort to improve upon the Department of Education's mechanisms for assuring the quality of day programs for children between the ages of five and 21, we included these mechanisms in our description of the existing quality assurance system in the interest of providing a more comprehensive picture of the developmental disabilities quality assurance system (DDQAS) in Colorado. With respect to the second exclusion, HSRI made no effort to formulate substantive recommendations concerning the service eligibility determination process.

Our most immediate concern in this study was with the non-generic residential, day and other support services devoted to

persons with developmental disabilities in Colorado. However, it should be noted that the generic services provided under the auspices of the Department of Education, Department of Social Services, Department of Health, and Department of Institutions will be of increasing concern in Colorado as the clients and delivery system become increasingly normalized.

C. Description of the Study Methodology

The study was organized into three phases each phase directed toward the achievement of one of the three study objectives. The results of each phase of the work are documented in Sections II, III, and IV of this report. Each phase consisted of several tasks as indicated below:

Phase I: Review of State-of-the-Art

Task 1 -- review of the literature;

Task 2 -- national survey of knowledgeable individuals and organizations;

Task 3 -- preparation of a working paper on the state-of-the-art including quality assurance system design tenets, system trends, and noteworthy methods together with a bibliography.

Phase II: Analysis of Colorado's Quality Assurance System

Task 4 -- review of relevant quality assurance system documentation;

Task 5 -- key informant interviews with service providers, quality information users, and others having a role to play in assuring the quality of services to persons with developmental disabilities.

Task 6 -- preparation of a working paper analyzing Colorado's existing quality assurance system.

Phase III: Design a Quality Assurance System for Colorado

Task 7 -- completion of preliminary quality assurance system design recommendations with options where appropriate.

Task 8 -- Preparation and submission of draft report for review by the project manager, steering committee, and other key informants throughout the state.

Task 9 -- preparation of the final quality assurance system design report.

1. Phase 1: Review of the State-of-the-Art

The study team's review of the literature built upon earlier reviews conducted for the United States Department of Health and Human Services. As part of the earlier review, the study team searched relevant journals in the Public Health Service, National Institute of Mental Health and other Department of Health and Human Services libraries, and completed "key word" searches with the National Health Planning Information Center, the Mental Health Clearinghouse, Project SHARE, MEDLARS, the National Technical Information Services, and OHDS-administered clearinghouses. HSRI also looked at reports of quality assurance mechanisms developed as part of court orders in the field of developmental disabilities, again borrowing from reviews done in a related study of the implementation of the federal court decree in Halderman v. Pennhurst funded by the Office of the Assistant Secretary for Planning and Evaluation of DHHS. While these reviews provided most of the grist for the general state-of-the-art assessment, as expected they did not prove to be a very rich source of state and local quality assurance methods per se, descriptions of which seldom find their way into the professional journals. For this reason HSRI augmented the literature review

with telephone interviews of knowledgeable persons at the national level, and of mental retardation/developmental disabilities program officials in a purposive sample of 20 states.

The Working Paper marking the end of Phase I was intended to provide a general assessment of the state-of-the-art in quality assurance system design, and of state developmental disabilities quality assurance system trends. The assessment was intended to serve as a backdrop for the analysis and design of a developmental disabilities quality assurance system in the State of Colorado. As the state-of-the-art and state trends in developmental disabilities quality assurance systems are intertwined, they were discussed as one. This working paper is essentially reconstructed in Section II of this report. The resulting bibliography is presented in Appendix A.

2. Phase II: Analysis of the Existing Quality Assurance System in Colorado

As part of this phase, HSRI reviewed current Colorado and Federal laws governing services for persons with disabilities as well as pertinent regulations, policies, contracts, standards, and other requirements imposed on the Colorado Developmental Disabilities System. The study team also reviewed over 60 other documents -- most collected and provided to HSRI by the Developmental Disabilities Council -- such as past studies of Developmental Disabilities Programs in Colorado, the home and community based Waiver Application for Medicaid, and relevant planning/budgeting materials.

Finally, the study team interviewed more than 100 persons concerned with the quality of services provided to persons with developmental disabilities in Colorado. Interviewed were:

- o individual client advocates (parents, citizen advocates, case managers and the clients themselves)
- o representatives of advocacy organizations (ARC, DDC, UCPA, CEPA, NASC, Legal Center for the Handicapped and Colorado Developmental Disabilities Council).
- o representatives of service providing agencies (Community Centered Boards, Regional Centers, residential program providers, day program providers, and case managers)
- o system administrators (Department of Institutions, Division for Developmental Disabilities; Department of Education; Department of Health; and Department of Social Services);
- o policy makers and budget makers (state legislators, legislative staff, gubernatorial staff, and budget office staff.

The interviews were conducted using interview schedules. These schedules contained questions general enough that they could be asked of most persons, yet comprehensive enough that, depending on the interests and knowledge of the respondents, could elicit quite specific and elaborate responses. A second working paper was prepared in order to provide a clear picture of the existing quality assurance system(s) intended to affect the quality of the following services to persons with developmental disabilities in Colorado: Regional Centers (Institutions); Community Residential programs for adults and children, including foster homes; Intermediate Care Facilities for the Mentally Retarded (ICF/MR's); host homes and group homes; Community day programs for children birth to five and adults 21 and older; Case Management, Follow Along, Family Resource, and

other home based services. The picture was intended to be of sufficient focus and scope to enable the study team and steering committee to identify and understand areas of system overlap, duplication, and gaps as a basis for recommending system improvements as part of Phase III.

The second Working Paper is essentially represented in Section III of this report. The results of the interviews are summarized in Appendix B. Appendix B also includes a copy of the interview schedule employed and a list of the individuals interviewed.

3. Phase III: Quality Assurance System Design Recommendations

Members of the study study team together with the Director of the Colorado Developmental Disabilities Council conferred for several days in May to develop a set of preliminary recommendations emanating from the analysis of the existing system, from suggestions of persons interviewed, from expressed positions of the steering committee members, and from their knowledge of quality assurance approaches as identified in the literature search and as identified in the state surveys conducted in the initial phase of the study. The study team drafted a set of preliminary recommendations aimed at bolstering weak quality assurance mechanisms, filling identified quality assurance gaps, and resolving areas of quality assurance overlap and duplication. In early June these general recommendations were presented to the members of the steering committee. A number of the recommendations consisted of optional ways in which they could be implemented.

The steering committee advised HSRI to modify a number of the recommendations in order to make them more efficacious and practicable in Colorado. The Committee also helped HSRI narrow the Implementation options to those most acceptable from an economic, administrative and political standpoint. In addition, members of the steering committee volunteered to provide the study team with written input on each of the recommendations in order to strengthen them and to better attune them to Colorado's situation. HSRI found this input to be of considerable value in drafting the quality assurance design recommendations described in Section IV of this report.

II. SYSTEMS FOR ASSURING THE QUALITY OF SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES: STATE-OF-THE-ART AND TRENDS

A. Some General Observations

The "state-of-the-art" in quality assurance system design and "trends" in quality assurance system design, while certainly related, are not to be confused. For instance, many state service systems are wrapped tightly in minimum program standards embodied in state licensing and regulatory procedures. They have standards covering every conceivable facet of program operations. Their program monitoring efforts are largely confined to periodic on-site reviews which have become less and less frequent with budget cuts in recent years. Quality control is heavily regulatory in nature with enforcement lax due to the lack of will and interest on the part of key state decision makers to bring in the heavy regulatory artillery in enforcing standards compliance. Also with the staff cut backs and the advent of information systems technology, states are relying more and more on program information and reporting systems for feedback on service quality.

These readily identifiable trends hardly represent the state-of-the-art and in many ways contradict it. As indicated in the following discussion, minimum program standards enforced through licensing and regulation are quite limited in terms of their ability to engender improvements in service quality. In the words of Ralph Nader (Institute of Medicine, 1975), "at best, regulation is a negative process occasionally enjoining bad behavior but rarely compelling good." Similarly, periodic on-site reviews and management information systems are known to be

of little value in distinguishing good and effective practice. Information and reporting systems are known to be notoriously poor agents through which to transmit information on service quality, information so rich and qualitative in nature. The inadequacies of these mechanisms are manifest in the repeated accounts in the news media of unsafe, abusive and fraudulent practices in nursing homes and other types of residential facilities housing disabled persons, all of which are licensed and periodically inspected and all of which submit numerous reports to state and federal officials.

And finally, the regulatory character and impersonal nature of these bureaucratic review, information system, and control procedures has been shown to foster an unhealthy "we/they" attitude between service providers and quality assurance agents -- an attitude widely reported to frustrate attempts by bureaucrats to influence provider practice and to frustrate attempts by providers to educate the bureaucrats.

All this is to say that it would be imprudent for Colorado to simply follow the lead of other states many of whom are now back tracking and even reversing direction. Rather it's in Colorado's interest to pursue those mechanisms best suited to its quality assurance objectives and service delivery system, and that are technologically, administratively, and economically feasible to implement.

This section is organized into three subsequent subsections corresponding to the core elements of any quality assurance mechanism as defined on page 1. Subsection B. discusses the

state-of-the-art in setting "quality" standards or criteria and measures for developmental disabilities programs. Subsection C discusses the two basic methods of feeding back information pertaining to the quality of service to decision makers. Subsection D discusses a number of control mechanisms for assuring service quality. Subsection E highlights the key findings and issues for consideration by members of the steering committee.

B. Setting Program Standards and Measures

1. Standard Setting

Different performance expectations or standards of performance are related to each of the five quality assurance responsibilities. These standards are grounded in both ideology and knowledge.

a. Ideologically Based Standards

The ideological base includes the social, ethical and cultural values, beliefs, and norms that govern the mission and purpose of various developmental disabilities service endeavors. Ideology stands above the system and to some extent dictates the influence that other factors -- specifically, theoretical, scientific and empiric knowledge -- will have on the service delivery system and the means employed. Ideology, stands somewhat apart since the values encompassed in an ideology define the general aims or goals of an enterprise as well as the range of acceptable courses of actions to be taken. Therefore, it can be said that ideology governs the ends of an activity (service) as well the means to be used to achieve these ends. The other knowledge bases provide guidance for carrying out the ends and for evaluating the relative effectiveness or efficiency of the intervention.

An example of this distinction can be seen in behavior modification programs for persons with developmental disabilities. If the end of such a program is to treat clients in a humanitarian fashion, then the use of cattle prods to control behavior -- even if it is an effective means of control

-- would be ruled out as an intervention. Any standards governing such a program would constrain the use of aversive techniques such as the one described.

In some instances, ideologically-based process standards may even take precedence over outcome standards. The designers of the Program Analysis of Service System, (PASS) and Accreditation Council on Mental Retardation and Developmental Disabilities (AC-MR/DD) standards would maintain that some process standards -- such as those related to dignified treatment and normalized environment -- are important to assess even if they show no discernible change in clients. It is the adherence to these process concerns in and of themselves that forms the basis for defining service quality.

Until the late 60's large custodial facilities were the accepted mode of care for most persons with developmental disabilities with little expected in terms of client development or change. Most clients were seen as wards of the state to be cared for in perpetuity. However, in the past two decades several values or norms have been introduced into the system, and today they permeate most developmental disabilities standards and policies:

- o the "normalization" ideal advanced by Wolfensberger (1972) fostered a dramatic shift in the perceptions of caregivers regarding the developmental potential of persons with developmental disabilities.

Related ideals also came to the fore at this time:

- o The principle of client rights, which has its roots in the general civil rights movement, became established through a series of court decisions.
- o The principle of maximization of independence (i.e.,

economic self-sufficiency and general self-reliance) was promoted as part of the Title XX, Vocational Rehabilitation Act, and Right to Education for All Handicapped Children Act.

Other principles or ideals that have been translated into program standards today are summarized below (Bradley, et. al. 1978):

- o Equal justice: All persons in the society have a right, both morally and constitutionally, to be dealt with in an evenhanded fashion by instrumentalities of government, to be protected from capricious actions of the government, and to be guaranteed access to the judicial process in order to redress wrongs.
- o Human dignity: Each person in the society has a core of personal integrity and uniqueness that defines his or her individuality. Human dignity is closely related to an individual's ability to make choices, to select and maintain possessions, to be treated with respect, and to live in surroundings that foster individuality and allow for privacy.
- o Equity: Equity is a value that speaks to the allocation of resources, services, and opportunities among individuals and groups in the society. Allocation or distribution of resources for governmental or social ends should be carried out in a fair and just fashion so that no individual or group receives less than its just due.
- o Individualization: Each individual has a unique range of human potential, and any service intervention must be tailored to that person's unique needs. As a society, we have an obligation to maximize human potential through the application of resources fitted to each person's strengths and weaknesses.
- o Right to reside in least restrictive setting: To the extent of their capabilities, all persons with developmental disabilities who have not committed a crime or proved themselves to be a danger to society have a right to be free of personal and physical restrictions. This right has been recognized in recent court decisions regarding the constitutional rights of persons with developmental disabilities residing in institutions.
- o Right to treatment: If an instrumentality of the government deprives a person of his or her liberty so as to provide care and habilitation, then it must provide care based on generally accepted standards. This value derives specifically from a constitutional argument that has been accepted in several judicial jurisdictions as a rationale for upgrading the level of institutional care

for persons held involuntarily.

- o Protection from harm: Protection from harm is a second value that has a basis in societal norms and that additionally has been recognized through litigation as being applicable to the rights of persons with developmental disabilities in institutions. In this context, it means that persons responsible for caring for the developmentally disabled are responsible for the continued physical and emotional well-being of those in their charge.
- o Efficiency: Efficiency is a value of a different order since it is essentially neutral and constant regardless of the ends to be pursued. It is simply that the operation of a program or system should be carried out in an expeditious, timely, and coordinated fashion.
- o Economy: Like efficiency, economy relates to the general functioning of a system and suggests that actions be carried out in a way that maximizes goal attainment and minimizes the cost in financial and other resources.
- o Effectiveness: Persons with developmental disabilities should receive those services that are expected to result in the greatest benefit according to the above values.

Colorado's legislation and planning initiatives clearly embody these ideals and there is little need to look elsewhere for direction.

b. Knowledge-Based Standards

Standards are also founded in knowledge. The knowledge may be theoretical, scientific or empirical in nature.

(1) Scientifically-Based Standards

Scientifically based standards involve proven explanations of how and why some service approaches work and others do not. In other words, they demonstrate relationships among service processes (interventions), inputs, and service outcomes. Very few standards of performance in the developmental disabilities field are scientifically based. To be categorized as such, there

must be scientific proof that a standard requires a particular input or intervention that consistently produces improved client outcomes. The core problem with linking the outcomes of developmental disabilities programs and specific program inputs or interventions is the enormous complexity of organizational (provider) behavior and individual (client) behavior, and the causal effects of the former upon the latter. It is difficult enough to indicate that a tenuous relationship exists let alone proving it and generalizing from it. As Haselkorn puts it, "[one] must cope with a chaotic array of interlocking client, worker, process, and social context variables which in spite of computer technology remain almost unmanageable" (1978, p. 334). The information lost in the course of simplification and the inability to control for the myriad of non-service factors possibly accounting for client changes usually frustrate the quest for scientifically definitive or conclusive results.

Moreover, to prove that particular program inputs or interventions lead to better outcomes is a costly proposition. The high cost coupled with the limited availability of funds to support human service evaluation research, makes it economically infeasible to conduct a lot of significant evaluations, and demands that the objects of such evaluations be prudently selected and properly conducted.

In an attempt to isolate the impact of a service intervention, evaluators run these measures in the presence (tests) or absence (control) of the human service intervention using the classical test/control group research paradigms.

However, given the limited ability to recognize and control for exogeneous factors affecting client outcomes, the results are often inconclusive.

The predominant problems, then, are the inability to isolate the effect of service interventions on client outcomes from the effects of the multiplicity of other variables influencing the client's state; the inability to control for bias through the differential selection of clients for the test or control groups; and the inability to generalize from one service situation to the next given the unique character of each situation. In other words, the evaluation researcher simply cannot fulfill the criterion for validity as required by the classical research model.

These problems are made manifest by the fact that findings and conclusions of many evaluative research studies are found to be in conflict (Lorish, 1977; Fischer, 1978; Wood, 1978). Eyman, DeMaine, and Lei (1979) found a relationship between environmental ratings (Program Analysis of Service Systems or PASS) of community homes and changes in adaptive behavior of retarded residents in facilities. Yet in a similar study, conducted within a public institution, Conroy and Lemanowicz (1981) failed to find any relationship between PASS ratings and changes in adaptive behavior.

While the evidence does not pinpoint those specific inputs or processes standards that are associated with desired client outcomes, it is possible to identify groups of program variables (e.g., developmental services, case management, and normalized

environment) that are associated with client outcomes and thus to strengthen the theories upon which many input and process standards are based. For instance, in the Conroy and Lemanowicz study mentioned above, the authors concluded that the most important variables, beyond initial client characteristics, were the amount of day program time away from the living unit, the number of daily medications administered, and the score given to the client's living unit on the Resident Management Team Survey (a measure of regimented versus individualized treatment).

(2) Theory-Based Standards

The theoretical basis for standards includes social, behavioral, physical, and other theories advanced to explain how and why some services seem to work and others do not -- specifically, why some service processes (interventions) and some inputs appear to lead to desired service outcomes while others do not.

All but a few input and process standards in the field of developmental disabilities are based on theory which reflects more or less plausible or scientifically acceptable principles. A human service theory explains the nature of the relationship between service inputs, processes and the client outcomes desired. Theories of service quality may be grounded in a variety of disciplines including social work, behavioral psychology, economics, and biology. Social and behavioral theories, however, predominate in the field. Numerous theories in the social and behavioral sciences have influenced both the definition of quality and the standards selected to measure

service quality.

Two of the most pervasive theories upon which developmental disabilities standards are based are: (1) management systems theory (Johnson, Rosenweig, and Kast, 1973) and (2) rational case work theory (Wood, 1978); Both of these theories represent the systems approach to management and differ only in the purpose for which they are applied.

Systems management as defined by Johnson, Rosenweig and Kast (1973) is: (1) goal oriented, with continual emphasis on objective achievement; (2) oriented to the optimization of the total system rather than the sub-systems, (3) is responsibility-oriented because each manager is given a specific assignment where results can be measured; and (4) is people-oriented, because workers are given challenging assignments and identified with results.

The systems management process begins with planning -- the managerial process of deciding in advance what is to be done, how and by whom. It involves selecting objectives and developing policies, programs and procedures for achieving them. The results of this process are plans. The plan then is a predetermined course of action resulting from the planning process. The remaining elements of the systems management process involve information feedback and control in order to assure that system accomplishments conform with plans. Standards for the administration of developmental disabilities programs are replete with requirements for standing plans and corresponding records of plan achievement.

Similarly, standards for developmental disabilities programs, like standards governing other human services, call for individual or case plans pursuant to rational casework theory. In the case of persons with developmental disabilities, they specifically call for individual habilitation plans (IHPs) and individual program plans (IPPs) that address agreed upon client goals and records of goal achievement. The AC-MR/DD standards contain no less than three dozen requirements for standing plans (AC-MR/DD, 1978). These written standing plans or procedures are intended to guide staff in lieu of ad hoc, personal management directives.

Preliminary data from the Longitudinal Study of the implementation of the Pennhurst decree in Pennsylvania suggest, but do not clearly demonstrate, that careful individual planning leads to measureably superior rates of developmental progress among clients (Feinstein, Lemanowicz, and Conroy, 1981). For Pennhurst class members in community living arrangements, detailed IHP guidelines exist, and formal review and approval by program specialists is required before implementation of the plan. Class members do display greater developmental growth than do non-class members in community living arrangements. However, class members also enjoy assistance from specially trained case managers with lower caseloads. Though the data do not allow one to say that IHP's alone make the difference, one may speculate that the IHP process helps make the difference.

While there are no known studies on the costs of preparing such program and case planning and monitoring documents, studies

in the health field may be instructive. As Brook notes in discussing the costs of monitoring ambulatory health care quality (1975, pp. 15-16):

Physicians in primary care spend, on average, about twelve minutes with each patient, of which less than one minute is devoted to recording information. If quality assurance activities increased this to three to five minutes, this could raise by one-third or more the price of an office visit; . . . on a national level this would increase the cost of care by about \$4 billion (\$4/visit x 5 visits/person x 200 million people).

The economics of documentation in the practice of medicine may be similar to the economics of documentation in the provision of developmental disabilities service. The question is not "whether the systems management approach is appropriate?" a systematic, goal oriented approach to program or case planning and control is unquestionably desirable. The question is how much of the planning must be documented. Certainly, the amount of formal documentation necessary for ease of internal management increases with the complexity and size of the project and organization. However, many programs for persons with developmental disabilities are small and the program management and case management processes are not that complex. To a large extent then, documentation requirements for smaller programs may be designed more for quality assurance purposes than to satisfy internal management requirements. One must then ask: (1) to what extent is such documentation needed and justifiable? (2) Would it be more efficient to devise less document-laden and burdensome means of monitoring developmental disabilities programs and client performance?

(3) Empirically-Based Standards

The empirical basis includes a body of practical experience relating to the delivery and receipt of services which gives rise to rules of accepted practice. The dictionary defines "empirical" as:

Relying on experience or observation alone often without due regard for system and theory; originating in or based on observation or experience; capable of being verified or disproved by observation or experiment.

The empirical method of setting standards may entail either a numerical approach (such as setting standards through the use of descriptive statistics) or it may call for a very judgmental process (such as might be used in peer review). In some cases, there are attempts to make judgmental processes numerical through the introduction of scales.

Standards, in an empirical approach, are sometimes set according to what the "typical" agency or provider achieves, as reflected in program reviews. What is "typical" may be defined as the mean, the mode, or the median performance. On the other hand, the norm, or generally accepted standard, may focus not on what is typical, but on what is the "best" or "worst." This approach is sometimes called "actuarial," in that expectations are based on observed patterns for large numbers of program settings such as an insurance company's estimation of expected mortality for a given individual based on the mean for many similar individuals. Each program or client experience is seen as a "natural experiment" and as providing a benchmark for judging other programs.

Efficiency and effectiveness standards or norms are

necessarily bound by experience since only experience can tell what level of productivity and client outcomes human service providers can reasonably be expected to achieve. While efficiency norms are typically set at the average "normal" level, they may also be set more liberally or conservatively. As a practical matter, however, efficiency standards in the form of fee or rate schedules are often set at whatever level funding permits (Gettings, 1981).

Reasonable standards can be exceedingly difficult to establish for most developmental disabilities services. This is because such services are highly individualized and problem specific, and can vary widely in terms of the amount of resources, principally staff time, required to address them. For instance, in studies of the average per capita cost of providing residential and day activities to mentally retarded persons, researchers have found that the staff time required is higher for more severely and profoundly retarded persons than for moderately and mildly retarded persons (Primrose, 1972; Jones and Jones, 1976; O'Connor and Morris, 1978; Mayeda and Wai, 1975; Jones et. al., 1982).

The diversity of client types and service approaches frustrates attempts to establish "efficiency" (input/output) standards that can be applied uniformly to a universe of providers. Bowers (1978), in "That Elusive Unit of Service," presents an excellent discussion of the enormous problems involved in trying to establish such standards and measures.

Program effectiveness (cost/outcome) standards and measures,

like the efficiency standards must be sensitive to workload (resource requirements) differences associated with different type of cases or presenting problems and with different types of services. As one can imagine, the hurdles faced in setting cost/outcome standards are even greater than those faced in setting cost/output standards, and the body of client outcome data is far too slim to even begin thinking about it.

Practically speaking, efficiency (input/output) and effectiveness (input/outcome) standards can only be set normatively, that is relative to what other providers are found to achieve. Moreover, they are best applied as part of cost effectiveness evaluations that attempt to control for key differences in clients and programs, or as part of large outcome monitoring efforts encompassing a sufficient number of providers to establish reasonable norms.

2. Measuring Developmental Disabilities Program Quality

Quality standards and measures of course go hand in hand. Standards establish what is expected and measures indicate whether the expectations(s) have been achieved. There are five types of measures of service quality corresponding to each of the five areas of quality assurance responsibility introduced earlier. They are:

- o Input measures which attempt to capture the capability to perform. They refer to resources applied such as the qualifications of staff, staffing levels, condition of facilities and equipment, and financial stability.
- o Process measures refer to the interaction between the client and the organization providing the service and to the administrative and support activities integral to the delivery of the service. Process criteria may also refer

to how well the client moves through the service delivery system.

- o Output measures refer to the level of effort expended by the provider and are commonly expressed in staff-specific terms (e.g., hours of direct staff time spent), client-specific terms (e.g., number of clients served), or activity-specific terms (e.g., hours of developmental service "x" provided). Input and output measures are often combined to form efficiency measures, that is the amount of output achieved per amount of resources expended.
- o Outcome measures reflect what happens to the client as an outgrowth of the service. Outcomes correspond to the client-related goals of the service and measure the extent to which the service has been effective in meeting these goals.
- o Accessibility measures relate directly or indirectly to those segment(s) of the developmental disabilities population who are served or unserved.

a. Input Measures

Input measures include measures of personnel resources, financial resources, and capital resources (facilities and equipment).

Personnel resources are by far the most prominent type of input generally accounting for 75% or more of a provider's operating costs. Typical measures pertain to the qualifications of staff as evidenced by their education and training and to staffing levels expressed relative to client levels or relative to workload.

Most financial standards and measures relate to the provider's financial condition. Does the provider represent a reasonable risk for the funding agency? Is the provider likely to be put in a position where financial constraints could seriously compromise the care provided individual clients? These

standards and measures are usually expressed as asset/liability and revenue/expenditure ratios. Most indicators gauge the adequacy and stability of the providers' base revenues and expenditures. The importance of this type of measure has grown with the proliferation of small community-based programs living on "low-fat" budgets and particularly vulnerable to cuts in revenue.

Though no national study has been done to assess the magnitude of the problem of stability, some emerging evidence raises serious questions. The surveys of residential providers done by the Center for Residential Community Services at the University of Minnesota (Bruininks Hauber and Kudla 1979) indicate that of the 4500 residential providers originally surveyed in 1977, 1,000 were no longer operating at the same address when the follow-up survey was conducted in 1982. The magnitude of this figure -- almost one fourth of the total respondents in 1977 -- suggests that the problem is real. While few stability measures are part of most developmental disabilities quality assurance schemes, the United Way (Hall, 1982; Young, 1982) have developed batteries of such measures that could be employed for purposes of assessing the resilience of programs.

Facility and equipment standards and measures relate to the size of the facility, programmatic areas within the facility, condition of the facility -- especially with respect to health, fire and safety conditions, and presence and condition of essential equipment. The condition of the provider's facility

and equipment are most relevant in the case of residential and day care providers where the primary concerns are with the safety and serviceability of the facility and equipment, and with the aesthetics of the environment.

The major drawback of using "inputs" as measures of quality is that they measure only the capability to perform and not actual performance. Focusing on inputs has the advantage of relying on concrete items that are easily observed (e.g., number of staff, number of fire doors, educational credentials, capital improvements to facilities and equipment). Most inputs change little in the short run and thus can be measured relatively infrequently. Revenues and expenditures seldom change significantly over a year. Staff credentials likewise change little in the short run. Staffing levels and training are about the only input that could conceivably change markedly within a given year.

b. Process Measures

The developmental disabilities service process must not only have quality in the technical sense but must also be conducted in an artful manner sensitive to the individual needs of the person being served. Similarly, the art of program management and administration can be as important or more important than the techniques or tools employed. Capturing the quality of the service process then involves measuring not only the technical skill with which the program is administered and with which the services are provided, but also the qualitative manner in which they are conducted. Logically, there should be a place for both

technical service approaches and art-of-service approaches to measuring service quality.

Brook, (1975 p. 134) proposes that quality of care is best defined as the sum of the "technical care" provided, the "art of care" provided, and the interaction between these two factors. He states that "technical care" includes the adequacy of the diagnostic and therapeutic processes, while "art of care" relates to the "milieu, manner and behavior of the provider in delivering care to and communicating with the client." He stresses that the two components are not just additive but interactive.

Most measures used to assess the technical aspects of the administrative support and service processes pertain to the existence of formalized program procedures and client-specific case planning and management procedures as discussed in the previous subsection.

(1) Art-of-Service Measurement

Measures addressing qualitative (art-of-service) concerns include the extent to which an agency displays concern, consideration, friendliness, patience, and sincerity toward clients. Such measures are particularly important given the program ideology in developmental disabilities, and the vulnerability of clients. Qualitative measures also gauge negative agency characteristics such as abruptness, disrespect, condescension, and inattentiveness toward clients. They are generally holistic in the sense that they are concerned with the overall service "gestalt" or even the total life situation of the client, rather than focusing on discrete aspects of the service

process or of the client's behavior or situation. The measures are heavily judgmental in that they draw principally on the conceptions and experience of the evaluator(s). They focus not on a particular service, but on the total context of the service process. This includes the client's current needs, resources, and past history; the organizational setting of the service delivery process; other demands upon the service professional; community attitudes and supportive services; the timing of particular actions during the service delivery process or the client's life cycle; and so forth. As Miles (1979, p. 591) observes:

. . . qualitative data are attractive for many reasons, they are rich, full, earthy, holistic, "real" and their face validity seem unimpeachable; their collection requires minimal front-end instrumentation. They tend to reduce a researcher's trained incapacity, bias, narrowness, and arrogance and their results reported in forms ranging from case studies to vignettes, have a quality of "desirability" (Smith, 1978). Finally, there are many reasons to believe that qualitative data can very usefully be played off against quantitative data information from the same organizational setting (Sieber, 1973) to produce more powerful analyses that neither sort of information could have produced alone.

The most serious and central difficulty in the use of qualitative measures is that methods of analysis are not well formulated. For quantitative data, there are clear conventions the researcher can use. But the analyst faced with a bank of qualitative data has very few guidelines for protections against self-delusion, let alone the presentations of "unreliable" or "invalid" conclusions to scientific or policy-making audiences. How can we be sure that an "earthy" "undeniable," "serendipitous" finding is not, in fact, wrong?

(2) Technical Measurement

Technical measures of the administrative and service processes, are by definition, amenable to quantification. As

indicated earlier, they concern such items as the existence of formal program and client specific planning and management procedures, response time for services of an urgent or emergency nature, and waiting time for scheduled services.

Johnson (1978), in a directory of environmental measures, listed about 50 indexes designed to capture the technical dimensions of the service process. Instruments include PASS, A Normalization and Development Instrument, the Resident Manager Survey, Characteristics of the Treatment Environment, Characteristics of the Physical Environment, and the Group Home Management Scale. Such measures are also prominent in the CARF and AC/MRDD accreditation manuals, state licensing handbooks, and so forth.

Given their formal nature, they are almost always documented as part of the provider's administrative records, case records and reports. Most measures are designed to verify administrative procedures and controls already in place. For instance, the review may establish whether individual habilitation plans are reasonably complete and up-to-date for purposes of individual client service planning and assessment, whether adequate procedures have been established for citizen participation, whether staff education and training programs are sufficient to retain qualified staff, and whether reasonable precautions have been taken to ensure that clients are not subject to abuse. Such formal controls are relatively static and need not be checked very often. Moreover, they appear easy to observe and verify directly through a review of standing operating procedures

(SOPs); and through random interviews with staff and clients.

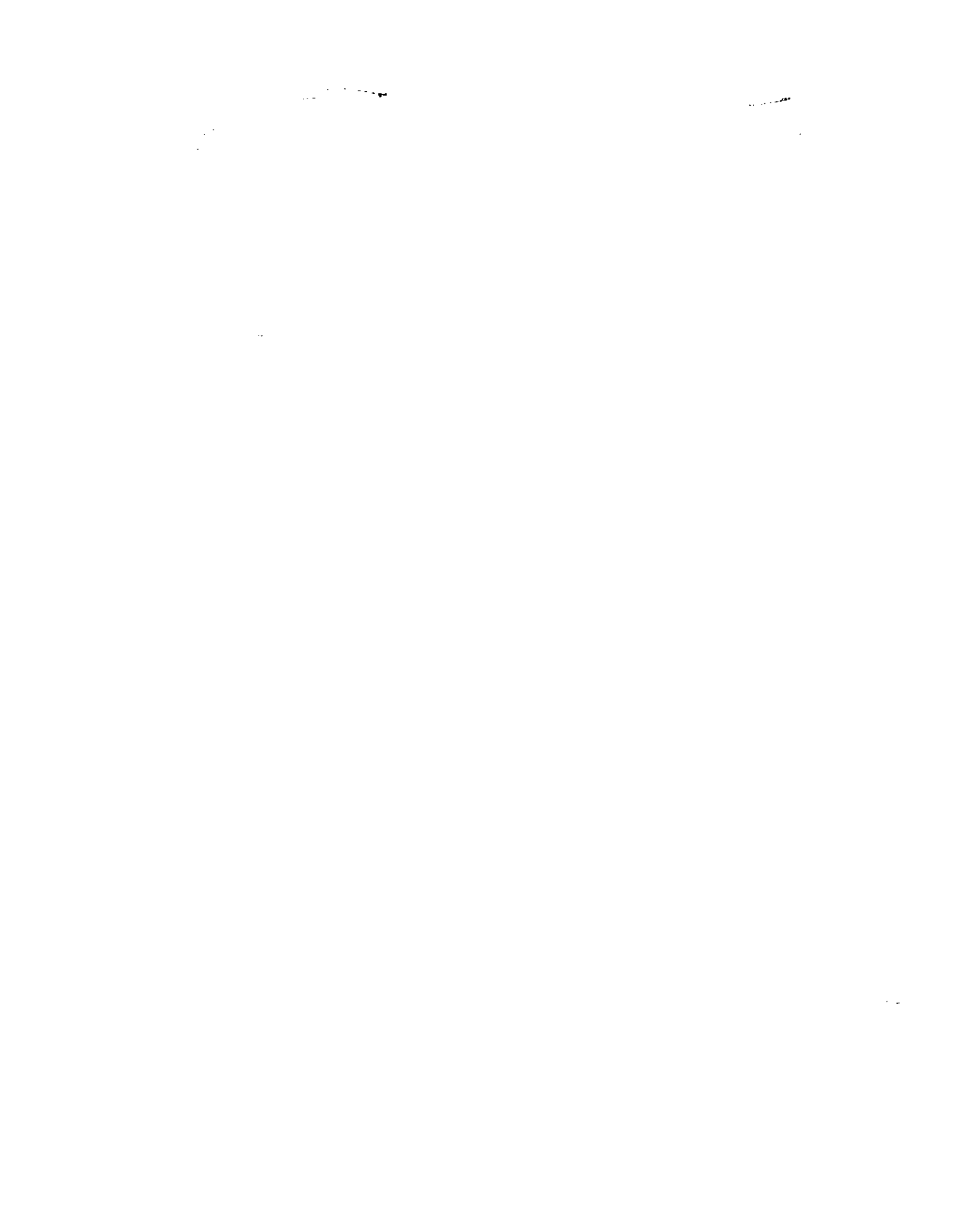
The assumption previously discussed is that such administrative and program management systems beget or are at least conducive to "good service." However, very few studies have been done to test such assumptions, and some front line workers ardently dispute the assumption. Moreover, they complain that the requirement to document takes scarce time away from clients while doing little to improve the quality of services. Haselkorn (1978) speaks of:

the mechanistic tools and rituals that trivialize the human experience, not to speak of the cost, the time, and the effort of the paper work involved. The morass of information being gathered and "data overload" bring to mind the query, "Where is the knowledge that gets lost in information?"

Others point out that the many formally documented procedures are little more than window dressing designed to satisfy outside reviewers, and that in practice less formal procedures, procedures often bearing little relationship to those formally documented, are routinely employed. Logic tells us that those providers accomplished in the art of documentation will fare better than those just accomplished in the art-of-service if such technical measures alone are used to rate provider performance.

The common disparity between formal organizational procedures and actual informal behavior has been well established in studies of organizational behavior for more than a decade (Azumi and Hage, 1972). Blau and Meyer (1971) say it well:

From an abstract standpoint, the most rational method of effecting uniformity and coordination in a large organization would appear to be to devise efficient



time interval may be the most appropriate measure.

In short-term programs where the volume of services per client is considered to be a prime indicator of program efficiency, the cost per period of service may be the most appropriate measure. However, in programs serving persons with developmental disabilities where the volume of services per client and/or the time spent in the program are both prime indicators of program efficiency, the cost per case is probably the most appropriate measure.

Unfortunately, reliable measures can be exceedingly difficult to obtain for most programs serving persons with developmental disabilities. This is because services are highly individualized and problem specific, and can vary widely in terms of the amount of resources, principally staff time and staff skills, required to address them (Jones, et al., 1982).

At the same time like services may be delivered by providers in a variety of ways. The ideal set of output measures would be those that are sensitive to workload (resource requirements) differences associated with different types of cases or presenting problems and with different types of services. Realistically such measures are difficult to obtain. In fact, after more than one year of intensive study aimed at obtaining reasonably valid and reliable measures of unit costs, Ashbaugh (in press) has concluded that a more cost/effective and reliable approach would have been to obtain measures of client outcomes as opposed to the less-telling measures of program output.

In most ongoing information and reporting reporting systems

concerning unit costs, the output measure categories (e.g., number of cases) are defined in a general way in order to keep the number of categories at a reasonable level and still embrace the wide spectrum of service approaches. Given such general unit definitions, such systems are not very sensitive to important differences in individual and provider service approaches. Thus they are of limited use for the purpose of analyzing the relative efficiency of providers, though they may be of some use for identifying exceptionally low output programs worth further investigation. Even more troublesome is the fact that the unit cost figures typically employed are effectively capped by the statewide rate setting procedures thus camouflaging rather than highlighting any real differences in provider productivity. It's not surprising then, that while a number of the states surveyed by HSRI (e.g., New York, Minnesota, California, and Washington) make some attempt to capture units of service figures as part of their management information systems, most are quick to acknowledge the limitations, possibility of bias, and uncertain reliability of this data.

d. Client Outcome Measures

As indicated earlier, the expected outcomes of developmental disabilities services are changes in client behaviors and capabilities, or changes in client situations. Changes in client situations can be relatively easy to measure (e.g., placement in a foster care home; placement in a residential home, etc.). However, the difficulties in obtaining valid and reliable measures of human behaviors and capabilities are well documented

in the psychological and sociological literature. In the context of service outcome measurement, the principal difficulties lie in developing reasonably economic methods for capturing the many dimensions of client behaviors and functioning that the provider may wish to affect. It is safe to say that given the many facets of client behavior, skills acquisition, and service situation, no one set of measures can begin to cover all of them.

In a few developmental disabilities service areas, unidimensional outcome measures may be appropriate. The use of reasonably straightforward outcome measures would seem to be well suited to vocational rehabilitation services. Typical measures are whether or not a client is working, percent of time employed, skills acquired, earnings, and so forth (Institute on Rehabilitation Issues, 1974).

While relatively easy to obtain, such single dimension client outcome variables are not as well suited to the bulk of services concerned with sustaining or building the capacity of clients with developmental disabilities to cope with the many exigencies of community living. The various and complex interrelationships of a client's problems and corresponding outcomes are simply too great to be adequately represented by a few one-dimension measures. The assessment of service quality using single dimension outcomes can be both incomplete and misleading. Even in the vocational rehabilitation field where single dimension outcomes are perhaps most appropriate, evaluators are moving toward more multi-dimensional indices of

client outcome incorporating measures in the physical, emotional and intellectual domains as they pertain to the work environment (Anthony, 1978; Institute on Rehabilitation Issues, 1974).

Changes in attitudes, behaviors and functioning targeted by service providers are commonly measured using scales and indices. An index is constructed through a simple accumulation of scores assigned to individual attributes. A scale is constructed through the assignment of scores and patterns of attributes (Babbie, 1975). These scales or indices range from those comprised of many explicit, discretely defined criteria or anchor points, which can be characterized as "tightly anchored" or "highly standardized" measures, to those comprised of loosely defined anchor points, which can be characterized as "global" or "less standardized" measures.

Well anchored measures based on a number of specific criteria are, of course, much easier to interpret than are global measures. Though anchored measures are just as dependent on personal judgment as global measures of client outcomes, the basis for that judgment is at least reasonably explicit. The quality assessor's attention is directed toward specific outcome dimensions, and the extent to which these dimensions have been realized is reasonably well marked (e.g., the ability to walk with the aid of a cane).

Most of the progress in the development of indices and scales of client outcome has been in assessing a person's level of functioning or, more broadly, his or her level of self-sufficiency or independence. These measures essentially address

four inter-related areas of functioning:*

- o Social adaptation -- covering interpersonal skills, activities of daily living, household work, etc;
- o Vocational/educational performance -- including work and job skills;
- o Self-care -- activities such as bathing, dressing, and feeding oneself;
- o Mobility -- the ability to travel from place to place.

There are many indices and scales that have been developed, pre-tested, and are currently in use in the measurement of developmental disabilities service outcomes. Mayeda and his colleagues at UCLA (Mayeda et al. 1978) have catalogued and described nearly 200 of these scales, indexes, and checklists. Yet, only a handful of them have been tested for reliability and validity. Moreover, for the few scales that include measurement of degree and severity of maladaptive behaviors, the reliability data are discouraging (e.g., interrater reliability of .68 for the maladaptive behavior section of the ABS). However, for the four areas listed above, very reliable (above .90 interrater and above .95 test-related) and efficient scales (under 25 minutes to administer) are available.

Outcomes indices and scales used for purposes of program assessment, as opposed to individual client assessment, must at some point be aggregated. For this reason, most client outcome

* Note: Westerheide, Lenhard, and Miller (1974) emphasize the need to address not only these outcome measures in developing an adequate measure of client outcome, but physical, psychological, and economic dimensions as well. These latter factors also influence a client's ability to cope with his or her particular situation.

scales and indices are "nomothetic" type measures, that is, based on the notion of similarity (aggregatability) of variables or traits across persons. Even the highly individualized goal-attainment scaling and the target complaint measures are nomothetic when used for program assessments to the degree that the attainment of goals and/or the degree of reduction of complaints are considered to mean the same thing across all clients. While it is possible to use ideographic measures -- measures that assess stability or change on variables defined within persons for purposes of monitoring or evaluating the outcomes of programs, there are few such schemes reported in the literature.

One problem with these measures is that not all changes in client behaviors and functioning are manifest at least in the short run, and the short-run effects may or may not be lasting (Donabedian, 1978). Longitudinal measures would certainly be of limited use for assuring the quality of a provider's services in the present. Moreover, the link between these longitudinal measures and the provider's intervention(s) grows quite weak as the client is subject to a wealth of subsequent life events (Vosburgh and Alexander, 1978). The rapid erosion of program effects is familiar phenomenon. One example is provided by the follow-up studies of Head Start, which virtually all have found that initial differences between experimental and control groups largely disappear by the end of the first year of school (Deutscher, 1979).

An added limitation to the measurement of outcomes among clients with developmental disabilities -- and alluded to earlier -- is the inability to prove that client outcomes were or were not attributable to the performance of individual providers. Unlike the input, process, and output dimensions of performance which are intrinsic program characteristics, client outcomes may well rest outside of a provider's control. As indicated earlier, in order to control for such variables, it is necessary to obtain measures for a sufficient number of clients to establish that particular client outcomes are not isolated events. The outcomes must be shown to be consistent and fair indicators of the provider's performance.

The California Department of Developmental Disabilities in response to legislative mandates, has spent significant amounts of time and money developing ambitious outcome monitoring and evaluation schemes which are now being pared back considerably. The most prudent approach to the use of outcome measures for quality assurance purposes would seem to be first, to monitor outcomes primarily in order to suggest how provider(s) might achieve more desirable client outcomes with changes in practice. Secondly, from time to time, client outcome evaluations designed to indicate the efficacy of different types of developmental disabilities program interventions could be conducted as part of policy-level evaluations of programs.

C. Feedback

There are two basic methods employed to feed back service quality information to quality assurance organizations. Feedback on service provider performance may be obtained indirectly through reports and/or directly through on-site reviews.

1. Self-Reviews and Reports

Self reporting relies on the service provider to report agency information to the quality assurance organization in an accurate fashion. The agency that opts for this method may decide to accept the data as supplied by the providers, or it may conduct personal spot-checks to verify the information. As a variation, the quality assurance organization might decide to check only those elements which had previously been reported as out of compliance (management by exception), or check only certain critical competencies or performance dimensions which the quality assurance organization is interested in verifying. For instance, a quality assurance organization may wish to verify a provider's education credentials, or to check the installation of an old facility's fire sprinklers.

The self-reporting method requires the smallest staff and thus is the most economical. It provides the data in a business-like way without overtones of inspection or punishment, and can promote self-evaluation as the service providers complete the forms. The obvious advantage of provider reporting procedures is that the marginal cost of bringing more providers into the system is minimal. One more set of reporting forms and instructions and another provider is included!

The temptation to make the reports more and more inclusive has been strong, especially with improved state computer processing capabilities and increased demand from the growing staff's of state legislatures eager for cost/output data. Consequently, developmental disabilities service providers have been inundated with reporting requirements covering more and more facets of their operations. What began as automated accounting systems for provider revenues and expenditures, and statistical reports on the numbers of staff and numbers and demographic characteristics of clients served, in many states and local jurisdictions has now grown to include reports on the numbers and types of services provided, client problems, and client outcomes. In a few cases, reports are automated all the way from the provider to the state central office. In most cases, provider reports are computerized after they reach the state regional offices or central office. Worth noting is the fact that most of the state officials surveyed by HSRI in phase I of this study confided that they considered much of the information obtained through reports, particularly the unit cost, client behavior and functioning data to be too unreliable to use.

1. Process Data

Logistically, information in reports must be reasonably uniform, quantified, and brief. Cost information reported by expenditure category, and information on the numbers of clients and their characteristics are relatively easy to capture in report form. It is much more difficult to categorize services since they vary widely in both content and intensity. The

problem is one of semantics and logistics. Services are "softer," and more difficult to define cleanly than are costs, numbers of clients, or staffing levels. In order to convey service information, an elaborate set of mutually exclusive and uniform service categories is required. Bowers (1978), and Coulton (1978) present excellent discussions of the overwhelming problems involved in obtaining such information in the human service arena.

It is a prohibitive if not impossible task to arrive at a manageable set of service categories given the enormous diversity of service approaches in the field of developmental disabilities and lack of consensus on standardized definitions. Without shared definitions among providers, reporting categories are construed differently by staff charged with completing reports. In light of these problems, the "no-win" choice is between: 1) a smaller, oversimplified set of service definitions which fail to distinguish adequately among service processes; or 2) an unmanageable number of discrete service definitions requiring an extensive dictionary of definitions that few if any providers have the time or inclination to understand and use.

In most cases states opt for the former defining services in a general way in order to keep the number of categories at a reasonable level and to accommodate the wide spectrum of service approaches. Because such systems are not sensitive to important differences in individual and provider service approaches, they are of limited use for the purpose of individual provider accountability though they may be of some use for identifying

"outliers" worth further investigation.

In short, the provider reporting medium is well suited to the transmission of that limited provider input, output, and outcome information that can be quantified and organized into a clearly defined, mutually exclusive and manageable set of categories. It is less well suited to the transmission of information pertaining to the type, let alone quality, of services provided for purposes of quality assurance.

2. On-Site Reviews

Personal observations of provider operations, and interviews with staff and clients are probably the only means by which to obtain reliable measures of service processes. There is a fairly typical set of steps established as part of an on-site survey of developmental disabilities service providers.

The site visit is scheduled well in advance. The initial activity of the survey team is to meet with key staff and board members of the program. At this time, the team leader reviews the survey procedures and purposes, and the program staff offers an overview of the program's operation and problems. The agenda is then reviewed and finalized, and specific team assignments and appointments are scheduled.

The survey itself may entail observations of staff activities, procedures, and the facility itself; examination of program records; and interviews with unit heads, program staff, board members, clients, and members of the community.

Before leaving the program, the team members individually rate the services and facilities to which they were assigned and

exchange the data with the other team members. This interchange of data, especially in the overlapping areas, serves as a check of the validity and reliability of the overall survey.

At the conclusion of the on-site survey, the team may in some cases hold an exit conference with the program or agency staff, at which time the team presents its findings relating to the program's strengths and weaknesses. Items that are out of compliance are identified and discussed with particular attention to a plan of correction. The team may make overall recommendations and listen to provider responses.

On-site reviews are the keystone of most state licensing, regulatory compliance, funding certification, and accreditation schemes in the field of developmental disabilities. They are generally conducted from once every six months to once every three years. They are well suited to the determination of a provider's capacity to offer an acceptable level of service. On-site reviews also provide a practical way to observe the program directly and to assure that the facility is safe and meets established program standards. Further, on-site reviews may be the only sure way to assure that providers are caring only for those clients they are authorized and funded to serve.

Most importantly, on-site reviews can be used to assure that the provider has the administrative procedures and controls in place to provide an acceptable level of service. For instance, the review may establish whether individual habilitation plans are reasonably complete and up-to-date for purposes of individual client service planning and assessment, whether adequate

procedures have been established for citizen participation, whether staff education and training programs are sufficient to retain qualified staff, and whether reasonable precautions have been taken to ensure that clients are not subject to abuse. Such formal controls are relatively static and need not be checked very often. Moreover, they are easy to observe and verify directly through a review of the standing operating procedures and through random interviews with staff and clients.

On the other hand, pre-announced on-site visits are not well suited to the observation of service processes and outcomes. The visits are too infrequent and short to obtain a reliable picture of service activities and results. More observations than the few possible during an on-site review are almost always necessary to assure a reasonably reliable result. It may well be that observations must be made on an episode (total service-per-client basis) rather than on a random client basis in order to make a valid assessment of the overall service being provided. In short, observation procedures require days -- and in some instances weeks -- of a trained observer's time.

Further, because of the potentially profound consequences of most on-site reviews for providers, the difficulty of obtaining an accurate picture of the service process is compounded. Negative reviews may directly or indirectly affect the provider's ability to attract clients, to obtain government sanctions to operate, or to obtain the funds necessary to support the service. For these reasons, staff may be "on-guard" during the review period. This confounds the ability to observe the service

process as it actually occurs. Bible and Sneed (1976) attest to this "best-foot-forward" behavior in their study of the effects of an accreditation survey on the performance of a state institution for persons with developmental disabilities. During the two-day accreditation survey period, these researchers found a dramatic increase in the percentage of scheduled client services actually implemented when compared to the surrounding nine week study period.

In short, periodic on-site reviews employed as part of state licensing, certification, and private accreditation quality assurance mechanisms can be effectively employed to ascertain if a provider has the service capacity and program and fiscal controls necessary to assure an acceptable level of service. However, they are too brief and obtrusive to obtain a reliable picture of provider practices and outcomes. Most importantly, they are too infrequent to protect the day-to-day interests of the clients and the community. The inability of these on-site monitoring schemes to prevent practices detrimental to clients is evident in repeated newspaper accounts -- including the Denver Post -- of consumer abuse, and of poor and even fraudulent practices by human service providers.

A few states allow unannounced visits to programs for persons with developmental disabilities -- some as part of ongoing monitoring schemes, others as part of ad hoc evaluations and investigations -- in order to catch candid glimpses of provider practices (e.g., Michigan and New York). At last report, one region in Michigan was using case managers to perform

continual program monitoring of the sort necessary to spot client abuse and other evidence of malpractice. However, advocates and providers alike are concerned that the monitoring advantage gained by surprise visits could be offset by the invasion of client privacy unless some reasonable protocols are established. While most states have the right to access programs unannounced, most refrain for fear of antagonizing the providers unnecessarily.

New York, Montana, and Minnesota reportedly have Boards of Visitors that have free access for purposes of investigating complaints. Some associations for retarded citizens in Canada coordinate the efforts of parents and other volunteers who drop in on providers from time to time for informal visits (Levy et. al., 1982). The purposes of these visits is not solely to provide the quality assurance agency with additional "eyes and ears," but to promote the integration of programs into the community, and to increase citizen involvement.

In recent years other states have decentralized their on-site review operations in order to reduce the time and travel expenditures. The review teams are housed at regional centers or in county offices (e.g., California and Florida). Finally, more and more states are bringing in volunteers to augment staff reviews (e.g., California, Colorado, Pennsylvania and Michigan). However, cuts in the funds available to organize and train these volunteers, and cuts in travel have impeded even these initiatives.

In other states, efforts have been made to streamline the

review process thus eliminating the time required on-site. Service providers and/or client case records may be selected purposefully to reflect those most likely to manifest service problems thereby increasing the monitoring yield (e.g., Texas). In the case of ad hoc provider and/or client (case) screening techniques, a variety of selection criteria can conceivably be employed. The most common selection method is to concentrate on those providers or cases in which complaints or incidents have been registered during the period preceding the on-site review.

A number of states ask all providers to complete preliminary self-reviews using a checklist or questionnaire designed to indicate the extent to which they are in compliance with the standards of concern in the on-site review. This information may be used to facilitate the review process and reduce the time that must be spent collecting information on-site. It may also be used as a screening device to identify those providers most out of conformance and warranting review.

D. Control

There is a rich variety of control mechanisms for coercing or persuading providers to take actions deemed necessary to maintain or improve the quality of their services. For purposes of this discussion we have chosen to distinguish eight types of mechanisms. These schemes are not mutually exclusive, and are often practiced in combination.

- (1) Licensure: the process by which an agency of the government grants permission to individuals or organizations to provide a service.
- (2) Regulation: a statutory based process that assures legal intervention by the government to punish infractions of the law by any individual or organization, but that does not require any assurance of quality prior to practice.
- (3) Performance Contracting: a process establishing a binding agreement between an agency or organization in a position to pay or provide monetary rewards, and a service provider. The agreement may require that the service provider meet certain pre-established qualifications and criteria. Payments may be different for different service providers, clients or practitioners.
- (4) Fiscal Sanctions and Incentives: schemes whereby the amount of funding a provider receives is a function of his efficiency or effectiveness. Such schemes may be part of regulatory or contract mechanisms.
- (5) Accreditation: a process whereby organizations providing a service are formally recognized by a non-governmental agency as capable of providing quality services.
- (6) Training and Technical Assistance: processes designed to instruct and persuade providers to deliver quality services.
- (7) Advocacy: a process whereby an individual or an organization acts to assure the quality of services to individual clients with developmental disabilities or classes of clients through legal, administrative or other appropriate means.
- (8) Client Complaint Procedure: a formal process for redressing the complaints of persons with developmental disabilities.

1. Licensure

While licensing certainly has a place in the arsenal of quality assurance controls, it is "a heavy weapon" to be used sparingly and prudently.

The two key questions that must be asked when deciding whether a program needs to be licensed by the state are:

- o Will the unlicensed practice clearly endanger the health, safety, or welfare of the clients with developmental disabilities and is the potential for harm easily recognizable and not remote or dependent on tenuous argument?
- o Is the service so technically complex and is the service provider so inaccessible that ordinary citizens have neither the expertise nor the access to inspect for quality and safety, and must rely on the authority of the state for protection?

State decision makers have answered "yes" to these questions, since all have some mechanism whereby new residential programs must be granted permission to serve clients with developmental disabilities. In most states the licensing function is left to those in the health department or other departments concerned with facility safety and with protecting the health of the clients with developmental disabilities. Most state mental retardation/developmental disabilities officials concentrate on the programmatic dimensions of care. Program staff may simply provide input into the licensing decision or may have separate approval procedures. In a few states, residential and day programs are licensed or authorized to operate by the program staff (e.g., New York, Washington).

2. Regulation

The fundamental question is how encompassing should the regulatory mechanism be in terms of the dimensions of service quality addressed? A mounting concern of federal and state policy makers is over-regulation. Havinghurst captures the current sentiments of those who oppose increased governmental regulation (1975, p. 577):

As a remedy for problems of public policy, regulation is overprescribed. Indeed, regulatory programs are to many legislators what prescription drugs are to some doctors: a useful tool which it is tempting to overuse in an effort to demonstrate to the "consumer" (voter or patient as the case may be) that the decision-maker cares and is trying to do something about the problem.

There are three important features of regulation as a control mechanism. First, it is based in statutory law and thus carries legal sanctions.

Second, by definition regulations are designed to handle the "rules" not the "exceptions." For instance, it may be appropriate for a rural sheltered workshop to provide transportation for its clients whereas for an urban service provider such a requirement would be superfluous. Such special provisions are generally ignored in regulations for reasons of simplicity and equity. The added administrative burden and cost of devising and administering a myriad of exceptions contradict one of the main purposes of regulations: to reduce the time public administrators must spend in ad hoc rule making and oversight of services.

Third, regulatory standards are relatively difficult to adopt and to change given the political process surrounding the

making of state laws and regulations. The Intermediate Care Facility for the Mentally Retarded (ICF/MR) standards offer a case in point. Many of the regulatory programmatic, physical plant, and life safety requirements in the ICF/MR regulations were formulated with larger residential facilities in mind. Their adoption has effectively discriminated against smaller ICF/MRs (15 beds or less) where such standards are not always appropriate. Some of these requirements have now been changed or modified but only through intense lobbying efforts by consumers and private agency groups. For example, ICF/MR regulations state that hot water temperature at all taps accessible to residents must be controlled so that the temperature does not exceed 110 degrees Fahrenheit. This prohibition impeded resident training programs on the use of hot water taps. Subsequently, regulations were changed to allow waivers in residences where clients were being trained in the use and control of hot water.

Other physical plant and life safety standards that reflect an institutional as opposed to a homelike setting include the use of slip resistant floor coverings, manual fire alarm systems, and -- for homes with more than one story -- the addition of a fire escape or other stairway accessible to the outdoors. Consumer and other agencies have recently completed work with the Center for Fire Research at the National Bureau of Standards to develop a life safety evaluation system for community based homes that would remove some of the institutionally oriented requirements.

The questions that must be asked when deciding what dimensions or standards to support through regulation are:

- o What individual standards, if violated, require the threat of force of law to remedy?
- o Is it reasonable to apply the standard to all developmental disabilities providers or are there numerous situations where the standard would be inappropriate?
- o Is it reasonably certain that the standard is and will continue to be a valid and reliable indicator of service quality and thus worth freezing and legitimizing in the form of regulation?

Again, there are no discernible state trends. In some states compliance with virtually all program standards is managed through the regulatory compliance mechanism. In other states, regulations cover some program standards and not others, and in still other states the belief is that few if any standards need be enforced through the regulatory mechanism.

3. Performance Contracting

The number of private providers of service to persons with developmental disabilities has grown dramatically over the past decade. This "privitization" of the DD delivery system has naturally given rise to the use of the contracting mechanism as a means of control (Bradley, 1982). Service contracts represent agreements between the state or local funding agency and the service provider calling for the provider to deliver service(s) to clients for which the governmental agency will provide a specified amount of fiscal and other support. Contracts have a number of general advantages and disadvantages as a quality control mechanism relative to regulation.

Conceivably, the range of quality criteria that could be included in a service contract may be even greater than in

regulations because the requirements need not be strictly based in statute but may include any number of additional provisos.

One advantage of contracting arrangements is that they are far more flexible and versatile than regulations. The sanctions agreed upon in a contract may be more or less severe. They may provide for non-payment, partial payment, or full payment for services, or they may provide for no further funding until some corrective action is taken and satisfactory service provider performance is demonstrated. Regulations generally provide for full payment or no payment; discretionary partial payments and other such arrangements are not usual.

Contractual provisions are also more amenable to change than are regulatory provisions. Reasonable contract amendments may be granted at almost any time, and at the very least, at the time of the contract renewal -- usually on an annual basis. Thus, service quality requirements and/or associated sanctions are much more susceptible to change than are regulatory requirements and sanctions.

The associated drawback is that the relatively changeable nature of contract provisions may diminish their weight in the eyes of service providers and the discriminating public. Practitioners may spend more effort seeking changes to contractual provisions than seeking ways to comply. Though such resistance certainly takes place with respect to objectionable regulatory provisions as well, the difficulty in obtaining waivers of regulatory requirements is generally understood and avoided where at all possible.

Another consideration is that the contracting mechanism allows government agencies to sidestep the legal problems involved in granting statutory sanction to a variety of special service arrangements and/or clients. If such arrangements are placed in statute, legal challenges on discriminatory grounds by unfavored providers or consumers are almost inevitable on the grounds of "greater goodness," selective or discriminatory enforcement, and arbitrary or capricious use of discretion. For example, Gwen Morgan (1974, p. 70), in discussing the legal aspects of the federal day care regulations, claims that an argument might be successfully made before the court on behalf of the children not in day care that "the high cost of meeting the FIDCR (which includes more than that deemed necessary for the child's protection) uses up the appropriation and leaves them without any services," thus generating a greater evil than the good it seeks. Individual contractual agreements seldom prompt such legal challenge.

The states surveyed vary considerably in the extent to which contracts incorporated quality standards. In most states contracts contain few strings and are purely fiscal in nature; however, they do require that the providers meet the quality standards fixed in state and federal regulation or in private accreditation codes. In a few states, contracts specify not only the services to be provided and types of clients to be served, but specify a variety of levels of process, output and even outcome requirements as well (e.g., California). Most states reported that the contracts were loosely enforced.

Interestingly, California's contracts have now reached a point where officials feel they have become too burdensome to manage and renegotiate each year, and they are considering removing some contractual provisions and placing them in regulatory form.

Performance contracts are most effectively used to effect changes in the types of services provided, or clients served, rather than to assure the quality of ongoing services. For instance, in Pennsylvania, a performance contracting system has been in operation for several years providing contractual incentives and sanctions to further the state's deinstitutionalization aims (Hadley, 1983).

4. Fiscal Incentives and Sanctions

Fiscal incentives and sanctions may be a part of regulatory or contracting mechanisms and thus are treated separately for purposes of this discussion. These funding incentives or sanctions are intended to encourage efficient operations and discourage inefficient, wasteful, and fraudulent operations. The influence of funding as a control mechanism is particularly strong in the case of developmental disabilities service providers, many of whom depend entirely on the single source of funds affected.

However, the literature on organizational behavior warns of the problems of establishing objectives and rewarding performance without considering possible "perverse" effects of such rewards. Researchers and administrators in many social service fields including the field of developmental disabilities are familiar with the phenomenon of "creaming" or choosing easy, low

cost cases in response to performance appraisal schemes that place a premium on serving a maximum number of clients at a minimum cost. In the vocational rehabilitation program, a legislative mandate to serve "individuals with the most severe handicaps" arose in part from the tendency of programs to reject severe or difficult clients in order to maximize success in terms of the sole criterion -- "number of cases successfully closed." It is hardly surprising that service providers do what they perceive as necessary to gain recognition, monetary advantage, or even survival (Funkhauser, 1979). This is especially a danger in the case of services for persons with developmental disabilities where costs have been shown to vary significantly as a function of client developmental levels and problems (Primrose, 1972; Jones and Jones, 1976; Jones et. al. 1982).

In private industry, where the outputs are tangible products and the quality varies little as a function of labor time and effort, a system that holds out rewards or punishments on the basis of volume may serve to increase productivity. However, in the case of labor-intensive developmental disabilities services where the worth of the service can depend heavily on the amount of effort expended by staff, such a system may cut short the amount of time devoted to each client to the point where it is no longer of value. Then again, a provider may simply choose to redefine the service or to overstate the outputs while continuing to perform the service as always. This avenue is easy to take since developmental disabilities services are by nature difficult to observe or audit independently.

Paradoxically, where states have instituted graduated reimbursement programs designed to pay more for more difficult cases and less for less difficult cases, they have encountered just the opposite problem -- "reverse creaming." This means that some providers may retain more difficult cases, and retreat from doing all they can to increase the functioning level of their clients. This is particularly troubling in the field of developmental disabilities where the aim is to maximize client functioning. In California and New York for instance, state officials suspect that providers are understating the levels of functioning of their clients in order to maximize revenues, and are trying to think of ways to correct this problem. Not long ago, the Medicaid offices in several states including Illinois abandoned their differential reimbursement schemes for developmental disabilities services under Title XIX. They concluded that the added cost of administering their increasingly complex reimbursement procedure, outweighed any possible program savings that might have ensued. Officials have recently devised a more refined system, but feel it may be too complex. In California, officials are contemplating a counterbalancing scheme providing financial rewards for reported improvements in client levels of functioning as evidenced in the client IPPs.

It our judgment the problems described above warn against such schemes. Donabedian is correct when he says that "everything that human ingenuity can devise will be used to tame [such] regulatory mechanism[s]," and that "[one must] anticipate such behaviors" (1976, p. 28). Moreover, given the inability to

make reliable causal connections between changes in client outcomes and individual provider interventions, rewards based on changes in client outcomes are out of the question. Given these limitations, the State of Washington for one has purposefully steered clear of using its client outcome and program output data to support differential funding.

5. Accreditation

Accreditation is defined by Ross (1979) as follows:

. . . a process of evaluating and recognizing performance and integrity of an institution that meets predetermined standards or criteria established by a competent agency or association, usually private. Accreditation entitles the institution to the confidence of the community and public and implies that a program of quality is being offered. The basic point behind accreditation is that the status of being accredited is assigned by some other party; it is not self assumed (p. 1).

Accreditation has two purported advantages over public licensing, regulatory, and contracting schemes as a quality control mechanism. First, the professionally-dominated accreditation and certification bodies are thought to have more influence over professional practice than do government agencies. As described in the next subsection, the professionalization of practitioners is believed to generate an ethic, attitude, or frame of reference rather than a recipe for behavior. As it pertains to compliance, standards developed by or approved by professional groups seem to have a greater likelihood of acceptance and influence than those arising from the public administrative domain. Professional or peer persuasion rather than administrative coercion is generally thought to be the most effective means of controlling human

service practice.

Benveniste (1977) emphasizes the importance of the influence that organized associations of practitioners have on the behavior of their members. He explains how sets of general rules about practitioner behavior, appropriate to various circumstances, evolve within these circles. These rules are gradually accepted by practicing organizations as the norm. He contends that professions create a formal secondary network cutting across task-oriented organizations. As such, they represent an informal network that serves to mediate and protect the behavior of its members from demands of the hierarchical structure. Since professions emerge from a basic knowledge or skill, they have considerable ability to exercise influence on the processes taking place within organizations.

Finally, he notes that professionally based forms of control tend to center on role performance. Formal standards and measures are rejected because they sharply narrow the practitioner's ability to exercise discretion based on his or her knowledge or experience. Professionals prefer to be judged by their peers trusting that their peers are experienced and sensible enough to weigh all aspects of their performance.

The second advantage of accreditation is that there is less danger of compromising service quality objectives in the interest of cost containment and public accountability concerns. The accreditation mechanism is a private rather than public medium of quality control and is therefore somewhat insulated from cost and funding eligibility considerations which may compromise service

quality requirements. Cost containment and productivity or efficiency standards, commonly found in regulations and contracts, may lower or distort service quality standards. As Orlans puts it (1975, p. 140): "public quality standards might be skewed to federal or state priorities, or distorted by political expediency." Most of all, quality standards might be lowered from an ideal level to a level which most, if not all, providers can attain in order not to jeopardize their life blood, funds. Accreditation and accreditation standards, on the other hand, may better serve to discriminate between those providers that can and do meet the higher standards, and those that can't meet them or aren't interested in trying.

The major disadvantage of credentialing is that it is ostensibly a voluntary scheme; organizations can and do choose not to participate, and the non-participants are likely to be those having the least ability to meet the accreditation requirements. Logically speaking, providers most in need of improvement fail to be certified or accredited, or fail to even apply, knowing or fearing that they would be denied. The professional domination of most accrediting/certifying agencies and their minor consumer/public representation raises questions concerning the professional vs. the public interest. Of the thousands of residential and day program providers in the United States, only a small percentage currently participate in AC-MR/DD and CARF accreditation programs.

As explained earlier, most accreditation schemes mentioned in the previous section are based on voluntary compliance. Some

accreditation requirements, however, have been adopted by state and federal agencies as prerequisites for recognition and funding. This is particularly true in the health and education fields. In health, federal and state funding agencies rely on some private accreditation standards as a condition for payment. For example, the standards of the Joint Commission on the Accreditation of Hospitals (JCAH), which were originally developed for voluntary accreditation, are now being used as a basis for funding decisions by the Health Care Financing Administration. In other words, the JCAH standards now have "deemed status" which means that they are used in deciding provider eligibility for Medicaid (Title XIX) funding.

In response to the mandate of the Rehabilitation Act of 1973 that states establish standards for all rehabilitation facilities as a condition of receiving federal funds, many states elected to require that rehabilitation facilities which provide services to clients of the state vocational rehabilitation agency be accredited by such groups as the Commission on the Accreditation of Rehabilitation Facilities (CARF), or the American Speech and Hearing Association (ASHA) rather than developing their own standards and assurance systems.

Advocates of such public/private quality assurance hybrids see them as having the advantage of both public and private control schemes; antagonists wonder whether such advantages are more apparent than real. The purported advantages are that the scheme retains the provider acceptability associated the practitioner-dominated accreditation associations, and provides

some insulation from political and economic pressures that they compromise service quality. At the same time, the government is able to take economic advantage of the work of the private credentialing bodies in making eligibility determinations, and is able to make its influence felt (in the public interest) through these groups (e.g., gaining a greater public/consumer say in the development and administration of the standards, in assuring non-discriminatory personnel practices, etc.). Finally, linking credentialing with provider eligibility for funds is bound to increase the number of organizations interested in participating, and thus increases the scheme's coverage.

Still, the primary concern is that the marriage of public and private quality concerns ultimately compromises the rigor of the standards. Once standards become prerequisites for funding, the accrediting body is under significant political pressure to moderate compliance requirements. Orlans (1975, p. 10) observes that the financial importance of eligibility influences the accreditation judgment and impairs the voluntary nature of accreditation.

Anderson identifies three areas of legal concern: possible liability under federal and state anti-trust laws, liability to consumers or individuals who rely upon the accreditation, and possible liability for injury to business (in Orlans, 1975, p. 86). The growing tendency to challenge or threaten to challenge accrediting agencies in the courts can be an unwelcome consequence of the linkage of accreditation to eligibility for federal funds in other areas. It is easy to understand how

accrediting agencies would think twice before denying accreditation to recalcitrant service providers for fear of incurring the expenses associated with lengthy court actions, and the possible exposition of untidy aspects of the accrediting agency operations.

Thus, it appears that private accreditation organizations may come under increasing legal and fiscal pressures associated with their dual role of accreditation and eligibility determination -- certainly enough to wonder to whom their first allegiance belongs.

States vary widely in their perceptions of the utility of the AC-MR/DD and CARF -- accreditation schemes. Some states are committed to using the AC-MR/DD (e.g., Maryland) and others to CARF (e.g., Florida) in lieu of state licensing and regulatory mechanisms and have been willing to underwrite their use. Others have given the providers the option of one or the other (e.g., South Dakota). Still other states favor their use but cannot afford to underwrite them and thus have declined to require providers to use them (e.g., Oregon). Most state officials still view them as desirable albeit somewhat superfluous additions to state regulatory compliance and licensing mechanisms, and are not willing or able to invest the funds necessary for their support. These state officials favor state regulatory compliance and licensing mechanisms for reasons of cost, responsiveness to state and local concerns, and a desire to maintain the state/provider interaction associated with state regulation and licensing (e.g., Washington, Texas).

6. Training and Technical Assistance

The control schemes as outlined above are characterized by the exercise or threat to exercise formal sanctions, many of which are relatively severe, negative, and impersonal in nature. They are coercive not persuasive. Such formalized quality assurance schemes seem well suited to the control of measurable and reasonably stable service inputs (e.g., staff, facilities or equipment), and even some measurable outputs (e.g., number employed, number served, or number completing training). However, they are less suited to assuring that service provider processes conform to "quality" protocols. This is because individuals providing services tend to respond negatively to negative sanctions and positively to positive sanctions.

In terms of controlling the practices of human service practitioners, the overwhelming evidence is that formal, bureaucratic mechanisms are less effective than less formal, less bureaucratic procedures (Blau and Meyer 1971; Carzo and Yanouzas, 1967; Azumi and Hauge, 1972; Weissman, 1973). The literature on organizational development strongly suggests the need to rely less on heavy-handed bureaucratic procedures, and to concentrate more on informal and constructive training and technical assistance activities.

While organizational standards can formally dictate the basic roles and responsibilities of each worker, attempting to dictate how s/he fulfills these responsibilities or how s/he plays a particular role is largely an exercise in futility. In fact, bureaucratic control mechanisms, if overdone, can alienate

the human service worker (Argyris, 1973). The corollary is that the most effective means of control are those that are less formal and that rely more on interpersonal networks than on impersonal procedures (Organ and Green, 1981; Azumi and Hage, 1972).

As Maloof (1975, p. 25) explains, the professionalization of practitioners, which can largely be effected through training, generates an ethic, attitude, or frame of reference rather than a recipe for behavior. The gentle persuasion of peers rather than administrative coercion is generally thought to be the most effective means of controlling human service practice. Practitioners are likely to respond to professionally based forms of control such as training and technical assistance more so than to administrative based forms of control when it comes to questions of methods or practice.

Most states report sponsoring staff training sessions mostly in the form of workshops on particular subjects such as proper administration of medications. However, relatively few have statewide training programs for developmental disabilities practitioners (California, Washington, New York, Kentucky). Fewer still have established programs for the certification (i.e., formal recognition) of staff completing specified programs of training (e.g., California). New York requires that entry-level staff in state programs complete a program of in-service training during the first year at the conclusion of which they are raised two pay grades. They are working on instituting a comparable scheme for private providers.

Unfortunately, a number of state developmental disabilities programs, Colorado's included, have had to abandon many of the training programs they once had in the face of past budget cuts.

7. Advocacy

In general, "advocacy" means persuasive activity, on the part of an individual acting on his or her own or on someone else's behalf, to secure services that the client wants or requires, and to safeguard and exercise the client's rights. Section 113 of the Developmental Disabilities Assistance and Bill of Rights Act, establishes a narrower purpose -- to organize a system whose mission is to safeguard the rights of people with developmental disabilities (Clarke and Stearns, 1977). However, federal Developmental Disabilities guidelines stated that these rights "must be construed in the widest way to include any legal or other rights which other citizens enjoy, especially the right of due process and equal protection under the law" (Developmental Disabilities Office, 1976, p. 1).

Section 113 also states that advocates should be independent showing undivided loyalty to their clients with developmental disabilities. The advocate's ethical responsibility is to exercise professional judgment solely for the benefit of the client free of compromising influences and loyalties. Neither personal interest, the interests of other clients, nor the desire of third persons should be permitted to dilute the advocates loyalty to his client.

Advocates have the capacity to seek the full range of remedies to redress violated rights as an extension of the canon of loyalty to the client. The full continuum of informal and formal approaches can range from informal grievance mechanisms and settlements, internal and external administrative reviews (e.g., special education hearings, welfare fair hearings), to appearances in any rule-making, legislative or court proceedings to protect client interests (Clarke and Stearns, 1977).

The AC-MR/DD standards maintain that advocacy may be performed by the clients with developmental disabilities themselves although not all are capable of doing so. Each individual with developmental disabilities should realize his or her potential for self representation, and agencies should assist individuals to develop and exercise this ability (AC-MR/DD, 1978). These individuals may be assisted in their self-advocacy efforts by involving them actively in their IHP and IPP planning and providing them with information about service alternatives allowing them to make informed choices along the way.

Citizen volunteers including parents, practitioners, and interested others may provide advocacy services. A number of states have organized groups of citizen advocates operating under their state protection and advocacy programs, state association for retarded citizens, or other private associations (California, Michigan, Kentucky, and Georgia). Given the proper direction and training, these individuals can provide the continual and incidental (sometimes unannounced) oversight necessary to detect critical service problems, and to warn of potentially explosive

instances of client neglect and abuse. Moreover, they can do so at a bargain price without the personnel and travel costs attending the deployment of state on-site review teams. As McCormack (not dated) explains, citizen advocates are proactive as opposed to reactive, that is they do not simply respond to complaints but are involved with programs on a continual basis.

In other states, citizen advocates operate under the auspices of the state. Institutional patient advocates commonly called boards of visitors, have been organized in at least a half dozen states including New York, Montana, and Minnesota.

Case managers, when they are independent of the agencies providing services to clients with developmental disabilities, may also serve as client advocates. This is the case in a number of states surveyed (e.g., Michigan and Minnesota) where, in addition to providing planning and follow along services, case manager professionals or volunteers are trained to identify service quality problems and are provided channels through which to initiate the informal or formal actions necessary to remedy these problems.

Case managers by definition are in a unique position to obtain information on the quality and appropriateness of the services their clients receive. They are sensitive to the needs of the client, understand the practical constraints and problems encountered by providers in delivering services to these clients, and should have an intimate knowledge of the individual client's situation given their involvement in the individual habilitation planning process. They have every reason to pay frequent visits

to those providers serving their clients; their presence, therefore, is likely to be seen by program staff as more routine and less threatening. They are often afforded a look at staff practices as they really are. The same cannot be said of standards compliance surveyors.

In many states, case managers are not administratively independent of the agencies providing services and are seen primarily as coordinators of service for individual clients. In a few states, there are no case managers.

Lawyers or lay advocates may be necessary when a client with a developmental disability requires intervention on his behalf in the courts or before administrative bodies. Even though such extreme steps may not be called for on a routine basis, the presence of an attorney in an advocacy organization makes the possibility of litigation a tangible factor in any negotiations on behalf of a client. Many states including Colorado rely heavily on legal advocacy programs.

The questions to be asked regarding the role of advocates in quality assurance and monitoring are:

- o To what extent can advocates be made routine monitors of services to persons with developmental disabilities?
- o If advocates become routine monitors of services, then do they risk losing some of their independence as they come to be seen as agents of a state quality assurance system?
- o What is the appropriate balance in an advocacy system between paid and volunteer staff, and legal and non-legal personnel?
- o What are the key factors that separate the role of the case manager from the role of the advocate?

In HSRI's judgment advocates represent a valuable proactive

resource that can be marshalled in many states for monitoring and influencing those aspects of service quality referred to earlier as the "art-of-service" dimensions.

8. Complaint Mechanisms (Reactive Control)

There are a variety of mechanisms that can be used for channeling, investigating and resolving complaints of clients with developmental disabilities. Ombudsmen are impartial officers charged with investigating complaints and framing advisory recommendations. They may operate under the aegis of a private organization or association, a quasi-governmental commission, or may sit in a public agency. Monk, Kaye, and Litwin (1982) describe an even more definitive breakdown of ombudsman programs as applied in the long term care and health fields.

Most ombudsman in the developmental disabilities field sit within state or regional offices and are impartial only in the sense that they are not employed by the provider. They are not independent of the department administering programs. However, this indirect conflict of interest may be offset by the ombudsmen's ability to more readily access state decision makers.

New York state employs ombudsmen as part of a semiautonomous agency established by the legislature for the sole purpose of assuring the quality of services to mentally disabled clients. This agency is called the New York State Commission on the Quality of Care for the Mentally Disabled. In the vast majority of states there are no ombudsmen to act on complaints, although most have some sort of formal mechanism for redressing client

grievances.

There are no known private organizations of ombudsmen in the strict definition of the word operating in the developmental disabilities arena. Most private organizations with related concerns would more properly be labeled advocacy groups. All states have some form of protective mechanism whereby a state agency or board has the authority to intervene in situations presenting actual or potential hazard to persons with developmental disabilities. This mechanism may be triggered with or without the consent of the person involved.

E. Summary

This subsection highlights the major points made in HSRI's review of the state-of-the-art and trends in the design of quality assurance systems for services to persons with developmental disabilities.

1. Setting Program Standards and Measures for Developmental Disabilities Services

a. Setting Standards

- o Very few program performance standards have been shown scientifically to lead to improved client outcomes.
- o Most process standards are based on systems management theory designed for large and complex organizations and tasks (e.g., such as NASA) and as a practical matter entail substantial documentation. Many developmental disabilities organizations are not large and many cases are not that complex. Documentation is costly. How much documentation is necessary and to what extent can it be trimmed without affecting the quality of service?
- o To be equitable, output, efficiency, and outcome standards must be sensitive to differences in client problems and capabilities, and to be reasonable such standards must be set normatively. The body of experience to date is too slim to support setting outcome standards in any but the most rudimentary fashion (e.g., clients do not on the average lose skills over time).

b. Measuring Program Quality

- o Input measures gauge only the capability to perform and not actual performance. They change little overtime, and consequently do not need to be checked frequently. Generally speaking, the same is true of technical process measures used to verify the existence of formalized plans and procedures.
- o Art-of-service process measures are qualitative in nature and not amenable to systematic quantification. They are dynamic and changing and should therefore be monitored continually -- especially in light of the vulnerability of clients with developmental disabilities and the central importance of process standards to program ideology.
- o Efforts to monitor and evaluate client outcomes can be

inordinately costly unless carefully conceived and well planned. However, client outcome information is essential for state developmental disabilities policy making and for the design of practitioner training programs.

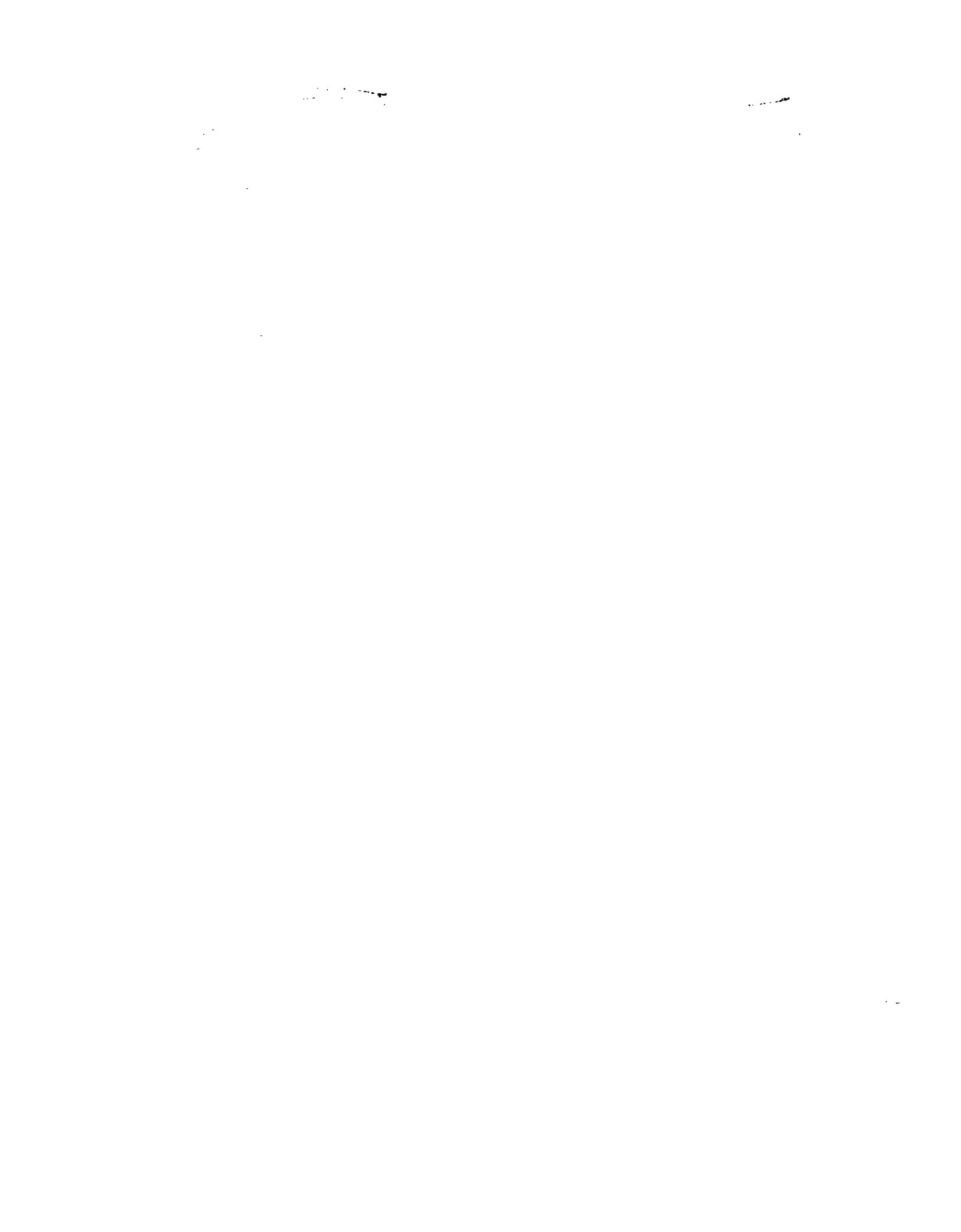
2. Feedback

- o The provider reporting medium is well suited to the transmission of provider input, output, and outcome information that can be quantified and organized into a clearly defined, mutually exclusively and manageable set of categories. Such reports are less suited to the transmission of information pertaining to the type let alone quality of services provided. The reporting medium should be used to transmit only that data actually used by the recipients of the reports.
- o Periodic on-site reviews are suitable for checking adherence to input, accessibility, and technical process standards. Continual, less formal and less obtrusive on-site reviews are required to check art-of-service standards. On-site reviews can be streamlined and made more economic through provider and case record screening techniques, decentralization of review teams, and use of trained volunteers.

3. Control

- o The licensing and regulatory mechanism should be used prudently and sparingly.
- o Some performance criteria should be included in provider contracts but only to the extent that they are reasonable, enforceable, and not present in regulation. Due to their dynamic or esoteric nature, such criteria require renegotiation each year.
- o The use of fiscal controls to either reward or punish providers has serious pitfalls including the "creaming" of more able clients in systems where improvement is rewarded, and reverse "creaming" in systems where the care of severely disabled persons is more generously reimbursed. Until the state-of-the-art is improved and ways can be found to reduce these potential distortions, Colorado officials should be very cautious in adopting such control techniques.
- o The peer-based and independent nature of accreditation is positive insofar as it has the ability to influence practice relative to public regulation. However, as a voluntary scheme accreditation, covers too few providers

- to satisfy the state quality assurance responsibilities.
- o Citizen, case manager and legal advocates can play important roles in monitoring provider practices and in persuading providers and other responsible decision makers to institute service improvements.
 - o A well-planned program of provider staff training and technical assistance is a positive and effective means of instructing and persuading practitioners to improve their practice; it is a primary and essential component of any quality assurance system. The certification of staff or staff pay incentives for the completion of a training program may be considered as ways to encourage staff participation and job satisfaction.
 - o Every state should have a complaint mechanism known to the clients and/or client advocates where they can register complaints and have them acted upon by responsible state decision-makers.



III. ANALYSES OF THE EXISTING QUALITY ASSURANCE SYSTEM IN COLORADO

A. General

This section is organized into four sub-sections according to the basic quality assurance responsibilities outlined in Section I. Section B addresses provider-specific mechanisms designed to assure that individuals and organizations providing services to persons with developmental disabilities have the capability to perform at an acceptable level. Section C. addresses provider-specific mechanisms designed to assure that services are provided in accordance with generally accepted standards of good practice. Section D. addresses provider- and policy-level mechanisms designed to assure a reasonable level of service for a given commitment of resources. Section E. addresses provider-level and policy-level mechanisms designed to assure that the services being provided have the outcomes intended. Most of the existing quality assurance mechanisms appearing in Sections B -- E are described in terms of: the services to which they apply, their statutory regulatory or administrative bases, how they work (standards, performance measures, feedback and control), and notable strengths and weaknesses.

B. Assure Capability To Provide Quality Service

This responsibility may be effected through the licensing or certification of providers. Licensure is the process by which the state grants permission or legal sanction for a provider to operate. It is based in statutory law. Certification refers to a process by which a funding agency of federal, state, or local government grants permission to a provider to receive public funds or serve in the public employ. It is usually based in contractual law. Both require a would be provider to spend the time and effort necessary to tool up, develop needed competencies, and to take the steps necessary to safeguard the health, safety, and welfare of the clients. The licensure and certification mechanisms may be applied to organizations or individuals.

1. Organizational Licensure and Certification

The licensing and certification of residential and day programs serving persons with developmental disabilities are processes conducted by the Departments of Health and Social Services in Colorado.

a. Residential Programs

(1) Regional Centers

The state operates three Regional Centers or Class IV facilities. These centers serve clients having few if any self-help skills and requiring significant medical attention; clients committed by the courts because of aggressive or delinquent behavior and who are sometime injurious to themselves and others;

clients exhibiting aggressive behavior; and clients lacking self-help skills and requiring intensive training services not presently available in the community.

As state run operations, Regional Centers are not subject to state licensing per se, however, they must undergo a similar review procedure in order to receive a certificate of compliance from the Department of Health. Moreover, in order for their clients to be able to receive Title XIX funds, the centers must be certified as in compliance with federal ICF/MR standards as contained in C.F.R. 45.249.12. Each year a survey team from the Health Facilities Regulation Division, Department of Health conducts an on-site review to check standards compliance. In addition, the survey team reviews all of the clients individually to assure that they are healthy and engaged in programs of active treatment.

(2) Satellite Homes

As part of Colorado's efforts to serve people with developmental disabilities in the least restrictive environment that meets their needs, a project was undertaken to move as many residents of large state institutions as possible into more normalized, homelike settings in the community. The result of that effort was the development and construction of 35 eight-bed (ICF/MRs) administered by the three state Regional Centers.

These satellite homes are subject to the same program of certification as the Regional Centers.

(3) Private Intermediate Care Facilities for the Mentally Retarded (ICF/MRs)

All community based ICF/MRs in Colorado are either Class II or Class III nursing homes. The Class II facilities serve clients requiring minimum supervision, moderate supervision and transitional living. Those Class II facilities over 15 beds must conform to Health Department regulations for nursing care facilities while the Class II facilities under 15 beds are licensed under residential facility regulations.

Class III facilities make up a new category of small ICF/MR facilities (8 beds). These facilities are designed to serve clients who require more intensive, specialized programming through intensive developmental training, behavior development programs, and social/emotional development programs.

Class II and III intermediate care facilities for the mentally retarded are licensed annually by the Department of Health in accordance with 24-4-104 C.R.S. 1973. Before an application for licensure is granted or renewed, the program must be approved by the Division for Developmental Disabilities, Department of Institutions. Until recently, all program approvals were based on on-site visits using a "checklist for monitoring community residential services" as a guide. The lack of funding this past year has forced the Division for Developmental Disabilities (DDD) to rely mostly on self reviews and reports by the ICF/MR providers.

According to Department of Health rules, the Department of Health is authorized to conduct on-site surveys unannounced to assure compliance with Department of Health Laws and

Regulations. However, as a matter of course, following program approval, a survey team of five to six persons schedules and conducts an on-site review of the program. The on-site review team checks compliance with state IHCF-MR standards (effective March 3, 1982). At the same time, the team checks compliance with the federal ICF/MR standards, (CFR 45.249.12) in order to certify the facility for federal Title XIX funding. In addition, the survey team reviews all of the clients individually to assure that they are healthy and engaged in programs of active treatment.

(4) Intermediate Care Facilities

These Class I facilities are general purpose nursing homes which accept all types of clients including those with developmental disabilities. The licensing and certification of general intermediate care facilities (Class I facilities) is not subject to prior approval by the Division for Developmental Disabilities and the facility reviews and inspections of individual client care are not pinned to developmental disabilities programmatic standards.

(5) Adult Residential Facilities

Adult residential facilities for persons with developmental disabilities requiring minimum supervision and housing less than 10 persons are also licensed by the state and subject to prior program approval by the Division for Developmental Disabilities. Essentially, the same on-site review procedure described for the ICF-MRs is employed, though the standards

applied are those pertaining to residential care facilities effective February 1, 1973. As these programs do not receive Title XIX funds, the facilities need not be certified for Title XIX funding.

(6) Respite Care, Host Homes and Individual Supervised Apartments

These facilities are not licensed or certified for funding by the state. Funding by the Division for Developmental Disabilities is contingent on approval by the Division. However, a lack of manpower has meant that many of these programs must be approved based on a paper review rather than based on on-site reviews.

(7) Child Care Facilities

Department of social services is the licensing agent for all providers caring for one or more unrelated children in a location outside the child(s)' or childrens home in accordance with the Child Care Act (26-6-1 through 26-6-112) C.R.S. 1973 as amended. Child care facilities include residential child care facilities (RCCF's), specialized group care facilities, and family care homes where most persons with developmental disabilities in Department of Social Services' facilities are found. Family Care Homes are facilities for child care in a place or residence of a family or person, intended for the purpose of providing family care and training for a child under the age of 16 years, who is not related to the head of the home. Residential child care facilities (RCCF's) provide 24-hour residential group care and treatment for 5 or more children

between 3 and 21 years old.

Minimum standards have been issued and published for these residential programs in conformity with Article 4 Title 24, C.R.S. as amended 1973, and minimal rules and regulations found in CRS-26-6-101 through 26-6-112 published in Section 7400, VII of the Social Services Manual. These standards and rules do not include specific provisions for developmental disabilities programming.

RCCF licenses are granted and renewed every two years directly by the Department of Social Services. The licenses are granted based on reviews of renewal applications and generally on on-site visits by Department of Social Services licensing staff. However, the number of programs actually visited has decreased in recent years as the number of Department of Social Services professional licensing and inspection staff has declined.

As part of the Department of Social Services (DSS) licensing procedure, approvals must be obtained from the local zoning, building, health and fire departments. Each RCCF must be approved by the state or local departments of public health as conforming to the sanitary standards prescribed by departments of public health under provisions of Section 25-1-107 C.R.S. 1973, and must conform to fire prevention and protection requirements of local fire departments in the locality of the facility, or in lieu thereof, the Department of Labor and Employment as required by 26-6-104(4) C.R.S. 1973 as amended.

24-hour family care homes may be certified by county

departments of social services or licensed child placement agencies, or they may be licensed directly by the state. Certified foster homes may receive placements only from the certifying agency. Certificates must be renewed annually based on renewal applications and on-site inspections. Licenses are renewed every two years, and an on-site visit is conducted both as part of the license application and renewal process.

b. Day Programs

Day programs serving persons with developmental disabilities are defined to include those serving children as well as those serving adults.

(1) Day Programs for Children

Day programs serving children with developmental disabilities include:

- o Infant Stimulation programs serving children from birth to three years. They provide early identification of developmental lags, one-to-one training for the child in the home, and train the parent in therapeutic and educational activities for the child. These programs allow the child to receive early training which will allow for a higher level of functioning as he or she gets older, and includes gross motor, fine motor, self-help, social, language, and cognitive skill development.
- o Preschool services are for children three to five years of age. Educational and therapeutic services, usually offered in half-day programs, are provided to assist the child in developing the skills needed to enter the highest level of school programming possible with an emphasis on integration in the public school system.
- o Day Training programs are for children ages five to twenty-one for whom the local public school education system has no appropriate program. Services include academic and enrichment learning experiences through gross motor, perceptual motor, sensory training, communication skills, interpersonal skills, health maintenance and leisure skills.

In accordance with the Exceptional Children's Education Act (ECEA C.R.S. 22-20), Rules for the Administration of the Handicapped Children Act (P.L. 94-142), and the Developmental Disabilities Act (P.L. 95-602 amended in P.L. 97-35), the Department of Education is responsible for assuring a free and appropriate education to all handicapped children ages five to 21 and for assuring that appropriate services are being provided to all handicapped children, ages 0-21 in programs offered by local administrative units, the Regional Centers, Community Centered Board's and other public agencies.

To this end, the Colorado Board of Education has promulgated minimum standards for program approval, and the Department of Education has entered into an interagency agreement with the Department of Institutions providing for the Special Education Services Unit, Department of Education to conduct annual reviews of Regional Center and Community Centered Board day programs for the purpose of approving the programs for funding under Title I, ESEA P.L. 89-313. The reviews are actually conducted in three phases as described in the state's Title I Plan. Each program is visited at least once every three years as part of the "monitoring" phase. The monitoring phase (1) includes a thorough review of the education programs, practices and processes as well as a review of Regional Center and Community Centered Board compliance with all applicable statutory requirements. It results in a report which describes the activities of the on-site team, findings of strengths and needs, recommendations for improvement, and directives for corrective action if needed. The

evaluation/compliance phase (2) and the audit phase (3) may or may not call for an on-site visit to the agency. Phase 2 involves the "follow-up" of the first year findings and includes technical assistance as needed. Phase 3 involves the audit of the student counts, student tracking procedures, and fiscal records. At the same time, these programs are licensed by the Department of Social Services (Staff Manual, Vol. VII). On-site visits are made from time-to-time by state or county social services staff to assure regulatory compliance. A number of Colorado Department of Education certification requirements and Department of Social Services licensure requirements are reportedly inconsistent (see p. 118).

(2) Day Programs for Adults

These programs include:

- o Intensive Habilitation Programs -- These services are provided to change the functional abilities of profound to severely involved clients with developmental disabilities and includes such training as self feeding, toileting, self care and maintenance skills.
- o Basis Skill Development Programs -- The purpose of these programs is to provide severely disabled adults with basic skills development which will enable them to attain increased levels of independence and pre-vocational skills.
- o Vocational Training Programs -- Vocational training provides moderate to long term employment and training to those individuals who do not yet meet the standards of the competitive labor market. The primary emphasis is on development of appropriate work skills and habits in a sheltered environment.
- o Transition Programs -- Transitional services provide time limited training in specific skills which are targeted toward a specific competitive job placement. Transition services augment those provided in vocational training.
- o Competitive Employment and Maintenance Programs -- These

programs involve employment in a competitive worksetting with support services available to both the client and employer as needed to maintain the individual in employment.

As provided in 27-11-104 C.R.S, Community Centered Board day programs are approved by the Department of Institutions for the provision of services to persons with developmental disabilities considering, "the adequacy and utilization of existing approved facilities and programs in the community, such as public and private nonprofit sheltered workshops, public school programs, preschool nurseries, day care centers, and universities and colleges;" essentially, adult day programs are approved for funding based on the judgment of the sponsoring or administering Community Centered Board and Division for Developmental Disabilities staff.

There are presently no minimum standards or criteria used by the Division for Developmental Disabilities and Community Centered Board staff in judging the capability of day program providers to provide quality services. However, for school-aged students, Community Centered Board and Regional Center staffs must hold a certificate in the area of exceptionality with which they work or in the area of service they provide.

2. Individual

The following professionals working with persons with developmental disabilities in Colorado require state licensure or professional certification:

- o registered nurse -- state *
- o licensed practical nurse -- state

- o psychiatric technicians -- state
- o medical doctor -- state
- o physical therapist -- professional certification *
- o occupational therapist -- professional certification *
- o occupational therapy assistants -- professional certification
- o speech pathologist -- state and professional certification *
- o dietician -- professional certification
- o psychologist -- state and professional certification *

In addition, teachers in programs for persons with developmental disabilities are required to have a bachelors degree in child development, special education or a related field; and those hired after January 1, 1977 are required to have a valid Colorado teachers certificate with an endorsement in an appropriate area of special education. The Department of Education has also developed certification standards for CCB positions providing educational services to children.

Finally, federal regulations require ICF-MR programs to have qualified mental retardation professionals (QMRP's) to oversee the implementation of the ICF-MR programs and resident Individual Habilitation Plans. These persons must generally have one year of experience in caring for the mentally retarded, and any one of a variety of social, medical, or therapeutic degrees.

* Those who work in school settings also must be certified as teachers (type E).

C. Assure Good Practice

Both proactive and reactive mechanisms may be used to assure good practice. **Proactive mechanisms** involve the continual monitoring of programs for the purpose of improving practice to the point where it surpasses minimum standards and for the purposes of heading off potential or minor problems in the delivery of services before they develop. **Reactive mechanisms** are designed to investigate the service quality problems as they arise and are brought to the attention of authorities. Proactive mechanisms are by nature positive, reactive mechanisms, negative. The proactive mechanisms are preferred; in fact they are essential for a healthy service delivery system, and should be the cornerstone of any quality assurance system.

1. Proactive Procedures

The three most prominent and important proactive mechanisms for leading providers to apply generally accepted principles of good practice include (1) procedures for the interdisciplinary review and planning of client programs, (2) the provision of training and technical assistance to provider staff, and (3) the active involvement of case managers, parents and others in overseeing program operations and advocating for program improvements.

a. Individualized Planning and Programming

Individualized planning and programming is a client-centered holistic approach for developing goals and objectives for each service recipient. It is a cyclical process with opportunities

to evaluate progress and develop new goals and objectives. Individualized planning is the primary tool and approach used to assure the provision of needed, appropriate, and effective services to the client.

Individual habilitation planning (IHP) is designed to assess the full range of client needs; whereas individual program planning (IPP) is service- or program-specific. The IHP represents the overall plan for services to persons with developmental disabilities and is completed for all persons served by Community Centered Boards, Regional Centers, or intermediate care facilities for the mentally retarded. The plan is to contain a statement of specific habilitation services to be provided, to identify each agency which will deliver such services, to describe the personnel (and their qualifications) necessary for the provision of such services, and to specify the date of the initiation of each service to be provided and the anticipated duration of each such service.

Individual habilitation planning is required under the Developmentally Disabled Assistance and Bill of Rights Act P.L. 94-103 (91-517), and state 27-10.5-113 C.R.S. Moreover, the existence of an IHP plan and review process is a requirement for developmental disabilities program approval and Department of Health licensing and for certification under Title XIX of the Social Security Act P.L. 92-223 (45CFR Part 249, Section 249.10). In addition the Division for Developmental Disabilities specifies in each contract with the Community Centered Board that the "contractor agrees to ensure that a current and complete

Individualized Habilitation Plan (IHP) shall exist for all persons with developmental disabilities served.

The Division for Developmental Disabilities/Community Centered Board contract also requires the Community Centered Boards to assure that current and complete individualized program plans (IPP's) exist for all persons with developmental disabilities in each program area they attend. The IPP's for client in day programs must also meet Individual Education Plan (IEP) requirements and possibly Individual Written Rehabilitation Plan (IWRP) requirements. Children with developmental disabilities participating in infant stimulation, preschool, or day training programs are required to have individual education plans (IEP's) under the Education for All Handicapped Children Act of 1975 (P.L. 94-142). The Special Education Services Unit checks client IEPs as part of its annual on-site review of programs. Adults with developmental disabilities placed in work activity centers and sheltered workshops by vocational rehabilitation counselors are required to have individual written rehabilitation plans (IWRPs) (P.L. 93-516).

All of these individualized plans provide for the assessment of individual client needs, development of individual plans to meet these needs including concise statements of client goals and objectives, statements of services to be provided, statements of the duration of these services, strategies for achieving the objectives, statements of persons responsible for implementing the plan, and procedures to be used in evaluating plan accomplishments. These plans are reviewed at multidisciplinary

staffings at least once a year. The individual habilitation plans must be reviewed every 6 months in ICF-MRs.

In order to ensure the development of individual program plans, several years ago the Research and Evaluation Unit in the Division for Developmental Disabilities periodically reviewed the individual program plans at the Regional Centers and in the Community Centered Boards' programs, and was able to reach the point where over 95% of the clients had written individual program plans.

b. Training and Technical Assistance

As stated in a recent planning document of the Division for Developmental Disabilities (Blakley, 1983), "providing effective services depends on having skilled, competent staff that can produce the desired services and outcomes. Staff training is an important component in strengthening the ability to provide the most appropriate services and in maximizing the efficient use of resources. Typically, however, training is a low priority and is subject to cuts and elimination as resources become scarce."

Until two years ago, the Department of Institutions staffed a training center to arrange workshops and training sessions for developmental disabilities service providers and administrators. In the past two years most all of the extramural training and technical assistance has been sponsored by the Developmental Disabilities Council and Association for Retarded Citizens in Colorado, Community Centered Board's and Colorado Association of Community Centered Boards. This training has focused primarily on introducing residential, day program and

other providers of services to persons with developmental disabilities to state-of-the-art treatment approaches and improved management techniques. A number of these training projects have been conducted by the Community Education and Technical Assistance Center at the Rocky Mountain Child Development Center, University of Colorado Health Sciences Center -- most notably the training of special education professionals in diagnostics, the development of video instructional programs for the clinical training of developmental disabilities professionals training in behavioral habilitation.

The Division for Developmental Disabilities Committee on Case Management has developed a case management model to guide Community Centered Boards in the development of case management programs. Some technical assistance and training has been provided by the developmental disabilities to promote its use. Currently, the Division for Developmental Disabilities is planning to develop training programs for case managers with Colorado Developmental Disabilities Council support.

In fiscal year 1981, the Developmental Disabilities Council awarded a contract to the Community Education and Technical Assistance Center in part to conduct an assessment of developmental disabilities training needs as a foundation for planning a comprehensive program of training and technical assistance in Colorado. The study concluded that:

- o staff development services should be sent to agency staff rather than making staff travel to obtain those services
- o staff development should emphasize the design of systems which will ensure the ongoing use of staff skills

- o the primary focus of staff and organizational development procedures should be on effective means of teaching and maintaining appropriate social-interpersonal client behaviors
- o there is a need for ongoing, statewide interagency planning for staff training.

The study also noted that it might be a good idea to develop a career ladder for developmental disabilities professionals in Colorado, one based on observed skills and demonstrated competencies, however, and not on the kind of degree or experience an individual has had.

The Division of Rehabilitation also sponsors extramural training workshops and conferences from time to time for day program personnel using federal rehabilitation program funds. The Division of Rehabilitation regularly uses the University of Northern Colorado training program; this program is designed primarily to improve the management and productivity of sheltered workshops.

There are in-service training programs at each of the Regional Centers. In-service training programs also exist at many Community Centered Boards with at least one program (the Pueblo CCB) where training is heavily emphasized and tied to career advancement.

Until this year, when the on-site residential program reviews conducted by the Division for Developmental Disabilities were discontinued, technical assistance was initiated following on-site reviews. Currently, some technical assistance is provided to Community Centered Boards on request, but no longer in connection with the on-site reviews. The Department of

Education also provides technical assistance in conjunction with its on-site reviews of infant stimulation, preschool, and particularly day training programs. Both the Division for Developmental Disabilities and Department of Education programs of technical assistance use peers who the review team members know to have "good" programs or practices worth emulating.

c. Program Oversight by Case Managers, Parents and Other Client Advocates

Repeated accounts of client abuse, violations of client rights, and absent programs in the "back wards of institutions" and more recently at the "Twin Pines Nursing Home" clearly indicate that such phenomena are more likely in operations run in isolation than in programs subject to continual outside observation. The simple presence of outside interests at facilities for persons with developmental disabilities can contribute to more healthy and normative environments so long as their presence is unobtrusive and so long as their suggestions are given and taken constructively. Case managers, parents, and other client advocates are in an excellent position to provide such casual observation.

The oversight role played by parents and other client advocates varies considerably from Regional Center to Regional Center, from Community Centered Board to Community Centered Board, and from program to program. In one of the three Regional Centers there is a citizen advocacy office. In most areas parents and other advocates serve on committees governing developmental disabilities programs. In some areas such

committees are active; in other areas not so.

The average case manager caseload at Community Centered Boards is 68; the average Regional Center caseload is 125. According to the Colorado Case Management Model there are six functions to be performed by case managers given a reasonable caseload of about 30: intake, coordinating the development and implementation of individual habilitation plans, coordinating the development and implementation of individual program plans, client-centered monitoring and review, transfer/termination, and continuing contact. Presently the Community Centered Boards are required by contract to perform only the intake, individual habilitation planning, individual program planning, transfer and termination functions. Individual monitoring and review, and continual contact are not required in consideration of the high case manager caseloads. The function of program-centered monitoring for broader DDQAS purposes is not embraced by the model.

A major factor constraining the monitoring role of case managers in Colorado is that case management services are only reimbursed by the state for those clients enrolled in Community Centered Board day programs. Another limiting factor is that in a number of Community Centered Boards, the case managers are not separate from the program staff and in some Community Centered Boards the same individual may play a treatment as well as a case manager role.

2. Reactive Mechanisms

Reactive quality assurance mechanisms provide for the formal

investigation and expeditious resolution of complaints, grievances or incidents reflecting possible violations of the rights, health, safety, and welfare of clients, or reflecting other specific problems pertaining to the quality of services provided clients. According to Department of Health rules (Chapter II), the Regional Centers are required to have patient grievance procedures as are any health facilities, public or private, having in excess of 50 beds. These procedures must be approved by the Department of Health. The Regional Centers also have procedures for the internal investigation and reporting to the Developmental Disabilities Division, Department of Institutions all deaths, accidents and injuries, and critical incidents. A number of persons interviewed during the study felt that these grievance procedures were insufficient to put some complaints to rest.

Though not statutorily or contractually bound to have formal grievance and complaint mechanisms, most of the Community Centered Boards reportedly have such mechanisms. In many areas, Community Centered Board complaints not resolved internally are reportedly directed to local advocacy groups (usually ARCs), parents, or other advocates. Advocates then follow through on the complaints with the program director, Community Centered Board director, state officials, legislative representatives, or with the Legal Center for the Handicapped. A number of persons interviewed believed that most Community Centered Board grievance mechanisms should be more uniform, more time-limited, and lead to the Division for Developmental Disabilities where necessary for final resolution.

D. Assure Program Efficiency

Arguments for the inclusion of efficiency as a legitimate quality assurance responsibility are pragmatic in nature, and are usually advanced from the standpoint of the collective client interest. Wasting limited service resources through inefficient service delivery effectively reduces the potential benefits of service to the aggregate number of clients served. Quality services for some should not be at the expense of less service or no service for others.

In the case of developmental disabilities services, efficiency is not only a function of provider "productivity", i.e., the amount of services provided for a given amount of resources, but of the "appropriateness" of the services provided considering client need. Provider productivity is to some extent controlled through the rate setting process. Service appropriateness is to some extent checked formally through case reviews as part of the Title XIX utilization review procedures and less formally through case reviews as part of IHP staffings.

1. Productivity

Rates for the Class I - IV residential care facilities are set by the Division of Medical Assistance, Department of Social Services in accordance with the uniform rate setting methodology set forth in the state Medicaid plan. Rates for each class are capped based on budget constraints and on actual provider cost experiences as verified by the state auditor. Rates for other types (classes) of residential programs and day programs are set in similar fashion by the Legislature in the Department of

Institution's budget. Again the rates are a function of budget constraints and past levels of expenditure. The maximum hours of service per eligible client are also fixed by the Department of Institutions. Variations in these rates are allowed in negotiation with the Community Centered Boards in consideration of special client problems and demands. Amounts allowed for case management and transportation services are negotiated separately with each Community Centered Board. The Department of Social Services sets rates for residential and day programs serving children including those with developmental disabilities in much the same way according to their legislative appropriation.

2. Service Appropriateness

The intermediate care facilities for the mentally retarded (ICF-MRs) are subject to Title XIX utilization review procedures. The Colorado Foundation for Medical Care (PSRO), under contract with the Department of Social Services, reviews the medical necessity for client admission and continued stay in the ICF-MRs. The PSRO may recommend that the Department of Social Services deny payment for inappropriate or unnecessary treatment. The individual habilitation planning (IHP) procedures provide for the periodic review of the appropriateness of other residential and day program services to clients; however, this process is not formally linked to the payment process.

Payment for other than Title XIX services is negotiated between the Division for Developmental Disabilities and the Community Centered Boards, and between the Community Centered Boards and any purchase-of-service providers.

E. Assuring Program Effectiveness

As indicated in the Section II, there are problems involved in obtaining reasonably valid and reliable measures of program outcomes at a reasonable cost. Nonetheless, the paramount importance of client outcomes is hard to deny. Outcomes are essential measures to be used, albeit cautiously, in any quality assurance system.

At the provider level, individualized or idiographic measures, built around individual client problems, goals and potentials, are regularly employed as part of the individual habilitation planning and individual program planning processes.

At the policy level, standardized or nomothetic measures must be used in order to allow for the aggregation and comparison of client outcomes across different types of programs (e.g., institutional versus community-based, privately owned versus publicly owned, and those employing behavior modification versus psychoanalytic approaches to changing client behavior). They are also used in some states to identify exceptional programs possibly worth emulating or possibly in need of technical assistance. The major drawback of standardized outcome measures is that they are less sensitive to individual problems, goals and potentials, and unless such factors are controlled for, these measures must be interpreted with a great deal of caution.

1. Provider Level

a. Day Programs

The vocational counselors in the Division of Rehabilitation routinely report the extent to which their clients were successfully rehabilitated as part of the R-300 reporting system. This reporting system is used for staff management purposes as well as for state and federal policy analyses. However, this information is kept only for those clients referred through the vocational rehabilitation system not for most of the clients with developmental disabilities who are accepted directly into the Community Centered Board programs. It should also be said that the closure reporting system has many detractors who are not convinced that the inordinate amount of paperwork involved has led to improved counselor or client performance. These doubts are also expressed by the Division of Rehabilitation which has been devising a process-oriented quality assurance system of its own design in an attempt to balance the outcome emphasis of the R-300 system.

In the Department of Education, state and local accountability committees were established by the "Educational Accountability Act of 1971" for the purpose of better assessing the cost effectiveness of education programs and improving their quality. While the Special Education Office of the Department of Education has paid much attention to programs for persons with developmental disabilities to date these committees have reportedly paid relatively little attention to the special education programs for persons with developmental disabilities.

A number of residential and day program managers, employ idiographic client outcome measures of their own design for internal program monitoring and evaluation purposes (e.g., Developmental Training Services Incorporated; Pueblo Diversified Industries Incorporated; and Goodwill Industries Incorporated of Denver).

Earlier attempts to institute standardized outcome measurement systems, specifically the Individualized Data Base (IDB) system, at the Regional Centers failed. Two explanations were offered by Regional Center staff interviewed: (1) Attempts were made to rate staff performance based on client IDB-score improvement; this undermined staff support. (2) Many staff saw little value in the standardized measures as they were not deemed sensitive enough to individual client problems and potentials; in other words, they favored idiographic measures.

b. Residential Programs

There are no known client outcome monitoring or evaluation procedures in operation other than those performed by providers in-house for internal purposes.

2. Policy Level

At the policy level, the Division for Developmental Disabilities and the Developmental Disabilities Council sponsor evaluations of particular programs from time to time which sometimes include indices of program effectiveness.

IV. QUALITY ASSURANCE SYSTEM DESIGN RECOMMENDATIONS

A. Overview

The recommendations included in this section relate to the "mechanics" of quality assurance. Taken together, they represent a comprehensive system for assuring the quality of services to persons with developmental disabilities. The individual recommendations are aimed at improving existing mechanisms, or in some cases, instituting new mechanisms.

However, before getting lost in the detailed recommendations, it is worth highlighting the major strengths and weaknesses of Colorado's existing system of quality assurance addressed in the previous section. As a whole, these points represent the study team's general sense of the state of the developmental disabilities quality assurance system in Colorado, and underlie the majority of the design recommendations.

The most positive aspect of Colorado's quality assurance efforts to date has been the lack of undue emphasis on minimum standards compliance as part of its licensing and certification responsibilities. Most of the Division for Developmental Disabilities staff have a nonbureaucratic approach and do not see service providers as the "n'er do wells" nor themselves as "police." Accordingly, the communication between Division staff and providers is not as strained and unproductive as it is in states with a stronger regulatory orientation. In fact, the peer review mechanisms established several years ago by the Division for community residential programs had a positive technical assistance emphasis and were generally well accepted by most

providers.

A possible corollary is that the community programs are not as constrained as they are in many states by rigid regulatory requirements and restrictive rates. Accordingly, the programs in Colorado are more diversified and innovative in approach, do not have to compromise the quality of their services because of unrealistically low rates of reimbursement, and are probably more efficient given their relative freedom to allocate resources in a manner that is responsive to the individual situations. Even more importantly, the lack of heavy handed state regulation has allowed community providers, in particular to establish more clearly their own program approaches and identities -- an important albeit intangible element in motivating staff to improve performance.

This is not to say that the state should adopt a purely laissez faire approach to assuring the quality of Regional Centers, and Community Centered Board programs, and other services to persons with developmental disabilities. As the principal payer for developmental disabilities services, the State has every right to identify clients and services they will support. In this instance, the State may well find it necessary to require the outplacement of clients from the Regional Centers overriding the demands of the local polity to place persons with developmental disabilities already living in the community. The state must also let program directors and staff know what is expected programatically. In this regard, the state has not provided enough programmatic direction in some areas particularly

with respect to day programs. Interestingly but not suprisingly it was the day program providers who were most outspoken in favor of some constructive system of performance measurement. Every program administrator interviewed was proud of his or her accomplishments, but wanted some recognition and guideposts regarding service organization. More direction in the form of plans, guidelines, and standards is called for possibly along the lines of Colorado's Case Management Manual. The development of the Manual provides an excellent example of the state taking the lead in formulating positive program and policy directions. While more resources are needed to implement the model, and though some case managers are still in positions where their actions on behalf of the interests of the client may be compromised by the service providers, it is clear that Colorado's case management system is steadily approaching the model described in the manual.

Undoubtedly, the major shortcoming in the Colorado Department of Institution's (CDI) existing system of quality assurance is the lack of a strong training and technical assistance program. Over the past decade, the CDI has backed away from it's leadership role and it not doing nearly enough to assure the competency of staff serving persons with developmental disabilities in Colorado. While the Developmental Disabilities Council, advocacy groups, University Affiliated Facility and some Community Centered Boards have taken-up the initiative to support and organize staff training, state leadership and the level of resources afforded to the area of training are woefully

inadequate. In view of the limited monetary rewards possible in the developmental disabilities service field, and the personal interest and commitment of most individuals entering the field, training is not only important from a technical standpoint, but from a motivational standpoint as well.

A second weakness is the state's lack of reliable information on the outcomes of clients in service as a basis for sound programming planning and budgeting decisions. In fairness, this weakness is due more to technological limitations in the measurement of program outcomes than to the intransigence of the Department of Institutions or its Division for Developmental Disabilities. In fact, the Department and Division have initiated outcome monitoring systems in the past but these systems have never gotten off the ground or withstood the test of time and reportedly for good reason: they were too burdensome and yielded biased and unreliable information. Nonetheless, information on client outcomes is essential for the state to assure the quality of the services being provided. We believe the technology has improved to the point where it is now possible to obtain essentially reliable outcome data at a reasonable cost, and are recommending that it be given another try in Colorado.

As in Section III of the report, the recommendations in Section IV are organized into subsections corresponding to each of the responsibilities of the state for assuring the quality of services provided to persons with developmental disabilities. Each recommendation includes:

- o A brief description of the recommended mechanism;

- o A brief explanation of the reasons for making the recommendation;
- o The pros and cons of recommended options where applicable;
- o An implementation plan comprised of the major tasks involved, the month and/or year they are to be completed, and the organization(s) responsible for each task;
- o An estimate of the additional resources required to complete the plan;
- o References to individuals or organizations having completed a mechanism such as that recommended, references to other materials not included in the bibliography, and references to pages in Sections II and III containing information relevant to the recommendation.

Some of the recommendations are more detailed than others. The study team elaborated more on those mechanisms of a technical nature where team members had something to offer, and less on those requiring a more intimate knowledge of ongoing administrative processes to which the study team members were not privy. The recommendations are prioritized, and a comprehensive timetable and summary of the costs associated with their implementation are presented at the end of the section.

B. Assuring the Capability to Provide Quality Services

1. Day Programs

a. RECOMMENDATION 1: THE DIVISION FOR DEVELOPMENTAL DISABILITIES AND DIVISION OF REHABILITATION SHOULD REQUIRE THAT ADULT TRAINING PROGRAMS IN COLORADO BE ACCREDITED EITHER BY THE COMMISSION FOR THE ACCREDITATION OF REHABILITATION FACILITIES (CARF) OR ACCREDITATION COUNCIL FOR SERVICES FOR MENTALLY RETARDED PERSONS OR OTHER DEVELOPMENTALLY DISABLED PERSONS (AC-MR/DD) AS A CONDITION FOR RECEIVING STATE FUNDS. RECOGNIZING THE FACT THAT SOME PROGRAMS MAY HAVE MORE DIFFICULTY THAN OTHER PROGRAMS COMING INTO COMPLIANCE WITH THE STANDARDS, THE STATE SHOULD IMPLEMENT THIS EFFORT OVER A PERIOD OF THREE YEARS WITH THE ACCREDITATION OF ONE THIRD OF THE PROGRAMS REQUIRED IN THE FIRST YEAR, ANOTHER THIRD IN THE SECOND YEAR, AND THE FINAL THIRD IN THE THIRD YEAR. CONSIDERING THE GENERIC NATURE OF THE CARF STANDARDS IN PARTICULAR, THE DIVISION FOR DEVELOPMENTAL DISABILITIES SHOULD CONDUCT BRIEF SITE REVIEWS FOLLOWING UP THE CARF REVIEWS AND ADDRESSING DEVELOPMENTAL DISABILITIES PROGRAMMATIC CONCERNS. THEY SHOULD ALSO PROVIDE OR ARRANGE FOR TECHNICAL ASSISTANCE AS APPROPRIATE.

(1) Rationale

In formulating this recommendation, the study team considered two other options:

- o That the Division for Developmental Disabilities and Division of Rehabilitation conduct joint program reviews mechanistically like the Division for Developmental Disabilities and Department of Health reviews of residential programs. This option was rejected primarily because, unlike the residential programs, the Division for Developmental Disabilities and Division of Rehabilitation are not organizationally or technically prepared to mount an effective in-house quality assurance procedure for adult training services.
- o That the Division for Developmental Disabilities and Division of Rehabilitation allow each provider of day program services to elect the CARF or AC-MR/DD option or the Division for Developmental Disabilities/Division of Rehabilitation review option. This combination was rejected primarily because it is duplicative and thus more expensive to implement than either of the other options alone.

There were a great many factors weighed in making this recommendation. The general arguments, pro and con, of

incorporating accreditation mechanisms as part of the state's quality assurance system are discussed in Section II. The chief advantages include: (1) a greater degree of freedom from political and fiscal compromise, and (2) the relatively greater degree of acceptance of accreditation and its related influence over provider practice. The chief disadvantages include: (1) the possible lack of responsiveness to state and local concerns as a result of a decreased state and provider interaction, and (2) the greater, some would say excessive, demands on providers to document all procedures. However, HSRI's decision to recommend the use of the accreditation mechanisms turns primarily on factors peculiar to Colorado.

First we feel that neither the Division for Developmental Disabilities nor Division for Rehabilitation is capable of mounting an effective program for reviewing adult training programs in the immediate future to fill the current vacuum. Unlike the residential program area, the Division for Developmental Disabilities lacks the staff expertise and experience and the commitment necessary to build an in-house program of review. There is a history of failed efforts to establish adult training standards and in-house review mechanisms, which prompted a number of providers interviewed by the study team to warn against our recommending yet another such attempt. These efforts have reportedly been stalled by the lack of interest and commitment from the past leadership in the Department, and by the belief of key staff in the Division for Developmental Disabilities that accreditation standards are too

paper oriented, of little useful consequence, and thus hardly worth imposing on providers.

To be in the best interest of the clients, an in-house program of review would have to be conducted jointly by the Division of Rehabilitation and Division for Developmental Disabilities in order to reflect the dual yet different client responsibilities that each agency currently carries out. However, the prospects for effective cooperation are dimmed by the announced desire of the Division of Rehabilitation to assume greater control over the adult training services continuum in order to make these services more training-oriented and more oriented to moving clients into the employment mainstream. Cooperation is further complicated by the reluctance of the Division for Developmental Disabilities' to relinquish this control to the Division of Rehabilitation for fear that adult training and support agencies now serving more severely impaired persons with developmental disabilities will begin serving less severely impaired persons and fewer persons with developmental disabilities.

Secondly, we were not convinced that most of the objections to the use of the CARF or AC-MR/DD mechanisms could not be overcome. The concern that the use of an accreditation mechanism leads to diminished state and provider interaction is a relatively hollow objection in Colorado since the degree of state and day training program interaction has always been negligible. The Community Centered Board directors and vocational rehabilitation counselors have historically provided

most of the program oversight. Also, CARF and AC-MR/DD make every effort to involve state offices in the accreditation process. They routinely ask officials in advance of the surveys if there are any particular problems they should look for, invite them to participate in the survey orientation and exit conferences, and check with them following the survey to make sure they are satisfied with the results. They also offer strong programs of technical assistance preceding, during, and following the accreditation reviews.

The conduct of programmatic reviews by the Division for Developmental Disabilities following the CARF accreditation surveys is a good way for the state to keep involved with the programs. This procedure is currently followed in the State of Iowa.

Thirdly, while HSRI is sympathetic to the claim that compliance with the CARF or AC-MR/DD standards can place a disproportionate burden on the smaller adult training programs, we do not believe it is ample reason to decide against CARF or AC-MR/DD. Instead, HSRI has recommended that the accreditation requirement be implemented on a three year staggered basis with better prepared programs going first in order to allow the less-prepared programs more time to ready themselves. The directors of CARF and AC-MR/DD expressed a willingness to work with the smaller, more rural Community Centered Board programs on survey logistics that would reduce the costs associated with the survey. Both cited special arrangements they had made with the county boards in Ohio as cases in point.

The study team is also sympathetic to the argument that the CARF and AC-MR/DD standards place too great an emphasis on "paper procedures." However, we are not convinced that the standards promulgated by the Division for Developmental Disabilities and Division of Rehabilitation would prove to be less so. Moreover, given the continued CARF and AC-MR/DD standards review and updating procedures, we believe that over time the standards will moderate the paper work demands in response to evolving management theory and the demands of informed providers.

Fourthly, HSRI believes that the cost of using the CARF or AC-MR/DD mechanisms approximates what it would cost to develop an in-house survey capability using teams made up of Division for Developmental Disabilities and Division of Rehabilitation staff and peers. There is no reason to believe that conducting the AC-MR/DD-like or CARF-like reviews in-house should be significantly different than the cost of having CARF or AC-MR/DD conduct the reviews. One cannot simply compare CARF or AC-MR/DD charges per surveyor day (\$500), to the cost of state staff persons per day, since the CARF and AC-MR/DD charges include the cost of administering the accreditation process, continually updating the standards, conducting three day programs of surveyor training, as well as travel costs and other direct costs. The state could conceivably mount a less expensive procedure only by cutting back on the standards and reducing the amount of surveyor time spent per program.

Finally a more qualitative consideration weighing heavily in favor of our decision to recommend that the state deem either the

CARF or AC-MR/DD standards is that, unlike a certification process administered by the Division for Developmental Disabilities and Division of Rehabilitation, the CARF AC-MR/DD process will not divert the attention of the Division for Developmental Disabilities and Division of Rehabilitation from their first-order quality assurance responsibilities -- to support good practice through training and technical assistance, and to foster a better network of programs informed by the monitoring of program outcomes and client movement. State recognition of CARF or AC-MR/DD accreditation diminishes the possibility of a growing state organization absorbed in the minutiae of minimum standards compliance, and viewed more as a watch dog than as a source of programmatic direction and support.

(2) Implementation Timetable

Establish a staggered program review schedule (Division for Developmental Disabilities/Division of Rehabilitation)	September, 1983
Issue Colorado Department of Institutions/Colorado Department of Social Services directives (Colorado Department of Institutions/Colorado Department of Social Services)	December, 1983
Hire adult day training specialist to conduct supplementary reviews and to provide technical assistance (Division for Developmental Disabilities)	August, 1983
Providers elect CARF or AC-MR/DD (Community Centered Board's and others)	November, 1983
Develop supplementary developmental disabilities review procedure (Division for Developmental Disabilities)	February, 1984
Arrange for regional CARF and/or AC-MR/DD workshops for state, Community Centered Board and contract providers	

(Division for Developmental Disabilities)	December, 1983
Begin on-site reviews (CARF and/or AC-MR/DD)	April, 1984

(3) Estimated Resource Requirements

It is estimated that one Division for Developmental Disabilities staff person will be required to conduct programmatic reviews and provide technical assistance complementary to that provided through CARF or AC-MR/DD. The costs of CARF and AC-MR/DD accreditations are the same, except that the fee for applying for AC-MR/DD accreditation is \$500.00 versus \$200.00 for CARF accreditation. Also current AC-MR/DD policy is not to accredit individual programs (e.g., day programs), only complete programs (i.e., CCB's). However, this policy may change. For purposes of estimating these costs, we are assuming that it will.

There are currently 53 adult training sites including satellite sites in Colorado; 9 of these sites are already CARF accredited. 44 sites remain to be accredited. The cost of accrediting each site is estimated to be \$2,200 for CARF and \$2,500 for AC-MR/DD; the total cost, then, is \$96,800 to \$110,000. It is estimated that about one in four or eleven sites will have to be reviewed in one year at an additional estimated cost of \$1,500 per site or \$16,500. The remaining programs will be approved for the three year cycle. The total cost then will be \$96,000 to \$110,000 plus \$16,500 or \$113,300 to \$126,500 over three years. Based on the 1982-1983 State Facilities Plan, Colorado Division of Rehabilitation (1982), it is estimated that 53% of the persons in these programs are developmentally

disabled. Thus, the Division for Developmental Disabilities will pay 53% of the \$113,300 to \$126,500 cost of CARF or AC-MR/DD accreditation over the next three years through client fees -- an average of \$20,016 to \$22,348 per year. The Colorado Division of Rehabilitation would pick up the balance. In addition, during the first year, it is projected that the Division for Developmental Disabilities will pay another \$5,000 for CARF and/or AC-MR/DD workshops and participant travel, and \$3,750 for staff travel and other direct expenses relating to the development and conduct of the supplementary review procedure.

Projected cost summary:

	<u>1983-84</u>	<u>1984-85</u>	<u>1985-86</u>
DDD Share	28,766--31,098	20,016--22,348	20,016--22,348
DR Share	<u>17,751--19,819</u>	<u>17,751--19,819</u>	<u>17,751--19,819</u>
Total	\$46,517--50,917	\$37,767--42,167	\$37,767--42,167

Division for Developmental Disabilities surveyor/consultant:

	\$35,000	\$40,000	\$40,000
Grand total	\$81,517--85,917	\$77,767--82,167	\$77,707--82,167

(4) References

Section II, pages 45-48, 61-66. Section III pages 87-88.

Interviews:

Alan Toppel, Director, CARF;

Ken Crosby, Ed.D., Director AC-MR/DD.

b. RECOMMENDATION 2: THE DIVISION FOR DEVELOPMENTAL DISABILITIES SHOULD HIRE A QUALIFIED PART TIME EMPLOYEE OR CONTRACT WITH A KNOWLEDGEABLE DESIGNEE TO PARTICIPATE AS A MEMBER OF THE COLORADO DEPARTMENT OF EDUCATION SURVEY TEAM IN THE PERIODIC REVIEW OF COMMUNITY CENTERED BOARD AND REGIONAL CENTER INFANT STIMULATION AND PRESCHOOL PROGRAMS. THIS INDIVIDUAL SHOULD PROVIDE OR ARRANGE FOR TECHNICAL ASSISTANCE WHERE NEEDED.

(1) Rationale

The Department of Institutions like the Department of Education has direct responsibility for assuring the quality of day programs for those children with developmental disabilities and served by the Community Centered Boards and Regional Centers. Accordingly, the Division too should be actively involved in the programmatic oversight of these programs. The individual involved should be qualified by virtue of training and experience in the provision of infant stimulation and preschool services to children with developmental disabilities. S/he should be responsible for reviewing on site reports of the Colorado Department of Education.

(2) Implementation Timetable

Write inter-agency agreement	February, 1984
Recruit day program specialist (Division for Developmental Disabilities)	October, 1983
Hire/contract for day program specialist (Division for Developmental Disabilities)	November, 1983

(3) Estimated Resource Requirements

\$35,000 1984-85 and ongoing

(4) References

Section II, pages 45-48. Section III, pages 85-87.

c. RECOMMENDATION 3: THE DEPARTMENTS OF SOCIAL SERVICES AND EDUCATION SHOULD RECONCILE CURRENT INCONSISTENCIES IN THEIR RESPECTIVE DAY CARE LICENSING RULES AND REGULATIONS AS APPLIED TO THE COMMUNITY CENTERED BOARD PRE-SCHOOL PROGRAMS.

(1) Rationale

The Community Centered Board and preschool program directors are unfairly put in the position of having to wrestle with inconsistent state regulations due to the lack of state agency coordination. The requirements of the Department of Social Services and Colorado Department of Education regarding periodic health examinations are a case in point.

(2) Implementation Timetable

Meet to resolve inconsistencies (Department Executive Directors)	September, 1983
Approval (State Board of Social Services)	March, 1984

(3) Estimated Resource Requirements

NOT APPLICABLE

(4) References

Section III, page 87.

Department of Social Services, Minimum Rules and Regulations for Child Day Care Centers, (September, 1975).

2. Residential Programs

a. RECOMMENDATION 4: THE DIVISION FOR DEVELOPMENTAL DISABILITIES AND THE DEPARTMENT OF HEALTH SHOULD JOINTLY REVIEW ADULT RESIDENTIAL PROGRAMS FOR PURPOSES OF LICENSING AND CERTIFICATION. THE DIVISION FOR DEVELOPMENTAL DISABILITIES SHOULD EMPLOY THE RESIDENTIAL CHECKLIST ITEMS AS MINIMUM STANDARDS, AND SHOULD FORMULATE MODEL STANDARDS OR GUIDELINES AS A BASIS FOR HIGHER LEVEL PROGRAM DIRECTION AND TECHNICAL ASSISTANCE. IN ORDER TO MAKE THE MOST OF LIMITED STAFF RESOURCES, THE DIVISION FOR DEVELOPMENTAL DISABILITIES AND HEALTH FACILITIES REGULATION DIVISION SHOULD DEVELOP A PLAN OF REVIEW THAT MEETS DEPARTMENTAL LEGAL RESPONSIBILITIES, THAT IS SENSITIVE TO THE DIFFERENT MONITORING NEEDS OF PROVIDERS AND THE CLIENTS THEY SERVE, THAT SCHEDULES THOSE IN GREATER NEED MORE FREQUENTLY AND THOSE IN LESSER NEED LESS FREQUENTLY, AND THAT ENSURES EVERY PROGRAM IS REVIEWED ON-SITE AT LEAST ONCE EVERY THREE YEARS. THE PROVIDERS SHOULD BE DEBRIEFED IMMEDIATELY FOLLOWING THE SURVEY, AND WRITTEN FEEDBACK SHOULD BE FORWARDED TO THE PROVIDERS WITHIN TWO MONTHS.

The Colorado Department of Institutions (CDI) and Department of Health (CDH) should proceed with their efforts to combine the standards compliance reviews of the Division for Developmental Disabilities (DDD) and Health Facilities Regulation Division (HFRD). They should employ a survey team made up of HFRD/DDD staff members with HFRD staff assuming prime responsibility for assuring compliance with minimum standards of health and safety, and the Division for Developmental Disabilities staff assuming prime responsibility for assuring compliance with minimum Developmental Disabilities program standards.

The Division for Developmental Disabilities should take the administrative steps necessary to adopt the Residential Checklist as minimum program standards in the Colorado Department of Institution's regulations. The Division for Developmental Disabilities' residential services staff should also formulate a more demanding set of residential program standards than those embodied in the checklist. These standards should be used by the

residential services staff to survey those providers that have met the minimum standards in years past and that are interested in rating their performance according to more rigorous standards. The standards should be applied on a voluntary basis only and should be used for the purpose of distinguishing program achievement. The standards may also be used by the residential services staff in providing technical assistance to the residential service providers. The residential services staff should subscribe to whatever training is required to apply the borrowed standards (e.g., PASS training, AC-MR/DD training, etc.).

The Residential Checklist should be modified and expanded to encompass the Regional Centers and Satellite Programs. The Checklist standards as applied to the Regional Center and Satellite Programs should be as consistent as possible with those applied to the community programs.

(1) Rationale

Joint Review

Currently the program reviews conducted by the Division for Developmental Disabilities and the Title XIX facility and medical reviews conducted by the Health Facilities Regulation Division look at a number of the same items, and the reviews take place in different points in time. This places a needless burden on the residential service providers. It also represents an inefficient use of surveyor time. This problem is of particular concern in view of the fact that in the past year the Division for Developmental Disabilities has not had sufficient staff time or

travel funds to conduct on site reviews of most residential programs. For this reason, the Division for Developmental Disabilities was forced to rely on mail surveys instead. The providers interviewed universally labeled these mail surveys "a waste of time," or of "no useful consequence."

Combining the efforts of the Health Facilities Regulation Division and Division for Developmental Disabilities will allow staff from the Division for Developmental Disabilities to be involved in the review of the Regional Center and Satellite Home programs which in past years was not possible.

The involvement of trained Division for Developmental Disabilities staff in the reviews will also infuse the process with needed developmental disabilities expertise. A number of residential providers interviewed observed that Health Facilities Regulation Division survey teams lacked individuals with expertise in developmental disabilities programming, and expressed dissatisfaction with the resulting inconsistency in the application of program standards, and with the minimum amount of technical assistance offered.

Standards

HSRI considers the Residential Checklist and the related review procedure to be well conceived, and in fact has included a description of the Checklist and procedure in a recent casebook of exemplary program review procedures prepared for the National Institute of Mental Health (Bradley, Allard and Mulkern, 1983). The Checklist was well accepted by most everyone interviewed by the study team during the course of the study, though a few

providers interviewed felt that the Checklist was no longer a challenge considering the advances made in their programs in recent years. The importance of challenging service providers to carry their performance beyond the minimum levels required by the Checklist should not be underestimated. The voluntary participation of providers in accreditation schemes indicates the desire of many to be evaluated, to better their performance, and to be recognized for it. Peters and Waterman (1982, pp. 266-277) present a strong case for the use of such evaluative schemes in private industry. We believe their arguments apply equally to the developmental disabilities service sector.

Scheduling

The increased number and geographic spread of residential programs in recent years has prompted many states to alter the basic character of their on-site review mechanisms as they apply to residential and day program providers. A number of states such as Texas have simply extended the period between reviews. However, other states such as North Carolina have been more judicious in their response using brief screening questionnaires or checklists, reports of complaints, and scores on past reviews to identify those programs needing to be reviewed more frequently.

The scheduling of reviews according to need is a long standing practice of accreditation agencies including CARF and AC-MR/DD. The Colorado Department of Education employs a variation of this approach in reviewing its special education programs. Full on-site reviews are scheduled at least once every

three years with interim year reviews scaled down to include only fiscal audits and some follow-up and technical assistance.

Feedback

A number of providers complained that they were not informed of the results of the surveys conducted by the Health Facilities Regulation Division and the Colorado Department of Education (CDE) for months after the reviews, and that after filtering down through the state bureaucracy the findings they did see often lacked substance. Exit conferences should be a routine component of on-site reviews. The survey team should highlight their major findings including both program strengths and weaknesses, and should take the opportunity to identify problems or offer helpful suggestions informally that may not suited for inclusion in the formal report. Conducting an exit conference gives an indication of the state's intent to help by providing feedback in a timely and personal manner.

The message implicit in such excessive delays in written feedback is at best a lack of state interest in correcting problems, and at worse an indication that political considerations have intervened. Worth noting is the fact that none of the providers interviewed had similar complaints about the Division for Developmental Disabilities residential surveys; this is likely explained by the fact that the procedure calls for the expeditious feedback of survey results.

(2) Implementation Timetable

Draft Review Procedures (Division for
Developmental Disabilities/Health Facilities
Regulation Division)

September, 1983

Sign Interagency Agreement (Colorado
Department of Institutions/Colorado
Department of Health) December, 1983

Establish three-year site-review
scheduling system (Division for Developmental
Disabilities/Health Facilities Regulation
Division) February, 1984

Adoption of checklist in Colorado Department
of Institutions regulation (Division for
Developmental Disabilities) July, 1984

Formulation of model residential program
standards (Division for Developmental
Disabilities) June, 1985

(3) Estimated Resource Requirements

One FTE surveyor	\$35,000
Travel/on-site reviews	\$7,000
Division for Developmental Disabilities staff training (PASS, AC-MR/DD)	<u>\$3,500</u> (1985-86 only)
Total	\$45,500

It is projected that Colorado can save up to one third of the person years and one third of the dollars projected for travel to residential programs by extending the period between on-site reviews of less needy programs to three years. Under the Medicaid Waiver only the Regional Centers must be reviewed on an annual basis.

(4) References:

- Section II, pages 45-48, 52-55. Section III, pages 79-83.
- o Normalization and administration: Program Analysis of Service Systems (PASS-3) (Wolfensberger and Glenn, 1975);
 - o Individualization: Resident Management Survey (RMS) (Balla and Ziegler, 1975; King, Raynes and Tizard, 1971);
 - o Group Home Management Schedule (Pratt, 1979);

- o Physical Environment: Multiphasic Environmental Assessment Procedures (MEAP) (Moos, 1979; Seltzer and Seltzer, 1982);
- o Characteristics of the Physical Environment (Rategard, Bruininks and Hill, 1981);
- o Client Satisfaction: Client Interview Schedule (Walsh and Conroy, 1981)

The States of South Dakota and North Carolina employ review scheduling procedures similar to those recommended.

Thomas E. Scheinost, Director, Division of Mental Health/Mental Retardation, South Dakota (605) 773-3438

Paul Rasmusson, Director for Mental Retardation, Division of Mental Health/Mental Retardation Services, North Carolina (919) 733-3654

b RECOMMENDATION 5: THE CURRENT STATUTE 26-2-103(11) CRS 1973 NAMING THE DEPARTMENT OF SOCIAL SERVICES AS THE RESPONSIBLE AGENCY FOR ADMINISTERING GROUP HOMES FOR CHILDREN AND THEREBY THE LICENSING/CERTIFICATION AGENCY FOR TITLE XIX GROUP HOMES FOR CHILDREN SHOULD BE CHANGED NAMING THE DEPARTMENT OF HEALTH AS THE LICENSING AND CERTIFICATION BUREAU. THE LICENSURE/CERTIFICATION REVIEWS SHOULD BE CONDUCTED BY THE HEALTH FACILITIES REGULATION DIVISION/DIVISION FOR DEVELOPMENTAL DISABILITIES JOINT REVIEW TEAM FOLLOWING THE STEPS DESCRIBED ABOVE.

(1) Rationale

This change will eliminate the need for DSS and the DOH to conduct duplicate surveys of the five ICF-MR's serving children. This change will also allow the combined expertise of the Division for Developmental Disabilities and Health Facilities Regulation Division to be brought to bear in assuring the quality of these programs allowing the Division for Developmental Disabilities to approve or disapprove Title XIX Group Home Programs.

(2) Implementation Timetable

Draft legislation; (Colorado Department of Health/Department of Social Services)

January, 1984

Introduce legislation; (Colorado Department of Health/Department of Social Services)

March, 1984

(3) Estimated Resource Requirements:

(4) References

Section II, pages 83-85.

c. RECOMMENDATION 6: THE DIVISION FOR DEVELOPMENTAL DISABILITIES SHOULD CONDUCT AN ANNUAL REVIEW OF THOSE AGENCIES RESPONSIBLE FOR CERTIFYING APARTMENTS AND HOST HOMES TO ASSURE THAT ACCEPTABLE AND RELIABLE HOME CERTIFICATION AND MONITORING PROCEDURES ARE IN EFFECT.

(1) Rationale

Ideally each home or apartment would be subject to individual on-site reviews similar to, but on a smaller scale than those recommended for the larger residential programs. However, this is not economically feasible and is after all what the certifying agencies themselves are to do by state contract.

The use of private certification agencies to assure the quality of services, and the periodic review of these agencies by the state has precedent both at the national and state levels. At the national level, the Accreditation and Institutional Eligibility Staff (AIES) and advisory committee in the Office of Education sets conditions for the recognition of accrediting agencies of higher education, proprietary and vocational education. Accrediting agencies are subject to AIES review every four years.

In Colorado as in a number of other states, the Department of Social Services licenses private child placement agencies to certify family care homes for children.

Once every two years a Department of Social Services surveyor interviews each local placement agency staff person and conducts a review of the agency records to assure that proper procedures have been followed in certifying foster or adoptive families for placement, in placing clients, and in checking on the health and welfare of the clients following placement.

(2) Implementation Timetable

Develop standards and review procedure; (Division for Developmental Disabilities)	December, 1984
Conduct initial survey(s) (Division for Developmental Disabilities)	July 1985

(3) Estimated Resource Requirements

Current staff

(4) References

Section III, pages 83-85.

Colorado Department of Social Services, Peggy Bremmer;

Child Care Act (26-6-10. to 112) CRS 73.

d. RECOMMENDATION 7: THE DIVISION FOR DEVELOPMENTAL DISABILITIES IN COOPERATION WITH THE ADVOCACY GROUPS, COMMUNITY CENTERED BOARDS, AND REGIONAL CENTERS SHOULD RECRUIT CITIZENS AND PROVIDER STAFF TO PARTICIPATE IN THE HEALTH FACILITY REGULATION DIVISION/DIVISION FOR DEVELOPMENTAL DISABILITIES REVIEWS OF RESIDENTIAL PROGRAMS.

(1) Rationale

This is really a matter of reinstating a procedure that was employed by the Division for Developmental Disabilities in 1979-81 as part of the Residential Program Review process. The perspectives and varied experience of informed citizens and providers can greatly enrich the program reviews and can yield insights that might not otherwise surface. The consumer representatives also serve to assure that the familiarity of providers and surveyors does not serve to obscure problems and solutions.

Involving peers, in addition to reducing the demand for state level survey and technical assistance staff, can provide a practical and valued source of ideas and assistance. In fact providers interviewed in the course of the study were among those most strongly in favor of the continued involvement of peers in the review process. The universal judgment of the provider agencies interviewed in this study was that to have any influence, the review should be positive and constructive in tone, should be linked with technical assistance and training, and should preferably include peers. The Colorado Department of Education regularly uses peers as part of their special education program review team, and in this sense their reviews have been favorably received by the providers.

(2) Implementation Timetable

Organize task force (Colorado Developmental Disabilities Council/Division for Developmental Disabilities) November, 1983

Plan recruitment campaign (Colorado Developmental Disabilities Council/Division for Developmental Disabilities) December, 1983

Initiate recruitment campaign (Colorado Developmental Disabilities Council/Division for Developmental Disabilities) January, 1984

(3) Estimated Resource Requirements*

Materials, advertising/phone/postage \$1,000 1983-84

(4) References

Section II p. 49-50.

* Mileage and travel resources for participants in training covered under Recommendation 8.

e. RECOMMENDATION 8: THE DIVISION FOR DEVELOPMENTAL DISABILITIES SHOULD PROVIDE A FORMALIZED PROGRAM OF TRAINING TO ALL PERSONS EMPLOYED AS SURVEYORS OF RESIDENTIAL PROGRAMS SERVING PERSONS WITH DEVELOPMENTAL DISABILITIES. PREFERABLY THE SURVEYORS SHOULD HAVE FIRST HAND EXPERIENCE IN THE DELIVERY OF SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES. THIS TRAINING SHOULD BE PROVIDED TO THE DEPARTMENT OF SOCIAL SERVICES SURVEYORS OF FAMILY CARE HOMES AND RESIDENTIAL CHILD CARE FACILITIES SERVING PERSONS WITH DEVELOPMENTAL DISABILITIES, AND PARTICIPATING PROVIDERS AND CITIZENS AS WELL AS TO NEWLY HIRED DIVISION FOR DEVELOPMENTAL DISABILITIES STAFF.

(1) Rationale

As in recommendation 7, implementing this recommendation basically involves reinstating the Division for Developmental Disabilities training program conducted in 1979-81. In order to conduct thorough program reviews instructive to the providers and of benefit to the clients, the surveyors must be qualified and well trained. Most providers interviewed during this study remarked that the Department of Health reviewers in particular were not experienced and were insufficiently trained to identify problems and offer helpful suggestions for improving programs. As a result, they reportedly missed program deficits obvious to provider staff, offered varying interpretations of the standards, and were not able to offer ideas and approaches of much practical utility to the providers.

Formalized surveyor training is a prerequisite of any systematic review process. Training is necessary in order for the surveyors to apply the instruments correctly and consistently. For instance, Program Analysis of Service System (PASS) surveyors undergo three to five full days of training prior to conducting PASS surveys. Similarly, CARF and AC-MR/DD surveyors receive three full days of training prior to conducting

surveys. This does not include basic training in the field of developmental disabilities which surveyors should have to be effective. The training should include information pertaining to client rights and due process.

(2) Implementation Timetable

Design training program (Division for Developmental Disabilities; Colorado Developmental Disabilities Council; Legal Center for Handicapped Citizens; and the Colorado Association for Retarded Citizens)

January, 1984

Arrange training session (Division for Developmental Disabilities)

February, 1984

Conduct training session (Division for Developmental Disabilities; Colorado Developmental Disabilities Council; Legal Center for Handicapped Citizens; and the Colorado Association for Retarded Citizens)

March, 1984

(3) Estimated Resource Requirements

Travel/materials, \$5,000; FY 1983-84 Suggested source: Developmental Disabilities Council

(4) References

Section II, pages 45-48.

C. Assuring Good Practice

1. Proactive Mechanisms

a. RECOMMENDATION 9: CASE MANAGEMENT SERVICES SHOULD BE OFFERED TO ALL PERSONS WITH DEVELOPMENTAL DISABILITIES WHO MEET THE BASIC ELIGIBILITY CRITERIA FOR DIVISION-FUNDED SERVICES REGARDLESS OF WHETHER THESE PERSONS CAN OR/SHOULD BE PLACED IN RESIDENTIAL OR DAY PROGRAMS.

This recommendation simply endorses the guidelines contained in Colorado's Case Management Model developed by the Division for Developmental Disabilities and documented in manual form in May of 1982. It is also consistent with a recent recommendation of the Eligibility Criteria and Target Population Committee. These eligibility criteria are being established by the Target Population Committee organized by the Division for Developmental Disabilities.

(1) Rationale

One of the five quality assurance responsibilities of the state, identified in Section I of this report, is "to assure that the limited supply of state-funded services is provided to those persons with developmental disabilities who are most in need." At one level, the eligibility determination process addresses this responsibility. At a second level, the case manager can help fulfill this responsibility by getting to know the individual and his or her needs and working to fill those needs by placing the individual in available services, or by planning and promoting the development of new services. Additionally, in the absence of residential and day programs, the case manager can at least monitor the individual to assure that s/he does not require services of an emergency nature.

The importance of this follow-along function is brought out in the Situation Analysis (Blakely, 1983):

"a survey of the patterns of admissions to the Regional Centers indicated that clients not enrolled in day programs, and consequently not receiving case management services, are those most often in need of emergency admission into an institution. In many cases, these clients are terminated from day programs because of behavioral and/or emotional problems which interfere with their ability to benefit from the programs. When they are no longer enrolled in day programs, they lose case management services. The irony is that without case management services, these clients frequently do not receive attention to their behavioral or emotional disturbances, thereby diminishing their chances for re-entry into appropriate day programs." (p. 32)

(2) Implementation Timetable

Project budget 1985-86.

(3) Estimated Resource Requirements

The prospective costs of providing case management services to all clients meeting the statewide criteria for eligibility are a function of the eligibility criteria, and a function of the scope of the case management services offered. The eligibility criteria are not yet established and we are recommending that the case management function be redefined. Accordingly, we are not in a position to provide a very reliable estimate of the additional resources needed.

According to figures currently available to the Division for Developmental Disabilities, there are currently 600 adults on program waiting lists, in nursing homes or in adult residential services who do not presently have a case manager. Using the annual cost of comprehensive case management services per client of \$1,073, as estimated for purposes of projecting the costs of the Title XIX waiver, the projected yearly cost of implementing

this recommendation would be \$643,800 (Note: this does not include the cost of providing case management services to school age children). It should be noted that funds for the provision of case management services to 341 persons with developmental disabilities in general (Class I) nursing homes and not enrolled in day programs (thus already having case managers) has recently been funded by the state legislature in response to a request from the Division for Developmental Disabilities, Colorado Department of Institutions and the ARC-C. However, this funding was for six-months only and funding continuation has yet to be decided.

We do not have the information needed to project the rate of community outplacement, related decline in Regional Center census, and corresponding marginal costs of case management. The cost of adding case managers to attend to the needs of Regional Center clients preceding and following outplacement may be offset by reducing the complement of Regional Center staff if, in fact, the census at the Regional Centers declines.

(4) References

Section III, pages 90-93.

b. RECOMMENDATION 10: A CASE MANAGER OR CASE MANAGEMENT UNIT REPORTING TO THE DIRECTOR SHOULD BE LOCATED IN EACH COMMUNITY CENTERED BOARD. THE CASE MANAGER SHOULD BE EMPOWERED TO ASSURE THAT ONLY SERVICES PRESCRIBED IN THE IHP ARE PROVIDED WITH STATE FUNDS, AND TO PLACE THOSE IN HIS/HER CASELOAD DEEMED MOST IN NEED INTO EXISTING SERVICES. FURTHER, CASE MANAGERS SHOULD MAKE NOTE OF TYPES AND LEVELS OF SERVICES IDENTIFIED IN THE INDIVIDUAL HABILITATION PLANNING (IHP) PROCESS AS NEEDED BY CLIENTS BUT UNAVAILABLE AND SHOULD SUBMIT THIS INFORMATION FORMALLY TO THE COMMUNITY CENTERED BOARD DIRECTOR WHO WILL SUBMIT INFORMATION TO THE STATE OFFICE OF CASE MANAGEMENT SERVICES FOR INPUT INTO THE STATE DEVELOPMENTAL DISABILITIES PLANNING AND BUDGETING PROCESS. STATE PAYMENT FOR CASE MANAGEMENT SERVICES SHOULD BE MADE ON A UNITS-OF-SERVICE BASIS.

Each Community Centered Board case management unit should develop written operating procedures governing the case management function and should be assisted in this effort by the Case Management Office, Division for Developmental Disabilities. The Case Management Office should review and approve these procedures and should monitor the Community Centered Board case management operations to help assure adherence to these procedures. It should be noted that the CORE system provides for the reporting of unmet service needs by the Community Centered Boards. However the reporting to date has been spotty and by most accounts does not appear to reflect reasonable levels of need.

(1) Rationale

The case manager operates as a member of an interdisciplinary team and his or her decisions should logically be informed by the IHP/IPP process. It is likely then that the IHP will reflect a plan of service judged appropriate by the team. It is unlikely that a case manager would routinely flout the recommendations of the team. However, it is the case manager

who is ultimately responsible for the best interests of the individual clients and for seeing that the individualized habilitation plan is implemented. The case manager must have the authority necessary to carry out this responsibility; otherwise the integrity of the case management function is open to question.

As explained in the Situation Analysis, in order to assure the continuity of services to clients as they move through the continuum of developmental disabilities services:

"case management should be organized so the clients may retain the same case manager as they progress through the continuum. As the system currently functions, a client's case manager changes if s/he transfers out of or into institutional services, and may change depending on the agency, as s/he changes programs within a Community Centered Board."

In view of state efforts to place or to move clients into community based services, a community locus makes eminently more sense than a Regional Center locus for the case management unit. The difficult issue is whether the case management unit should be organized as part of or apart from the Community Centered Boards and it has been the object of considerable debate in Colorado over the years. The advocacy groups have been outspoken in favor of a case management unit independent of the Community Centered Boards, if and only if, the Community Centered Board's refused to implement a case management unit reasonably independent of the program units (Harvey, Panza, and Smith, 1982). Their view is consistent with the model case management/service coordination design specifications developed by the Rehab Group for the Administration on Developmental

Disabilities (ADD), Office of Human Development Services, Department of Health and Human Services (Morell, 1980). The design specifications state:

The service coordination system should be administratively separate from a specific service-providing agency, institution, or organization. Several service providers and community resources may be competing for dominance in serving the individual. Therefore, to assume the role of negotiator, coordinator, and moderator requires a free-standing service coordination system.

Such independent case management mechanisms are in place in a number of states (e.g., California, Ohio, and Massachusetts).

More moderate positions have been expressed by the Developmental Disabilities Council (May, 1982) and Division for Developmental Disabilities (Meeker, 1981 and 1982; Division for Developmental Disabilities, 1982). These positions allow for the case management function to be administered by the Community Centered Board but with a number of administrative safeguards designed to provide the case manager with sufficient authority and autonomy to carry out his or her responsibilities to the client. While this position is not favored under the ADD case management/service coordination design specifications, it is acceptable under two conditions:

- o The first is the recognition by the agency of the inherent conflict of interest between service provision and service coordination [case management]. The second is the development of a separate operating board to administer the service coordination agency. The separate boards will safeguard against some of the conflict of interest (Morell, 1980 p. 2-19).

Though little empirical evidence is yet available on the efficacy of different case management models, what does exist in our judgement weighs more for the Community Centered Board case

management model and less for the independent case management model. Carragonne's studies of case management operations in Texas and Colorado and other states leads her to argue in favor of an interpersonal, more informal approach as the way to get the job done. Dr. Carragonne finds that the most effective case managers as perceived by the service providers, administrators and case managers themselves are those that are skilled in the art of "mediation through the use of analytic communication and arbitration skills," and that have an intimate "knowledge of client needs, agency constraints, and range of alternatives possible" (Caragonne, undated, # 1). Where case managers are apart from the service mainstream, she finds that they tend to find that "little or no information is solicited from them . . . and little attempt is made to provide them with feedback on the effect of their activities" (Caragonne, 1983 p. 71).

At the same time, current studies are pointing to the problems associated with independent case management agencies set up to deal with service providing agencies at arm's length, acting essentially as service purchasing agents for clients, and acting as outside service planners and monitors of service quality.

Discussing the early findings of a nationwide evaluation of several case management models sponsored by the Administration for Developmental Disabilities, one evaluator describes the "California" model under evaluation in decidedly negative terms as "top heavy, mechanistic, nonhumanistic, and in need of considerable redirection" -- the same characteristics of the case

management working environment that Caragonne's study of 22 case management operations (undated # 2) indicates to be least associated with provision of **comprehensive** case management services.

While these studies are far from conclusive, they certainly point to no one model that stands above the Community Centered Board model that we are recommending, and that would justify the cost and disruption associated with a shift of the case management function away from the Community Centered Boards. On the other hand, they do point to the difficulty in retaining the integrity of the case management function when administered by agencies, such as most of the Community Centered Boards in Colorado, that are also providers of service. These studies point out why the administrative safeguards recommended are so important.

As Caragonne observes in her studies of case management operations (1983), that the central purposes and functions of case management are often diluted by the lack of organizational support:

The lack of support may be manifest in one of two ways. In the first instance, case managers are relegated to the status of client monitors or client flow coordinators . . . and permitted to operate only if traditional hierarchical relationships are not disturbed in the process. The case management role, in this case, merely becomes an administrative exercise. [In the second instance], the definition of case management approaches omnipotence. He or she offers services such as crisis stabilization, emergency referral, counseling, securing of additional social services, assessment procedures, and advocacy with other involved agencies. The worker is designated as primary point of accountability and responsibility for extensive documentation, attendance at staff and training meetings, and attendance at supervisory conferences. Because of limited staffing patterns, they are additionally responsible for travel

arrangements, chore services, and any other assistance the client might need, such as physical assistance in moving from one residence to another, or training in the use of public transportation. Case managers may also be required to be "on-call" at some agencies, a procedure which requires 24-hour attendance. Workers are also required to handle all emergency situations involving clients, which can involve at times physically substituting for clients in employment situations. Case managers are also constrained to arrange, secure and coordinate all external services required by clients" (Caragonne, 1983, p. 70).

Considering the already high case loads in Colorado and the upcoming paper work burden to be borne by the Community Centered Board case managers under the Title XIX Waiver, the primary concern of the study team is with Caragonne's "omnipotent" case manager. What makes the tendency to overload case managers even more ominous is its insidious nature. At fully two-thirds of the 22 case management programs studied by Caragonne, case managers reported spending less time in actual case management activities than was perceived by their supervisors. Conversely, case managers reported spending more time in direct service activities than was perceived by their supervisors (Caragonne, undated # 2). Andreasen (1983) reports that in New Hampshire's county MH/MR boards, the erosion of the case management function continued in spite of the fact that the case management units have separate operating boards.

Caragonne emphasizes the importance of clarifying the roles and responsibilities, authority and protocols of the case management unit both to maintain the integrity of the case management function, and to better ensure that it works to the mutual satisfaction of the case managers, service providers and agency administrators alike. Hence the study teams

recommendation that the Community Centered Boards develop standing operating procedures approved and monitored by the Division for Developmental Disabilities Case Management Office. Such monitoring procedures are reportedly already being developed by the Case Management Office, Division for Developmental Disabilities (Division for Developmental Disabilities, 1983). In doing so, we suggest that the Community Centered Boards and Division for Developmental Disabilities Case Management Office consider the Administration for Developmental Disabilities' design specifications for service coordination (Morell, 1980). The Division for Developmental Disabilities and Community Centered Boards would also be well advised to consult with Lesa Andreasen, BLF, Inc. since she has spent years helping agencies develop practical and effective case management procedures. Of course, a number of Community Centered Boards have procedures that might serve as guides to other Community Centered Boards (e.g., the Weld County Community Centered Board and Pueblo County Community Centered Board). The States of Michigan and New York have case management standards which might also be worth reviewing.

In summary, recommendation 10 is submitted recognizing the problems inherent in such an arrangement. The study team's concern is not that the Community Centered Board case managers will be faced with repeated instances where the interests of the Community Centered Board as a service providing agency and the interests of the clients will come into strong conflict (i.e., where client access to needed services is being unjustifiably

denied or the rights of a client are being clearly violated). We are satisfied that the recommended due process mechanisms (recommendations 14 and 15), and the advocacy agencies in Colorado will serve to protect client interests in this regard.

Our concern is with the more subtle erosion of the case managers' capacity to perform the central case management functions associated with the IHP and IPP (service coordination) and with individual and program monitoring. Such erosion will predictably coincide with declining responsiveness on the part of Community Centered Board to client needs. While the recommended administrative safeguards may help retain the essential autonomy and authority of the Community Centered Board Case Management Unit, in the final analysis it will require the commitment of the Community Centered Board directors and case managers. In the words of one Community Centered Board director, the key to the quality and scope of [case management] services seems to rest with the individual case managers and their willingness to move the system in order that their clients' needs are served. We need to design systems that foster and encourage this kind of "client-orientation" and reinforce these individuals in their desire to serve their clients in the best way they can. The study team is recommending this sort of system, one fully consistent with the guiding principles of the Community Centered Board system in Colorado (CACCB, 1983), and one we believe will carry the support of most Community Centered Board director's. However, where the Case Management Office in their ongoing review of case management operations, finds that the administrative

safeguards are not sufficient to protect the integrity of the case management function, the Division for Developmental Disabilities should move to separate the case management units from the Community Centered Board's.

(2) Implementation Timetable

Complete development of Community Centered Board case management procedure approval and monitoring procedure (Division for Developmental Disabilities, Case Management Office) April, 1984

Develop Community Centered Board case management procedures (Community Centered Boards) June, 1984

(3) Estimated Resource Requirements

1 FTE staff	\$30,000	1983-84 and ongoing
Consultant	\$2,500	1983-84

Suggested source: Colorado Developmental Disabilities Council

(4) References

Section II, pages 49-50. Section III, pages 96-97.

Andreasen, Lesa, President, BLF, Incorporated, Freeport, Maine (207) 865-4097.

Colorado Association of Community Centered Boards, Guiding Principles for the Community Centered Board System (Draft), 1982/83.

Colorado Developmental Disabilities Council, Case Management Position Paper (May, 1982).

Harvey, Mary Anne, Panza, Joe and Smith, Fran, "Preliminary Statements on Case Management," Position Paper, (April 16, 1982).

Lynn, Alice, re: New York Case Management Standards (518) 474-6553.

Meeker, John, letter to Gary Smith and Imojean Vollack, re: Case Management, October 1, 1981.

Meeker, John, Memorandum, Community Centered Board
Coordinators, FY 82-83 Case Management Budget Initiative,
January 15, 1982.

Mulberry, Carol, re: Case Management Standards (517) 373-
2900.

Read, Davey, re: Oregon Case Management Evaluation System
(503) 378-2429.

c. RECOMMENDATION 11: IN ORDER TO ALLOW COMMUNITY CENTERED BOARD CASE MANAGERS TO UNDERTAKE SERVICE COORDINATION (IHP/IPP), CLIENT MONITORING AND PROGRAM MONITORING FUNCTIONS ESSENTIAL TO ASSURE ACCESS TO SERVICES AND THE QUALITY OF SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES, THE DIVISION FOR DEVELOPMENTAL DISABILITIES IN COLLABORATION WITH THE COMMUNITY CENTERED BOARDS, REGIONAL CENTERS AND ADVOCACY GROUPS SHOULD IMPLEMENT RECOMMENDATIONS 11.1, 11.2 AND 11.3.

We believe that the implementation of recommendation 11.1 through 11.3 will reduce the total cost of providing case management services in the long run. We do not mean to imply that the implementation of these recommendations will be sufficient to offset the costs of the improved case management coverage recommended earlier.

RECOMMENDATION 11.1: INSTITUTE PROGRAMS TO TRAIN PARENTS, GUARDIANS, AND CLIENTS WHO ARE INTERESTED IN SERVING AS THEIR OWN CASE MANAGERS.

(1) Rationale

Parents, legal guardians and clients have the right to seek or not to seek case management assistance in much the same way as they have the right to accept or not to accept the offer of direct services. However, the complexity of the service coordination function (IHP and IPP activities), is such that a comprehensive program of training is required to give families and/or clients the ability to negotiate their way through the system effectively, and to recognize for themselves good services from poor. In order to assure that they are able to act responsibly in their own behalf, the Community Centered Boards should provide a program of training for these persons. Such a program is in operation in the Regional Center of Orange County California.

The Center trains parents for the job of program coordinator or case manager of their child's individual program plan (IPP). In this capacity as program coordinator, a parent is responsible for developing and monitoring the IPP of their child, coordinating evaluations and other services, advocacy, and performing attendant paper work . . .

Parents begin by making a formal written application for the position of program coordinator. After they have been accepted, the trainees move through a three-phase training program.

The first phase is a ten week course offered by the Rancho Santiago Community College District. Subjects covered are legal rights, normalization, the history of social services systems, and other areas addressed by guest speakers knowledgeable in their own fields. If the parent decides at that time to go into actual program coordination, s/he takes an additional two weeks of practical instruction. The parent then goes into the second phase, a one year in-service in actual casework. Phase three is the independent program coordination by the parent. Contact is maintained between a program supervisor and the parent program coordinator according to need.

According to ORC staff, the program may be seen as a viable alternative to professional techniques. Recent performance by the fifty PPC's at the Center has shown that they can effectively serve as competent program coordinators. (Jennings, 1983)

(2) Implementation Timetable

Prepare training program plan and budget
(Division for Developmental Disabilities,
Case Management Office, Legal Center for
the Handicapped and Colorado Association
for Retarded Citizens)

May 1984

Implement training program (Division for
Developmental Disabilities, Case Management
Office, Legal Center for the Handicapped
and Colorado Association for Retarded
Citizens)

FY 1984-85

(3) Estimated Resource Requirements

Training sessions \$7,500

Suggested source: Colorado Developmental Disabilities
Council

(4) References

Bradley, Nancy, MSW, Regional Center of Orange County,
Central Tower, Union Bank Square, 500 South Main Street,
Orange, California 92668.

RECOMMENDATION 11.2: INSTITUTE PILOT PROGRAMS OF RECRUITMENT AND TRAINING FOR PARENTS, GUARDIANS, FOSTER GRANDPARENTS, AND OTHERS TO OBSERVE PROGRAMS AND TO FEEDBACK ANY NOTEWORTHY INFORMATION RELATING TO THE QUALITY OF THE PROGRAMS TO RESPONSIBLE CASE MANAGERS OR TO AGENCY LEADERSHIP AS APPROPRIATE.

(1) Rationale

Like the case manager, parents, guardians, foster grandparents and others who visit clients regularly are in an excellent position to observe programs in operation. Other members of the community may be interested in monitoring programs as well. Certainly these individuals would require training and would have to be informed of the proper visiting protocols in order to make their visits useful and nondisruptive. Again, we are not advocating for the development of a highly formalized and obtrusive process.

The importance of involving members of the community in the provision of residential and habilitative services cannot be over-emphasized. Citizen involvement is essential if the provider is to gain community acceptance and to open the community and all its aspects to the residents. The simple presence of outside interests at facilities for persons with developmental disabilities can contribute to more healthy and normative environments.

Traditionally, citizens have become involved in the delivery of developmental disabilities services as members of provider boards or as volunteers augmenting administrative and service staff. Few program administrators have been willing to subject their program to review by lay persons, and few citizens have felt comfortable in evaluating the specialized work of

"professionals." Still, where programs have invested the time to educate and train citizens as program monitors, their efforts have reportedly paid dividends. Administrators have found that citizen reviewers bring a valuable common sense perspective to provider reviews and are in a good position to represent the interests of potential and current consumers of services the Administrators have also found that educated and involved citizens do much to promote the interests of the service provider in the community.

Citizen monitoring programs range from highly formalized programs such as that in Lancaster County Pennsylvania to less formalized programs such as those in Michigan and Kentucky.

In Lancaster County, local citizens have been actively involved in the evaluation of the county's mental health and mental retardation providers for the past several years. Each year an advertisement appears in the local newspaper requesting volunteers for the annual citizen evaluation. Volunteers who respond are trained in a modified evaluation techniques approximately 400 local citizens have been trained to date. Upon completion of the survey, a report is prepared and submitted to the county and the particular agency for review and action. Many of the citizen evaluators return year after year to participate in the survey, and the response from the service providers has been very encouraging (Nelson, 1981). Programs similar to Lancaster County's program have been established in parts of California.

At the Macomb-Oakland Regional Center in Michigan, a less

formal procedure is in operation. The Association for the Macomb-Oakland Regional Center, a parent advocacy organization, has a Special Monitoring Committee whose purpose is to ensure that the best possible care is being given to mentally retarded persons in community placement. The Monitoring Committee consists of eight core persons who, with other monitors, visit homes usually unannounced.

The response of program administrators has reportedly been very positive. One administrator writes, "In my opinion, as an administrator of four group homes, the monitoring group of parents from the Association for MORC is one of the most positive steps ever implemented for review of the group homes. A parent will perceive the appearance and atmosphere of the home in a different manner than most monitoring groups. I have yet to know an administrator who has denied the need of parental involvement for successful homes" (Patrick, undated). A program similar to this has been established by the Association for Retarded Citizens in Kentucky. A wealth of other citizen review approaches are described in a recent report by Bradley, Allard, and Mulkern, 1983.

The use of citizens to advocate for persons with developmental disabilities is certainly not new in Colorado; a number of citizen advocacy programs (e.g., Ridge, Denver, Boulder, Aurora, Arapahoe, Colorado Springs, Fort Morgan, . . .) have been operating for nearly a decade throughout the state. In fact, what we are proposing is that these advocacy groups take the lead in establishing a specific role of citizens in program-

centered monitoring. Similar undertakings have reportedly been proposed already and submitted for funding to the Colorado Developmental Disabilities Council and private foundations by the Colorado Association for Retarded Citizens.

(2) Implementation Timetable

This program should be implemented in several communities by the advocacy groups in Colorado.

Design program and submit proposal for funding (Advocacy Groups)	May, 1984
Invite Community Centered Board Participation (Developmental Disabilities Council)	June, 1984
Award citizen monitoring project contracts (Developmental Disabilities Council)	September, 1984
Recruit monitors (Advocacy Groups)	December, 1984
Train monitors	March, 1985
Implement monitoring program (Citizen Advocacy Groups)	May, 1985
Evaluate programs	May, 1985

(3) Estimated Resource Requirements

Pilot implementation	\$20,000	1984-85
Pilot evaluation	\$10,000	1984-85

Suggested source: United Way, private foundations, Developmental Disabilities Council

(4) References

Section II, pages 69-73. Section III, pages 96-97.

RECOMMENDATION 11.3: REDEFINE THE COMMUNITY CENTERED BOARD CASE MANAGEMENT FUNCTION TO EXCLUDE MANY OF THE INTAKE, INFORMATION AND REFERRAL, TERMINATION AND TRANSFER ACTIVITIES OF A CLERICAL NATURE WHICH COULD BE PERFORMED AS WELL AND MORE ECONOMICALLY BY TRAINED CLERICAL STAFF AND TO INCLUDE PROGRAM-CENTERED MONITORING ACTIVITIES.

(1) Rationale

While the intake, information and referral activities are generally recognized as legitimate case management functions, too often (as in Colorado) the clerical aspects of these functions absorb a disproportionate amount of the case manager's time taking time away from those service coordination (IHP/IPP) and monitoring functions that are most critical to client development and well being, and that are more demanding of professional knowledge and skills. This practice is, in fact, encouraged in Colorado. Presently the Community Centered Boards are required by contract to perform only the intake, individual habilitation planning (IHP), individual program planning (IPP), and transfer and termination functions. Individual monitoring and review, and continual contact are not required. In our judgment, and consistent with the Administration on Development Disabilities case management design specifications (Morell, 1980), it is the individual monitoring and review function that should take precedence at least over intake activities of a clerical nature, specifically: records collecting and completion, phone calls and filing. As noted earlier, the Medicaid waiver will demand that an even greater proportion of the time of Community Centered Board case managers be spent on intake and termination activities of a clerical nature considerably reducing the amount of time

case managers will be able to spend on service coordination and on individual and program-centered monitoring activities needed to assure service access and quality.

The program-centered monitoring function has not traditionally been recognized as a legitimate case management function. The author of the Colorado Case Management Manual (Division for Developmental Disabilities, 1982) goes so far as to say that conflicts between the program staff and case managers "are likely to arise when the case manager is perceived to be undertaking program-centered monitoring" (1982, Chapter V, p. 2). We do not agree, and although program-centered monitoring, is identified here as distinct from individual-centered monitoring we find the two hard to separate. We are not talking about the formal pad and pencil form of monitoring, but rather the casual, albeit purposive, process of observation -- being alert to tell-tale signs of program strengths and problems, good practices and poor. It is, and should be, a natural concomitant of any conscientious approach to monitoring. It is, in fact, this sort of monitoring that reportedly alerted Community Centered Board case managers to the poor quality of care being provided by the Twin Pines Nursing Home. Had their warnings been heard and heeded, the Twin Pines "nightmare" might have been avoided (Association for Retarded Citizens of Colorado, 1983). It is a credit to the state that in the wake of the Twin Pines episode, the Colorado Department of Institutions spurred on by the ARC-C quickly requested and the legislature approved funds for case management services for nursing home clients in order to

to reduce the likelihood of such incidents in the future.

Frequent unannounced and unobtrusive on-site reviews represent the only way to obtain an accurate view of these service dimensions, and case managers are uniquely equipped and positioned to carry out such reviews. They are sensitive to the needs of the clients and understand the practical constraints and problems encountered by providers in delivering services to these clients. They also should have an intimate knowledge of the individual habilitation planning process. Moreover, they have every reason to pay frequent visits to those providers serving their clients; their presence, therefore, is likely to be seen as more routine and less threatening than visits by most any other outside observers.

(2) Implementation Timetable

Arrange for presentation by Ms. Andreasen (see Recommendation 10) to CACCB on the separation of case management and clerical functions (Division for Developmental Disabilities, Case Management Office)

November, 1983

(3) Estimated Resource Requirements

The costs of additional clerical staff will be more than offset by the decline in case management costs.

(4) References:

Section II, pages 49-50, 69-73. Section III pages 96-97.

Colorado Association for Retarded Citizens, Annual Meeting, Fort Morgan, Colorado (June 9, 1983).

d. RECOMMENDATION 12: THE DIVISION FOR DEVELOPMENTAL DISABILITIES SHOULD PLAN, DEVELOP, AND AGGRESSIVELY PROMOTE AND SUPPORT A COMPREHENSIVE PROGRAM OF STAFF DEVELOPMENT FOR PERSONS ADMINISTERING AND DIRECTLY PROVIDING SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES IN COLORADO. THIS SHOULD BE DONE IN CLOSE COLLABORATION WITH THE COMMUNITY CENTERED BOARDS, REGIONAL CENTERS, STATE AGENCIES PROVIDING SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES SUCH AS COLORADO DEPARTMENT OF EDUCATION, DEPARTMENT OF SOCIAL SERVICES, DEPARTMENT OF HEALTH AND OTHER AGENCIES PROVIDING SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES.

(1) Rationale

Before entering into the specifics of this recommendation it is important to appreciate the preeminent importance of training and technical assistance as a quality assurance tool. The strongest argument is not that it helps to assure good practice by increasing staff competence, though certainly this has been shown (Schinke and Wong, 1977; Bernstein, 1981; Maloof, 1975; and Benveniste, 1977), but that it serves to build and maintain a cadre of direct care staff positive in their approach to their work and committed to good practice.

It goes without saying that, more than most fields, in the field of developmental disabilities people are central. The programs are designed to provide services to people with developmental disabilities and the services are provided by people, caring people, very few of whom enter the field for monetary gain; the overwhelming majority come to the job already motivated to perform well. They have entered the field for humanistic reasons and ask little more than to be recognized and supported in their efforts. The somewhat contrived, rah! rah! efforts of commercial enterprises to motivate their employees are hardly necessary; yet, most state offices of mental

retardation/developmental disabilities have failed to give service staff even the barest amount of recognition and support. Instead, by their actions, most states display little regard or concern for these individuals and are more ready to check and coerce than to train and persuade. Aside from the inverted logic of this approach -- sanction first, train second -- the negative message is clear and breeds a system of care governed by distrust between direct care providers and state. It is the same phenomena, though at a broader level, that Bruininks et al. (1979) note in their study of large residential facilities and that Lakin and Bruininks (1981) note in their study of community and institutional residential programs. "Mary Wilbur, Director of the Quality Assurance Bureau of the New York State Commission on Quality of Care for the Mentally Disabled, is close to this problem . . . [and makes] a compelling point that abuse and neglect of facility residents is secondary to a primary institutional abuse and neglect of direct care staff. She notes that 'these problems also affect staff working in the community, although the emphasis is different. Many staff members working in community residences complain of a sense of isolation -- as though they are far away from the center of things and nobody cares'" (Lakin and Bruininks, 1981, p. 160 -161).

If Colorado is to avoid this debilitating phenomena, the Division for Developmental Disabilities and departmental leadership must demonstrate their belief in the basic integrity and importance of the caregiving staff by fighting as hard for funds to support staff training and technical assistance as they

do for funds to add program surveyors. The lament reflected in a number of state planning documents and repeated in a number of interviews, "that training generally receives low priority and is subject to cuts as resources become scarce," is simply too weak.

In the early 70's, there was a respectable departmental commitment to staff development, however, over the past decade this commitment has dissipated. It's not too late for the Division for Developmental Disabilities and Department of Institutions to restore this commitment. In our judgment it is the single, most instrumental step the Department could take to assure the quality of services to persons with developmental disabilities in Colorado.

RECOMMENDATION 12.1: THE DIVISION FOR DEVELOPMENTAL DISABILITIES SHOULD HIRE AT LEAST ONE STAFF MEMBER RESPONSIBLE SOLELY FOR PLANNING AND COORDINATING THE TRAINING OF STATE, REGIONAL CENTER, COMMUNITY CENTERED BOARD, AND OTHER TRAINING AND TECHNICAL ASSISTANCE EFFORTS IN COLORADO. THE RESPONSIBILITY OF THE STAFF DEVELOPMENT UNIT SHOULD INCLUDE:

- o Assessing the needs for training and technical assistance -- On an ongoing basis, the needs for training should be determined through the systematic review of residential program and day program survey results and debriefing of program surveyors. The vocational rehabilitation training program in the State of Georgia employs just such systematic followup to the CARF surveys of day programs. In New York, the members of the training program staff are also in close contact with the program surveyors.

A comprehensive study of staff development needs in Colorado was completed by the University Affiliated Facility in 1981 under a Developmental Disabilities Council grant. This study should provide a sufficient basis to begin the staff development planning process. In addition, the Technical Assistance Center recently completed a survey of Community Centered Boards to learn their perceived needs for management training. Results of this survey should likewise be of use for planning.

- o Planning a statewide program for staff development in close collaboration with Community Centered Boards, Colorado Department of Education, Regional Centers, University Affiliated Facility, Association for Retarded Citizens and Developmental Disabilities Council -- The planning process is essential to work out a program meeting Colorado's particular requirements. The issues are too involved to be addressed adequately in this study. The planning process should lead to the following decisions:

- minimum training requirements for all staff working with persons with developmental disabilities in Colorado;
- the extent to which the state should have a hand in developing training and educational resources throughout the state;
- the possibility of staff training exchanges between the Community Centered Boards and Regional Centers (Re: Situation Analysis);
- the projected costs of staff training in Colorado. The cost estimates should distinguish between the funds needed for state discretionary training

projects, Community Centered Board in-service training and Regional Center in-service training.

Developmental disabilities staff development plans are prepared annually in a number of states. California and New York have also prepared statewide training curricula, and procedures for assessing the efficacy of their training and for assessing staff competency. However, these state-directed approaches may well not suit Colorado's needs.

- o Distributing discretionary state training funds to community Centered Boards, Regional Centers, Department of Social Service programs, the Department of Rehabilitation, and other agencies public and private, to conduct training projects consistent with the state plan, and monitoring the use of these funds -- These funds should amount to no more than 25% of the in-service training funds provided directly to the Community Centered Boards.

- o Serving as an information center and central repository for training materials produced around the country and in Colorado in support of staff training efforts in Colorado -- There is a wealth of information and materials available for the training of staff of persons working with persons who are developmentally disabled both in hard copy and video tape form. References to this material can be found in most of the journals and newsletters in the field. Some of the best known sources are listed in section (4).

State Offices of Mental Retardation, Developmental Disabilities and Vocational Rehabilitation also have or have access to materials to their states. In recognition of this fact, the Director of Staff Training and Development in the Office of Mental Retardation and Developmental Disabilities in New York State has requested information from other MR/DD offices and has proposed that they arrange to share training materials. The Division for Developmental Disabilities should join in this cooperative effort. We suggest that the training and technical assistance coordinator consult with Dr. Marc Litvin, Director of the Division of Rehabilitation, in view of his former position as head of the Federal Programs Information and Assistance Project.

We also suggest that the coordinator check with John Pride of the Administration for Developmental Disabilities, Department of Health and Human Services. The Administration for Developmental Disabilities is compiling a directory of individuals and organizations providing technical assistance to developmental disabilities programs.

- o Building and maintaining a file of prospective consultants to use in staff training and technical assistance efforts in Colorado -- There are hundreds of individuals within the state and around the country who have expertise in particular programmatic areas and who would be willing to serve as consultants.

(2) Implementation Timetable

Recruit and hire staff member (Division for Developmental Disabilities)	July, 1984
Prepare training and technical assistance plan (Division for Developmental Disabilities/Community Centered Boards, Regional Centers/ARC, Colorado Developmental Disabilities Council)	September, 1984
Develop system for organizing training materials and begin collection of materials (Division for Developmental Disabilities)	March, 1985
Begin building file of prospective consultants (Division for Developmental Disabilities)	August, 1985

(3) Estimated Resource Requirements

Staff person	\$30,000	1983-84
Travel and other direct costs associated with plan preparation	\$10,000	1983-84
Discretionary training	\$10,000	1983-85
Discretionary training	\$20,000	1985-86 and ongoing

(4) References:

Section II, pages 67-69. Section III, pages 93-96.

State sources of information:

- o John Keegan, Director, Staff Training and Development, Office of Mental Retardation and Developmental Disabilities, New York State (518) 473-8396;
- o Ron Welch, Director, Bureau of Mental Retardation, Maine;
- o Ralph Valedone, Department of Developmental Services,

California (916) 323-4821;

- o Dave Evans, Director, Office of Mental Retardation, Nebraska (402) 471-2851, ext. 457.
- o John Pride, Administration for Developmental Disabilities, Department of Health and Human Services.

Journals/Newsletters:

- o Education and Training of the Mentally Retarded, Council for Exceptional Children, Division of Mental Retardation;
- o Applied Research In Mental Retardation, Pergammon Press;
- o American Journal of Mental Deficiency, American Association on Mental Deficiency;
- o Mental Retardation, American Association on Mental Deficiency;
- o Journal of Autism and Developmental Disabilities, Plenum Press;
- o Exceptional Children, Council on Exceptional Children;
- o New Directions, National Association of State Mental Retardation Program Directors, Inc.;
- o Information Management, A Newsletter for Administrators of Rehabilitation Centers, P.O. Box 259, Akron, Iowa

Syracuse University Training Institute for Human Services Planning, Leadership, and Change Agency, 805 South Crause, Syracuse New York 13210.

RECOMMENDATION 12.2: THE STATE SHOULD PROVIDE ADDITIONAL FUNDS FOR THE IN-SERVICE TRAINING OF COMMUNITY CENTERED BOARD PROGRAM AND ADMINISTRATIVE STAFF AND BOARD MEMBERS. THE DIVISION FOR DEVELOPMENTAL DISABILITIES SHOULD EARMARK THESE FUNDS IN THE COMMUNITY CENTERED BOARD CONTRACT(S). THESE FUNDS SHOULD BE USED BY THE COMMUNITY CENTERED BOARDS TO BUILD INSERVICE TRAINING PROGRAMS TIED TO CAREER ADVANCES AND TO OTHER TANGIBLE AND INTANGIBLE INCENTIVES.

(1) Rationale

In the same way that the state's investment in staff training and technical assistance will contribute to a healthier state/provider relationship, the Community Centered Board Director's support for a comprehensive staff development program will serve to communicate his/her appreciation for staff members as people and as professionals, and his/her appreciation of the importance of their work. In-service programs have been shown to be associated with reduced staff turnover, and improved performance (Luecking, 1973; Velasco, 1983; Lakin and Bruininks, 1981; Bernstein, 1982).

The arguments for training administered by Community Centered Boards rather than by the state are well presented in a recent proposal to develop a Community Centered Board in-service staff development model submitted by the Division for Developmental Disabilities to the Office of Human Development Services, Department of Health and Human Services (Meeker, 1982) and in Bernstein's study (1981) of staff development.

These include:

- o the inclination and ability to make training arrangements more accessible to staff. This is particularly important in the more rural areas and in situations where it is difficult to free up large blocks of staff time for training;

- o the ability to individualize the training to staff needs;
- o the ability to more easily evaluate the impacts of training on staff performance through observation and testing; and
- o the ability to design promotion, pay and other training incentives that fit the Community Centered Board's particular constraints, management approach, and employee interests.
- o Most importantly, systems designed by Community Centered Boards, are more likely than are state designed systems to obtain the essential support of the Community Centered Boards and administrative staff. There are a number of staff development models which -- Community Centered Boards might want to consider: most notably, that developed at the Pueblo Community Centered Board by Larry Velasco, and that developed at the Winnebago County Association for Retarded Citizens in Oshkosh, Wisconsin by Richard Luecking.

(2) Implementation Timetable

Design program (Division for Developmental (Disabilities)	March, 1984
Begin funding (Division for Developmental (Disabilities)	July, 1984

(3) Estimated Resource Requirements

\$50,000	1984/85
\$75,000	1985/86
\$100,000	1986/87

(4) References

Section II, pages 67-69. Section III, pages 93-96.

Meeker, John, Staff Development and Training, A Low Cost Approach for Establishing Permanent Local Agency Capability, Division for Developmental Disabilities, (January 14, 1982);

Velasco, Larry, Director, Pueblo County Board for Developmental Disabilities, Pueblo, Colorado

Luecking, Richard, Winnebago County Association for Retarded Citizens, 1628 North Main Street, Oshkosh Wisconsin 54901.

b. RECOMMENDATION 13: THE COLORADO DEVELOPMENTAL DISABILITIES COUNCIL IN COLLABORATION WITH THE UCP, CEPA, NSAC, AND ARC SHOULD INITIATE A BRIEF AND SIMPLE SURVEY OF NEXT OF KIN TO ASSESS SATISFACTION WITH THE SERVICES THAT THEIR RELATIVES ARE RECEIVING IN ONE REGION OF THE STATE. THE DIVISION FOR DEVELOPMENTAL DISABILITIES, COMMUNITY CENTERED BOARDS, AND REGIONAL CENTERS SHOULD COOPERATE IN THIS EFFORT. IF THE COLORADO DEVELOPMENTAL DISABILITIES COUNCIL AND ADVOCACY ORGANIZATIONS FIND THE RESULTS INFORMATIVE AND USEFUL FOR GUIDING THEIR EFFORTS, THE COUNCIL MIGHT CONSIDER SUPPORTING FAMILY SURVEYS IN OTHER PARTS OF COLORADO, AND REPEATING THE SURVEY PERIODICALLY.

The pilot should be designed and planned in cooperation with UCP, CEPA, NSAC, and ARC, as well the Division for Developmental Disabilities, Community Centered Board(s) and Regional Center(s). The survey form itself should be reasonably short and simple, and should include an open ended question to allow for comments other than those solicited. The survey should be mailed by, returned to, edited by, and analyzed by the Colorado Developmental Disabilities Council. A summary report should be prepared and distributed to the Developmental Disabilities Council Board, Advocacy Groups, Community Centered Boards, Regional Centers, and others concerned. In those cases where families report extreme dissatisfaction or urgent concerns that need to be addressed, the Council should be prepared to refer these matters to appropriate agencies for action (e.g., Division for Developmental Disabilities, Community Centered Boards, Regional Centers, Training and Technical Assistance Agency).

In designing the survey the Colorado Developmental Disabilities Council should consult with organizations that have conducted similar surveys. Three such organizations are referenced in subsection (4).

(1) Rationale

To a large extent, families of persons with developmental disabilities are the true consumers of services (Klaber, 1969), and should be heard. They can alert administrators and providers to important problems that might otherwise go unnoticed, and can provide developmental disabilities advocates with information needed to argue for system change. The President's Commission of Mental Retardation recently conducted a nationwide survey of families of persons with developmental disabilities, and considers it the centerpiece of their national quality assurance initiative. In Denver, the Special Education Advisory Committee and Denver School Board in District 1 recently completed a survey of parents and guardians of children in the District special education program; they report that the feedback obtained has been extremely helpful in guiding the committee's efforts. Staff at the Temple University Developmental Disabilities Center use a Family Impact Survey as part of their study of the impact of court-ordered closing of Pennhurst State Center, and have considered using it to monitor the quality of residential and day services to residents placed out of the institution.

(2) Implementation Timetable

Survey design	September, 1984
Mailing list development	November, 1984
Mailing	January, 1985
Analysis	April, 1985

(3) Estimated Resource Requirements

1600 families x \$1.25 = \$2000 FY 1984-85

Suggested source: Colorado Developmental Disabilities Council

(4) References

Ashot Manatzakanian, Presidents Committee on Mental Retardation (202) Re: PCMR Survey of Families

Bill Muth, Chairman, Special Education Advisory Committee, Denver School District 1, Re: Parent Survey (303) 755-6416

Jim Conroy, Temple University, Re: Family Impact Survey, Philadelphia, PA (215) 787-6560

2. Reactive Mechanisms

a. RECOMMENDATION 14: CURRENT STATE REGULATIONS GOVERNING INSTITUTIONAL GRIEVANCE MECHANISMS FOR CHILDREN AND ADULTS SHOULD BE MODIFIED TO ENCOMPASS THE FOLLOWING GENERAL PROCEDURES.

A suggested outline follows:

- o Every resident of a state Regional Center has the right at any time to complain or bring a grievance which claims a violation of a right afforded by state regulations or by any state or federal law or regulation. In addition, residents have the right to complain if they believe they have been treated unfairly, been denied services, or have otherwise been significantly wronged. Any other person may complain or bring a grievance on behalf of an individual client or group of clients if such person can demonstrate that he or she represents the interests of an aggrieved resident. Reports of abuse must be reported within 24 hours of the incident. Reports of child abuse must be made to the local county department of social services.
- o Grievances may be brought to the attention of any staff member at a Regional Center and must ultimately be filed with the Superintendent of the Regional Center. Copies of the grievance should be filed with the Director of the Division for Developmental Disabilities.
- o Grievances may initially be filed orally or in writing. Persons initially filing grievances orally shall be advised to file the grievance in writing. The written grievance shall state the background information regarding the grievance. When any resident of a Regional Center expresses a grievance orally to any staff member at a Regional Center, the staff member shall file that grievance in writing with the Superintendent of the Regional Center.
- o Upon receipt of the grievance, the Superintendent of the Regional Center shall have 15 working days to investigate and resolve the grievance to the satisfaction of the client or other person bringing the complaint.
- o If the Superintendent is unable to resolve the grievance within 15 working days, the grievance should be forwarded to the Director of the Division for Developmental Disabilities and shall be accompanied by a written report of the steps taken to resolve the issue.
- o The Director of the Division for Developmental Disabilities shall have 10 working days to resolve the grievance. The Director must issue a written decision and findings supporting his or her decision.

- o If a decision is not issued within 10 working days, and party not satisfied with the Directors decision, a fact finding board shall be convened to conduct a hearing to resolve the grievance.
- o The fact finding board shall be appointed by the Director of the Division for Developmental Disabilities and shall consist of three members. None of the members of the fact-finding board shall have any personal or institutional interest in the case nor shall they be employees of the Division for Developmental Disabilities. At least one member of the fact-finding board shall be a consumer representative, one member shall be a person with experience in and knowledge of programs for mentally retarded persons, and one member shall be a representative of the public interest.
- o The fact finding board shall conduct a hearing within 20 working days of receipt of the grievance and shall issue a decision within 10 working days of the hearing. THE decision of the fact finding board shall be final and binding upon all parties to the grievance. The decision shall be in writing and state the findings supporting the decision.
- o Throughout this grievance process, all parties shall have the right to be represented by counsel or any other person they choose.
- o Any party aggrieved by the decision of the Director of the Division for Developmental Disabilities and/or the fact-finding board may pursue any further legal remedy available challenging that decision, but all parties shall comply with the decision pending any further legal review.
- o No person shall suffer recrimination or discrimination because of participation in this grievance process.

EMERGENCY PROCEDURES

- o Emergency action shall be taken on all grievances that allege abuse, neglect, or mistreatment of a resident of that involve an act or circumstance that:
 - * is ongoing or likely to recur; and
 - * is not promptly corrected or otherwise resolved;
 - * is likely to result in serious harm to the resident.
- o A complainant may request that emergency action be taken

on any complaint or appeal at any stage of the complaint process. Within one (1) day after receipt of a request for emergency action, the Superintendent of the Regional Center or the Director of the Division for Developmental Disabilities (depending on what stage the grievance has reached), shall approve or deny the request and shall immediately notify the resident, or other interested party, of the decision.

- o A decision to take emergency action, or an approval of a request for emergency action, shall reduce the periods set out for various stages of the grievance procedure to two days each.

(1) Rationale

Though there are institutional grievance procedures currently in regulation in Colorado, a number of the Regional Center staff interviewed believed that the current procedures were not sufficient to resolve many complaints and to absolve Regional Centers of blame when appropriate to do so. The recommended procedure calls for more external, independent reviews to better resolve such problems.

Because persons with developmental disabilities may not be capable of lodging grievances because of the severity of their handicap, the proposal described above makes it possible for any person interested in the well-being of a resident of a Regional Center to file a complaint. The procedures also recognize that some grievances may constitute emergency situations since the precipitating incidents may pose potential threats to the health or psychological well-being of the resident.

It should also be noted that these proposals reflect only the outlines of a systematic of institutional grievance process. Other areas that should be addressed in such procedures include the nature of the hearing to be conducted by the fact-

finding board, the type of evidence to be presented before such a body, the ways in which the grievance procedure should be made known to residents and other interested persons, a further delineation of the rights afforded to institutional residents and penalties (i.e., loss of job, incarceration, . . .) that might be imposed in the case of client abuse and other critical and severe acts of malfeasance.

(2) Implementation Timetable

The initiation of a grievance mechanism could be done either through regulation or state legislation. In formulating the procedures, the experiences of both the Legal Center for Handicapped Citizens and the Association for Retarded Citizens of Colorado should be canvassed since both groups are currently operating institutional advocacy programs. Once the procedures are formalized, it will be necessary to initiate training sessions with institutional staff, consumer representatives, residents, and other interested constituencies regarding the grievance process.

One option that Colorado may pursue is the appointment of grievance examiners within the Regional Centers whose responsibility it would be to investigate each grievance filed at the facility. Such examiners could report directly to an advocacy/grievance coordinator in the central office or to the superintendent of the Regional Center. If grievance examiners or advocates become part of the grievance system in the Regional Centers, then time must be set aside to recruit and train new staff or to retrain existing staff regarding the requirements of

this new role.

Draft grievance procedure (Division for Developmental Disabilities/Regional Centers/ Legal Center/Department of Social Services)	December, 1983
Conduct hearings (Division for Developmental Disabilities/Regional Centers)	March, 1984
Prepare legislation and/or regulations (Colorado Department of Institutions, Division for Developmental Disabilities)	June, 1984
Conduct training (Legal Center)	September, 1984

(3) Estimated Resource Requirements

With the exception of perhaps \$2,000 to cover the direct costs of training sessions regarding the grievance procedure, this recommendation can be carried out within existing resources. The only ongoing expenses will be the costs of the fact finding body and the salaries of grievance examiners if these positions become a part of the Regional Center grievance system. One way in which these ongoing investigative costs might be reduced is through the use of trained volunteers or "boards of visitors" as they are called in New York and Montana -- two of the states where the concept has been implemented.

(4) References

Section II, pages 73-74. Section III, pages 97-98.

There are a variety of state grievance mechanisms around the country that can be reviewed to determine the appropriateness of such provisions to Colorado. Specifically, the States of Michigan, Wisconsin, and New Hampshire have well worked out and systematic procedures that could be adapted to the context of Colorado.

b. RECOMMENDATION 15: STATE REGULATIONS AND/OR STATUTE SHOULD BE DEVELOPED ESTABLISHING STATEWIDE PROCEDURES FOR THE INVESTIGATION AND RESOLUTION OF GRIEVANCES OF CHILDREN AND ADULTS WHO ARE CONSUMERS OF COMMUNITY-BASED DEVELOPMENTAL DISABILITIES SERVICES OR OTHER INTERESTED PERSONS.

A suggested outline follows:

- o Every client, or discontinued or disallowed client, of a Community Centered Board has the right at any time to complain or bring a grievance which claims a violation of a right afforded by state regulation or by any state or federal law or regulation. In addition, clients or potential clients have the right to complain if they believe they have been treated inequitably or unfairly, been denied services, or have otherwise been significantly wronged. Any other person may complain or bring a grievance on behalf of an individual client or group of clients if such person can demonstrate that he or she represents the interests of an aggrieved resident. Reports of abuse should be reported within 24 hours. Reports of child abuse must be filed with the local county department of social services.
- o If grievances cannot be resolved through less formal means, clients, potential clients or other interested persons may file a grievance with the Director of the Community Centered Board.
- o Grievances may be filed orally or in writing. Persons initially filing a grievance orally shall be advised to file the grievance in writing. The written grievance shall state the background information regarding the grievance. When any person with a developmental disability orally files a grievance with any staff or board member or Community Centered Board program, that staff or board member shall file that grievance in writing with the Director of the Community Centered Boards.
- o Upon receipt of the grievances, the Director of the program shall have 20 working days to investigate and resolve the grievance. This investigation and decision may involve a review by the board of directors of the Community Centered Board program.
- o If the Director is unable to resolve the grievance to the satisfaction of the client or other person bringing the complaint within 20 working days, the grievance should be forwarded to the Director of the Division for Developmental Disabilities and should be accompanied by a written report of the steps taken to resolve the issue.

- o Grievances reviewed by the Director of the Division for Developmental Disabilities should be limited to those instances where there is reason to believe that the complaint was improperly or unfairly handled by the Community Centered Board and/or that the grievance is of sufficient significance to require a further hearing.
- o The Director of the Division for Developmental Disabilities shall have 10 working days to resolve the grievance. The Director must issue a written decision and findings supporting the decision resolving the grievance.
- o In order to reach his/her decision, the Director of the Division for Developmental Disabilities may find it necessary to appoint a fact-finding board to hold an impartial hearing on the facts. If a fact-finding board is appointed, it shall be composed of three persons. None of the members of the fact-finding board shall have any personal or institutional interest in the case nor shall they be employees of the Division for Developmental Disabilities. At least one member of the fact-finding board shall be a consumer representative, one member shall be a person with experience in and knowledge of programs for persons with developmental disabilities, and one member shall be a representative of the public interest.
- o The fact finding board shall conduct a hearing within 20 working days of receipt of the grievance and shall issue a decision within 10 working days of the hearing. The decision of the fact-finding board shall be final and binding upon all parties to the grievance. The decision shall be in writing and state the findings supporting the decision.
- o Throughout the grievance process, all parties shall have the right to be represented by counsel or any other person they choose.
- o Any party aggrieved by the decision of the Director of the Division for Developmental Disabilities and/or the fact-finding board may pursue any further legal remedy available challenging that decision pending further legal review.
- o No person shall suffer recrimination or discrimination because of participation in this grievance process.

EMERGENCY PROCEDURES

- o Emergency action shall be taken on all grievances that allege abuse, neglect, or mistreatment of a client of

Community Centered Board services or that involve an act or circumstance that:

- * is ongoing or likely to recur; and
 - * is not promptly corrected or otherwise resolved;
 - * is likely to result in serious harm to the resident.
- o A complainant may request that emergency action be taken on any complaint or appeal at any stage of the complaint process. Within one (1) day after receipt of a request for emergency action, the Director of the Community Centered Board or the Director of the Division (depending on what stage the grievance has reached), shall approve or deny the request and shall immediately notify the client, or other interested party, of the decision.
 - o A decision to take emergency action, or an approval of a request for emergency action, shall reduce the periods set out for various stages of the grievance procedures to two days each.

(1) Rationale

As with grievance procedures for institutionalized persons, there are also existing provisions at the community level for filing complaints. However, some of those interviewed noted that the process varied from area to area, that there was inconsistency in the way similar issues were treated and resolved, and that the process in some communities was long and drawn out. The purpose of the proposed grievance procedure is to provide interested persons with an orderly process for presenting their complaints to the directors of the Community Centered Boards and Division for Developmental Disabilities officials.

One of the strengths of the Colorado community system is the spirit of local control and the willingness of local communities to plan for and provide services to persons with developmental disabilities. One of the accompanying pitfalls of this type of system, however, is the lack of standardized procedures. Though

this isn't inherently detrimental, it can cut against equal treatment and equity for clients across the system especially insofar as service eligibility and the level of service provided. It was this issue that prompted some interviewees to suggest a more routinized and accessible grievance mechanism in all areas of the state.

Also, given that clients in the community may in some instances be subject to the same types of emergency situations encountered by institutional residents, a provision for emergency action similar to that included as part of the institutional grievance recommendation has been added to the community grievance recommendation.

Since the Community Centered Board may be convened to review a grievance, another five working days (over the 15 allowed for Regional Center superintendents) has been added to the time limit for Community Centered Board review. Further, the involvement of fact-finding body for community grievances is optional in the community grievance system since the review by the Director of the Division for Developmental Disabilities already constitutes an outside review.

Again, as with the proposals for the institutional grievance system, these recommendations constitute only an outline for a more systematic process. There are numerous details that will have to be worked out before regulations and/or a statute are developed including the procedures to be developed by individual service agencies operating under contract to the Community Centered Board, the process to be followed by Community Centered

Board directors if they are called upon to rule on a dispute, the types of rights that are afforded to community clients, and the parameters of the eligibility process.

(2) Implementation Timetable

A similar process to the one described for the institutional system should be set up to develop grievance procedures for community programs. Representatives of the Division, the Community Centered Boards, and consumer spokespersons (e.g., representatives of the Association for Retarded Citizens, Protection and Advocacy agency, etc.) should work together to prepare a final package of regulations and/or statutory provisions. Once the procedures have been formalized, training of a variety of groups will be required including Community Centered Board administrators, board members, service professionals, and clients and their representatives.

As with the recommendations for the institutional system, Colorado may wish to explore the recruitment of grievance investigators to explore the legitimacy of particular complaints. If such individuals are designated, then time should also be set aside for their training and orientation.

Draft grievance procedure (Division for Developmental Disabilities/Community Centered Boards/Legal Center/Department of Social Services)	December, 1983
Conduct hearings (Division for Developmental Disabilities/Community Centered Boards)	March, 1984
Prepare legislation and/or regulation (Colorado Department of Institutions/Division for Developmental Disabilities)	June, 1984

Conduct training (Legal Center)

September, 1984

(3) Estimated Resource Requirements

Costs for the community grievance mechanism will be similar to those for the Regional Center procedure, although training will involve more individuals and should cost approximately \$2,500 more for a total of \$4,500. As with the institutional grievance system, this cost could be reduced by the use of volunteers as grievance investigators.

(4) References

Section II, pages 73-74. Section III, pages 97-98.

Both New Hampshire and Michigan have community-based grievance mechanisms that can serve as models for the development of community-based systems in Colorado.

D. Assuring Program Appropriateness and Effectiveness

1. Program Appropriateness

a. RECOMMENDATION 16: THE COLORADO DEPARTMENT OF INSTITUTIONS, COLORADO DEPARTMENT OF SOCIAL SERVICES AND COLORADO DEPARTMENT OF HEALTH SHOULD CONSTITUTE A TASK FORCE TO STUDY THE COSTS AND BENEFITS OF ALTERNATIVE MECHANISMS FOR REVIEWING THE APPROPRIATENESS OF SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES AND TO RECOMMEND THE MOST COST/BENEFICIAL ALTERNATIVE.

(1) Rationale

Medicaid requires that admission to long term care services be approved by individuals or agencies with medical expertise. In Colorado, this occurs through the Colorado Foundation for Medical Care which is also the state's designated Professional Services Review Organization (PSRO). The PSRO reviews individuals against level of care criteria established for admission to SNFs, ICFs, or ICF/MRs; certifies individuals as meeting a particular level of care; and consequently authorizes Medicaid reimbursement for such care. The PSRO also performs periodic reviews to redetermine whether level of care criteria are still being met. The state Department of Social Services designation of the PSRO as the level of care certification agency is a matter of state choice. Federal regulations do not require that the PSRO in particular perform this function. The regulations do describe a state-level review and certain types of medical expertise.

The value of the PSRO review was questioned by a number of persons interviewed as part of this study, particularly as it concerns programs for individuals with developmental disabilities. In general, level of care criteria for admission

to programs for people with developmental disabilities are not principally medically based. Rather, with the exception of some linkages to level of mental retardation, the criteria address the individual's functioning or behavioral characteristics. The PSRO has no specialized expertise in these areas. Additionally, PSRO activities do not generally, involve any face-to-face contact with the client. Communication occurs over the telephone or through document transmittal and review. It is viewed by many as a "rubber stamp" procedure. If in fact reviews are not pertinent or are without fundamental impact on client service delivery, then the usefulness of such reviews is questionable.

(2) Implementation Timetable

Appoint Task Force (Colorado Department of Institutions/Colorado Department of Health); October, 1983

Complete study (Task Force) May, 1984

Implement Study Recommendation (Colorado Department of Institutions/Colorado Department of Health). September, 1984

(3) Estimated Resource Requirements

NONE

(4) References

Section III, pages 100-101.

The rationale underlying this recommendation was drawn entirely from a memorandum from Gary Smith, Deputy Director, Division for Developmental Disabilities to Merrill Stern, Director, Colorado Developmental Disabilities Council (July 15, 1983), and from interviews with Colorado Department of Health officials.

2. Program Effectiveness

a. RECOMMENDATION 17: WE SUGGEST THAT THE DATA MANAGEMENT SECTION OF THE DIVISION FOR DEVELOPMENTAL DISABILITIES DEVELOP AND IMPLEMENT A CORE (CLIENT ORIENTED RECORD ENTRY) PROGRAM FOR MAPPING THE MOVEMENT OF CLIENTS ALONG THE RESIDENTIAL SERVICE CONTINUUM AND ADULT TRAINING SERVICE CONTINUUM

(1) Rationale

This information would provide an indication of the ability of the developmental disabilities delivery system in Colorado to foster client movement through the service continuum. When presenting the client movement statistics for use by state policy-makers, Division for Developmental Disabilities analysts should be careful to explain, to the extent possible, the degree to which the movement might have been triggered by client growth, by changes in service supply, by correcting inappropriate initial placements, or by other factors unrelated to client skill acquisition. Supplementary mini-studies may be necessary to uncover alternative explanations or to arrive at more definitive explanations for client movement trends. However, without such explanations this information cannot be considered germane to the quality assurance concerns addressed in this report.

(2) Implementation Timetable

Design system (Division for Developmental Disabilities); January, 1984

Test system (Division for Developmental Disabilities); May, 1984

Implement system (Division for Developmental Disabilities) July, 1984

(3) Estimated Resource Requirements

Contracted programmer and other direct costs \$20,000, FY 1983-84.

(4) References

Section II, pages 42-45. Section III, pages 101-103.

Robert Schalock, Ph.D. in Nebraska and Warren Bock, Ph.D. in Minnesota have both done considerable work in the development of such report-based performance indicators. They should be consulted and their work reviewed in the course of implementing this recommendation (Schalock and Harper, 1982; Schalock and Harper, 1983).

Robert L. Schalock, Department of Psychology, Hastings College, Hastings, Nebraska, 68901.

Warren Bock, Assistant Director, Systems and Evaluation, Mental Retardation Program Division, Department of Public Welfare St. Paul, Minnesota, 55155 (612) 296-4421.

c. RECOMMENDATION 18: THE DIVISION FOR DEVELOPMENTAL DISABILITIES SHOULD DESIGN A SYSTEM FOR MONITORING THE SKILL ACQUISITION OF CLIENTS WITH DEVELOPMENTAL DISABILITIES OVER TIME. IN ORDER TO ASSURE POLICY MAKERS AND PLANNERS OF THE COST AND BENEFITS OF SUCH A SYSTEM, AND TO ASSURE THE DIVISION FOR DEVELOPMENTAL DISABILITIES STAFF, REGIONAL CENTERS AND COMMUNITY CENTERED BOARD PROVIDERS THAT IT IS ECONOMICALLY AND ADMINISTRATIVELY FEASIBLE, THE SYSTEM SHOULD BE IMPLEMENTED ON A TWO YEAR PILOT BASIS AT TWO COMMUNITY CENTERED BOARDS AND ONE REGIONAL CENTER AND THE MONITORING SYSTEM SHOULD BE SUBJECT TO AN INDEPENDENT EVALUATION OF ITS COSTS/BENEFITS AND OF ITS ADMINISTRATIVE AND ECONOMIC FEASIBILITY. THE EVALUATION SHOULD INCLUDE A PLAN FOR FULL SCALE IMPLEMENTATION IF THE RESULTS OF THE EVALUATION ARE SUFFICIENTLY POSITIVE. THE OUTCOME MONITORING SYSTEM SHOULD IN NO WAY BE TIED TO FISCAL OR LEGAL SANCTIONS THROUGH THE RATE SETTING MECHANISM, THE PERFORMANCE CONTRACTING MECHANISM, OR THE REGULATORY MECHANISM.

The outcome monitoring system should be used for:

- o Policy-making purposes, supporting comparative studies of client skill acquisition in alternative modes of service;
- o Budget making purposes, supporting arguments for continued federal, state and local support of programs for persons with developmental disabilities;
- o Provider training and technical assistance, identifying providers possibly worth emulating or in need of technical assistance (e.g., by virtue of exceptionally high or low rates of psychotropic drug use, exceptionally high or low rates of client growth, etc. over time);
- o Client monitoring purposes, identifying clients whose rate of development is exceptionally high or low to inform the case management, IHP and IPP processes. (note: the information is intended to complement and not supplant the individualized measures used as part of the IHP and IPP processes);

The Division for Developmental Disabilities should utilize an established (tested) standardized instrument for measuring client adaptive behaviors that is known to be reliable (inter-rater reliability above 80), and that is sensitive to the range of skills acquired by severely impaired persons. The instrument preferably should also record client demographics, services planned and rendered, family situation, health, medications,

Individual Habilitation Plan (IHP) content and recency. The instrument preferably should take no more than 30 minutes to administer and should be completed by interview with the primary resident care giver. The instrument should be applied not less than once each year by trained interviewees. Purely from the behavior measurement perspective, the Behavior Development Survey (BDS), the Minnesota Developmental Programming System (MDPS), the Old Vineland, the Program Assessment Chart, and one or more of the Fairview scales are worth consideration.

Provider staff should not be requested or required to administer the instrument themselves. The interviews and evaluation should be conducted by an organization independent of the publicly funded system of services for persons with developmental disabilities in Colorado.

(1) Rationale

Outcome Monitoring

In contrast to most other human services, the central goal of services for citizens who are developmentally disabled is clear and measureable. The primary goal is the reduction of the consumer's dependence on others. In other fields, (e.g., aging, drug abuse, penology), there is no consensus on a single unifying objective that is quantifiable. In drug abuse, for example, it is unclear whether social programs are aimed at changing drugs (methadone), changing life style to end all drug use (therapeutic communities), stopping theft (incarceration), improving health (medical care programs), breaking the physical addiction (kick pads), teaching marketable skills (job training programs), or all

of the above. In developmental disabilities, there are multiple goals as well (including health, safety, a secure and permanent place to live, employment, socialization), yet the notion of continued reduction of dependence remains central. This is the meaning of the "developmental model" which is prominent in the AC-MR/DD standards, underlies the "active treatment" notion in the ICF/MR standards, and is reflected in PASS-3.

The entire developmental approach arises from the relatively recent realization that all people can grow and learn. The behavioral technologies have helped make this a matter of fact rather than faith.

The extent to which persons with developmental disabilities have acquired the ability to perform tasks necessary for functioning in the mainstream of our culture, is indeed measureable. Reliable, standardized scales of adaptive behavior are available and can be applied economically to differentiate client levels of development for the purpose identified earlier.

Instrument Selection

In 1978, the Individualized Data Base Project of the University of California at Los Angeles reported on a review of 134 behavior scales. Those authors selected 21 scales that appeared noteworthy. Below, we condense their work by eliminating less reliable or clearly inappropriate scales and add five instruments that have recently gained prominence.

1. AAMD Adaptive Behavior Scale: adaptive and maladaptive, reliability .86 adaptive and .57 maladaptive, broad range, about 40 minutes.

2. Balthazar Scales of Adaptive Behavior: adaptive and maladaptive, reliability .59 to .97 for domains, severe and profound focus, about 30 minutes, 3rd party interview.
3. Bayley Scales of Infant Development: adaptive only, infants age 2 to 30 months, or severely impaired, reliability over 90% inter-rater agreement, at least 45 minutes direct observation.
4. Behavioral Characteristics Progression, adaptive and maladaptive, broad range, nonstandardized criteria-reference, 10 to 20 hours, direct observation plus interviews.
5. Cain-Levine Social Competency Scale: adaptive only, higher functioning focus, .99 to .97 inter-rater reliability, about 30 minutes, 3rd party interview.
6. Fairview Development Scale: adaptive only, developmental age up to 5 years 10 months, .82 inter-rater, about 20 minutes, 3rd party interview.
7. Fairview Language Evaluation Scale - Birth to 6 Years: Adaptive only, severe and profound, .95 inter-rater, about 10 minutes, 3rd party interview.
8. Fairview Problem Behavior Record: maladaptive only, broad range, reliability unknown, about 10 minutes, 3rd party interview.
9. Fairview Self-Help Scale: adaptive only, up to developmental age 10 years, .87 inter-rater, about 10 minutes, 3rd party interview.
10. Gesell Developmental Screening Inventory: adaptive emphasis, infant or severe/profound focus, reliability unknown, about 25 minutes, 3rd party interview.
11. Koontz Child Development Program: adaptive only, 1 to 48 months developmental age, reliability .95 inter-rater, about 40 minutes, 3rd party interview.
12. Minneosta Developmental Programming System Behavioral Scales: adaptive (and optional maladaptive), broad range, reliability available but not reported, about 60 minutes (or 30 minutes for a newer short form), 3rd party interview; optional sections available for service and goal and health data.
13. Progress Assessment Chart: multiple forms covering adaptive and maladaptive, broad range, reliability available but not reported, 20 to 60 minutes for various forms, 3rd party interview.

14. Vineland Social Maturity Scale: adaptive only, broad range, .92 inter-rater, about 30 minutes, 3rd party interview.
15. Vineland 1983 Revision adaptive and maladaptive, broad range, reliability studies in progress with successive revisions, about 60 minutes, 3rd party interviews, in draft stage, available for research purposes.
16. Behavior Development Survey: shortened research version of ABS, adaptive and maladaptive, broad range, adaptive reliability .94 inter-rater, maladaptive .65, about 15 minutes, 3rd party interview; optional sections.
17. Unnamed Scale: in late stages of development and testing at University of Minneosta, characteristics unknown, included here because of known competence of the developers headed by Dr. Robert Bruininks. Scale now available for trial implementations.
18. PACE Student Progress Record: system implemented 6 years in the state of Oregon, measures adaptive behavior of students with developmental disabilities in special education programs (broad range, .95 to .97 inter-rater reliability; 2 hours to administer; completed by special education teachers). Included demographics, a biannual on-site review, health, and services outline.
19. PACE Client Evaluation Record: system implemented 1 year in State of Oregon; measures adaptive behavior of adults in day program and residential programs (broad range, .69 to .89 inter-rater reliability). Concurrently administered by day program and residential program staff, and scores reconciled by case manager as part of the IHP process; includes demographics and annual on-site review, health and service outline.

The Behavioral Characteristics Progression, the new Vineland Student Progress Record and Client Evaluation Record, are too long to be used in Colorado. The BDS and MDPS have also been developed in conjunction with additional client-specific data (demographic, services, IHP, health, etc.) and site-specific data (staffing, size, site review results, etc.). New York State uses the short MDPS with tailored additional modules. The most widely used short instrument available, known to be sensitive to growth across wide ranges of functioning, is the BDS. Virginia has used

the BDS for over six years. A BDS (short form) is being used by Temple University to identify exceptional client rates of development or regression for follow-up by the direct care staff at the Woods School in Pennsylvania, and at those residential programs serving clients outplaced from the Pennhurst Mental Retardation Center. Dr. Leonard Kenowitz, Program Director at the Woods Schools, follows up on every client who appears to have lost more than 12% of his/her adaptive skills. He reports that over 90% of the regressing clients identified have been determined to be having very genuine difficulties, which can be addressed by special arrangements. He also reports that over half of these individuals would probably not have been otherwise detected.

Temple University has also used the BDS data to perform special studies of the efficacy of alternative service patterns. For instance, they recently conducted an analysis of client growth at the Pennhurst Center as a function of client levels of medication while controlling for key client characteristics. The results identified marked variations among Center physicians in their clients' use of medications, and found that the number of medications given daily to a client was the second best predictor of growth; the more medications, the less growth.

Misuse of Outcome Data

We strongly recommend against the use of the outcome data to sanction providers, and in fact would suggest that providers agree to participate in the outcome monitoring system only with the guarantee that the information will not be used in this way.

Unfortunately, every state known to collect client outcome data has already, or has plans to eventually use this data to sanction providers. As indicated in Section III, where these sanctions have been employed or are threatened, it has undermined the integrity of the outcome measurement system and resultant data. The system dissolves into a game. The information obtained from the providers is biased to gain advantage relative to the sanction. Even when this is not the case, the information becomes suspect with the result that it is useless for most intents and purposes. The outcome monitoring system becomes a pseudo-accountability mechanism and every one loses, most particularly the client

As Peters and Waterman (1982) so convincingly argue, the measurement and feedback of the growth of the clients cared for by service providers should be enough to motivate most direct care staff to improve their programs; and if not, there is simply little else that can be done short of "bountiful supplies of technical assistance" (Walker, 1972 p. 53). As Hage says, "there is a difference between saying something is wrong, and pointing out how it can be done better" (1974, p. 83).

Aside from the perverse affects of attempts -- we say attempts since no system we know of has yet worked to the

designer's satisfaction -- the fact is that the validity and reliability of these measures is simply not sufficient to justify using them as sanctioning criteria.

Survey Application

We have recommended that the outcome monitoring procedure be administered by a third party. This makes good sense for the pilot testing of the method. It will allow for the method to be implemented more expeditiously, will better assure an impartial and credible evaluation and will avoid institutionalizing a process in Colorado that has yet to be proven. It will also avoid imposing an additional burden on the already overburdened Division for Developmental Disabilities staff and case managers.

The use of an outside group will probably make sense in Colorado on a continuing basis should the evaluation rate the procedure a success since few providers interviewed wanted anything to do with administering such an instrument themselves. They saw little value in such a method for their own purposes. A number of providers have developed their own, more individualized, methods of evaluating client progress and were quite content with them (Jensen, 1983; Zarnick, 1983; and Daugherty, 1983). As Judy Ruth of the Data Management Section of Division for Developmental Disabilities so correctly pointed out in discussing the CORE system, "if the providers are not using the information produced, they are unlikely to give it the attention necessary to produce timely and reliable data" (Ruth, 1983).

Worth noting, however, is the fact that a number of

providers in Colorado and other states do appreciate or have come to appreciate the value of standardized outcome measures for their own purposes. For instance, in Oregon, the Program for Mental Retardation/Developmental Disabilities has taken great pains to feedback comparative results of the Student Progress Record (SPR) in a timely fashion to the special education teachers. As a result, the teachers reportedly have come to value this information, and over the past six years the SPR ratings have been an integral and important part of the IEP process in Oregon (Read, Davey 1983). Thus while we are recommending that the outcome monitoring procedure be administered by a third party during the pilot test, if enough providers can be convinced of the value of this information in the interim, the final system design could conceivably include completion of the survey instruments by providers as part of the IHP process.

(2) Implementation Timetable

Secure funding (Division for Developmental Disabilities)	July, 1984
Select appropriate private group to perform data collection and analyses (Division for Developmental Disabilities)	September, 1984
Identify Community Centered Boards and Regional Center to be included in the pilot study	September, 1984
Train data collectors	January, 1985
Identify clients within the three service settings to be included in the pilot study	February, 1985
Collect data on site	March, 1985 and 86
Data reduction and analysis	June, 1985 and 86

Independent evaluation

September, 1985 and 86

(3) Estimated Resource Requirements

If the pilot project were designed to cover one average Community Centered Board and one Regional Center, the field costs (including recruitment, training, and quality control) should be less than \$27,000 and could cover more than 500 clients. The process, once in the field, can be completed in two to three months.

The analysis and synthesis of the results will require another \$23,000; \$11,000 is allowed for the added costs of evaluating the project during the first year. Another \$34,000 is projected for the evaluation and planning of a full scale implementation of the system in 1984-85 contingent on the results of the evaluation.

Summary

\$61,000	1983-84
\$84,000	1984-85

(4) References:

Section II, pages 35-41, 58-61. Section III, pages 101-103.

Read, Davey, Program for MR/DD, Mental Health Division, State of Oregon (503) 378-2429.

Jensen, Roger, Executive Director, Developmental Training Services, Inc. Box 1249, Canon City, Colorado 81212.

Daugherty, Jerry, Executive Director, Pueblo Diversified Industries 2929 Burnt Mill Road, Pueblo, Colorado 80204.

Zarnik, Jon, Rocky Mountain Child Development Center, 4200 E. Ninth Avenue, C-234 Denver, Colorado 80220.

Ruth, Judy, Interview, March 1983.

E. Summary

1. General

Colorado is in an enviable position relative to that of most other states with which we are familiar. The delivery system is not unduly tethered by regulation and starved for resources. Most provider staff appear to be proud of what they have accomplished and are motivated to do more, and there is a healthy degree of tension and communication between the state program administrators, service providers, and advocacy groups.

The higher priority recommendations are those that are continual, proactive and constructive in nature and concerned with higher level performance. This is not intended to slight the importance of the periodic review mechanisms and reactive mechanisms designed to safeguard the health and safety of clients. However, given the effective implementation of the first-order recommendations, the resources required to implement the second order recommendations should be minimized.

It's important that Colorado be positive in its approach to quality assurance through the development and strengthening of its proactive quality assurance mechanisms, (mechanisms synonymous with good management). These mechanisms emphasize model rather than minimum standards, are characterized by personal, continual and less formal monitoring of program performance rather than less personal, less frequent, and more burdensome on-site reviews and reporting systems. Strongly emphasized is the provision of training and technical assistance designed to foster good performance, and techniques designed to

identify good performers and to recognize them. The recommendations contained in this report are submitted with this notion preeminent.

2. Recommendations

The table on the following pages lists the 18 recommendations. It indicates suggested funding priorities for state general funds administered by the Division for Developmental Disabilities (DDD) and federal developmental disabilities grant funds administered by the Developmental Disabilities Council (DDC) -- one being the highest priority. It also identifies the lead agencies responsible for implementing each recommendation and the time period targeted for implementation. Finally, it shows estimates of the resources required to implement each recommendation.

DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE SYSTEM:
SUMMARY OF DESIGN RECOMMENDATIONS

RECOMMENDATION	Funding Priorities	Implementation Time Period	Estimated Resource Requirements			Suggested Sources of Funding	Lead Agency(ies)
			1983-85	1985-86	Ongoing		
<p>ASSURING CAPABILITY TO PROVIDE QUALITY SERVICES:</p> <p>1 Adult Day Program Reviews and technical assistance(TA) Recognize CARF or AC-MR/DD accreditation for purposes of program certification; conduct follow-up programmatic reviews and T.A.</p>	DDD 2	Sep 1983- Apr 1987	17,751- 19,819	17,751- 19,819	17,751- 19,819	State General Fund	DR DDD
<p>2 Child Day Program Reviews & T.A.--DDD participation with CDE</p>	DDD 9	Feb 1984- Jul 1985	35,000	35,000	35,000	State General Fund	DDD, CDI & CDE
<p>3 Reconcile inconsistencies in CDE certification and DSS licensing requirements as applied to CCB child day programs</p>	N/A	Nov 1983- Jan 1984	--	--	--	--	DSS, CDE

DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE SYSTEM: SUMMARY OF DESIGN RECOMMENDATIONS

	Funding Priorities	Implementation Time Period	Estimated Resource Requirements			Suggested Sources of Funding	Lead Agency(ies)
			1983-85	1985-86	Ongoing		
<p>[4] Residential Program Reviews-- Joint HFRD/DDD reviews differentially scheduled and designed according to program need with timely feedback of results</p>	DDD 4	Sep 1983-- Jun 1985	42,000	45,500	42,000	State General Fund	DDD, CDI, HFRD, & DOH
<p>[5] Title XIX Child Residential Programs-- Statutory change to allow HFRD licensure/DDD certification reviews rather than DSS licensure reviews</p>	N/A	Nov 1983-- Jan 1984	--	--	--	--	DOH, DSS
<p>[6] Host Homes-- Annual review of host home certification agencies</p>	N/A	Dec 1984-- Jul 1985	--	--	--	--	DDD
<p>[7] Residential Program Reviews-- Recruit citizens and providers to participate</p>	DDD 6	Sep 1983-- Jun 1984	1,000	1,000	1,000	State General Fund	DDD

DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE SYSTEM: SUMMARY OF DESIGN RECOMMENDATIONS

Funding Priorities	Implementation Time Period	Estimated Resource Requirements			Suggested Sources of Funding	Lead Agency(ies)
		1983-85	1985-86	Ongoing		
<p><input checked="" type="checkbox"/> 8 Residential Programs-- Surveyor training</p> <p>DDC 3</p>	<p>Jan 1984-- Jun 1984</p>	<p>5,000</p>	<p>3,000</p>	<p>2,000</p>	<p>CDDC</p>	<p>DDD</p>
<p>ASSURING GOOD PRACTICE:</p> <p><input checked="" type="checkbox"/> 9 Case Management-- Services should be provided to all persons meeting DDD eligibility criteria</p> <p>N/A</p>	<p>Jul 1985-- Jun 1987</p>	<p>--</p>	<p>643,800</p>	<p>643,800</p>	<p>State General Fund</p>	<p>DDD</p>
<p><input checked="" type="checkbox"/> 10 Case Management-- Services should be CCB-based with administrative safeguards to assure integrity of case management function</p> <p>DDC 1</p>	<p>Nov 1983-- Jun 1984</p>	<p>32,500</p>	<p>30,000</p>	<p>30,000</p>	<p>CDDC</p>	<p>DDD, CCBS</p>
<p><input checked="" type="checkbox"/> 11 Case Management-- Improve economy and efficiency by (1) training parents ... to serve as own case managers (2) recruiting and training advocates</p> <p>DDC 2</p>	<p>Nov 1983-- May 1986</p>	<p>7,500</p>	<p>?</p>	<p>?</p>	<p>CDDC</p>	<p>Advocacy Groups</p>

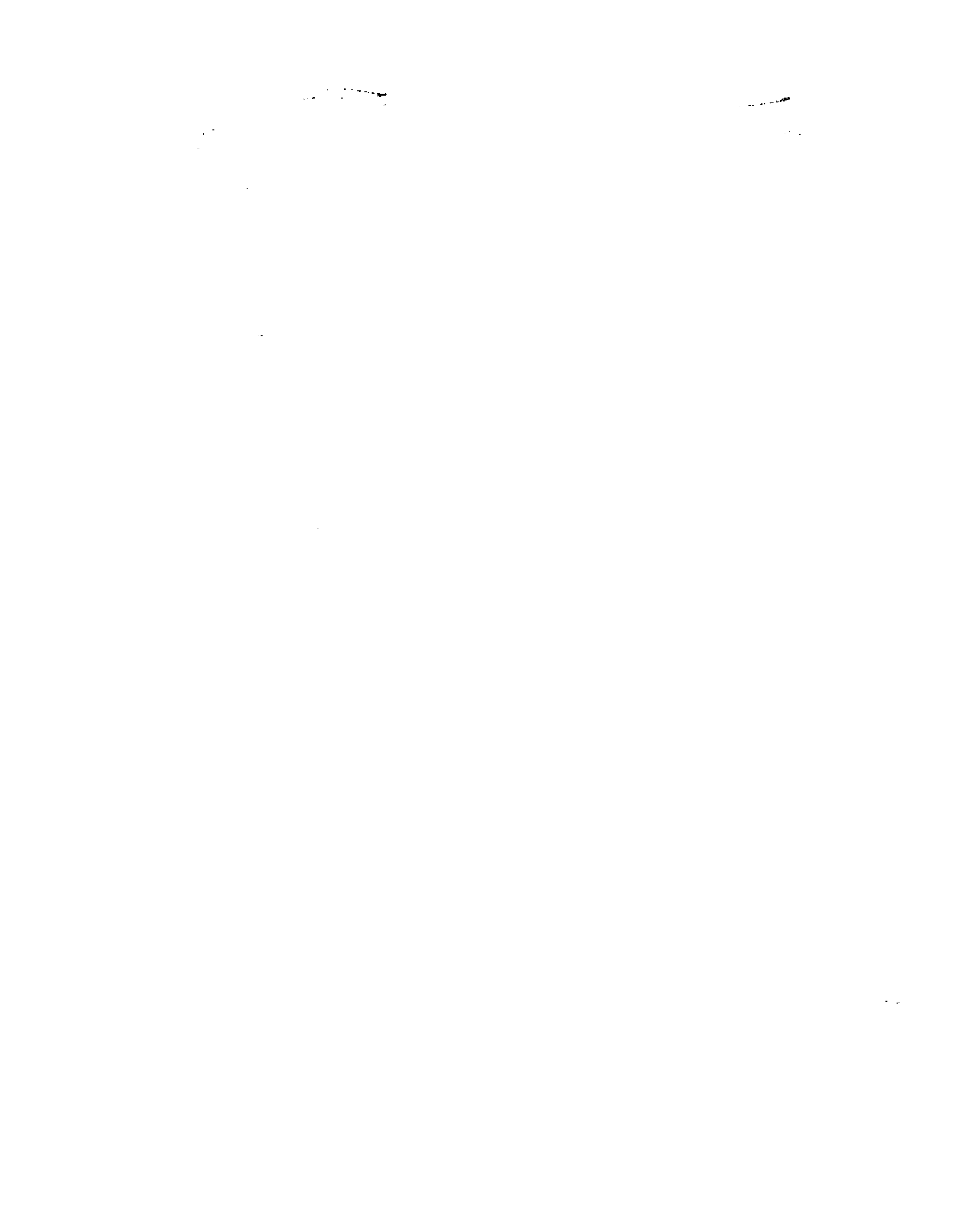
DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE SYSTEM: SUMMARY OF DESIGN RECOMMENDATIONS

Funding Priorities	Implementation Time Period	Estimated Resource Requirements			Suggested Sources of Funding	Lead Agency(ies)
		1983-85	1985-86	Ongoing		
to monitor programs continually and effectively; and (3) assigning clerical functions to clerical staff	Nov 1983- May 1985	20,000	10,000	?	CDDC/ United Way/Pvt. Foundation	Advocacy Groups
N/A	Nov 1983- Jun 1985					DDD
12 Staff Development-- Statewide planning and coordination; and marked increase of state support of staff in-service training	Jul 1984- Jun 1986	100,000	125,000	150,000	State General Fund	DDD
13 Conduct periodic surveys to assess satisfaction of families with DD services	Sep 1984- Jun 1985	2,000	--	?	CDDC	CDDC
14 Strengthen regional center grievance procedure	Dec 1983- Sep 1984	2,000	--	--	State General Fund	DDD/Regional Ctrs/Legal Centers
15 Establish uniform CCB grievance procedure	Dec 1983- Sep 1984	4,500	--	--	State General Fund	DDD/CCBs/ Legal Centers.

DEVELOPMENTAL DISABILITIES QUALITY ASSURANCE SYSTEM: SUMMARY OF DESIGN RECOMMENDATIONS

	Funding Priorities	Implementation Time Period	Estimated Resource Requirements			Suggested Sources of Funding	Lead Agency(ies)
			1983-85	1985-86	Ongoing		
<p>ASSURING PROGRAM APPROPRIATENESS AND EFFECTIVENESS:</p> <p><input type="checkbox"/> 16 Assess efficacy of PSRO mechanism and recommend alternatives</p>	N/A	Oct 1983- Sep 1984	--	--	--	CDI, DOH	
<p><input type="checkbox"/> 17 Develop client movement and reporting system</p>	DDD 5	Nov 1983- Jul 1984	20,000	--	--	State General Fund	
<p><input type="checkbox"/> 18 Pilot test a system for monitoring client outcomes in one regional center and two CCBs</p>	DDD 3	Jul 1984- Sep 1986	61,000	84,000	?	State General Fund	

APPENDICES



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SUMMARY OF INTERVIEWS

May 5, 1983

The interviews were conducted using the interview schedule attached. These interview schedules contained questions general enough that they could be asked of most persons yet comprehensive enough that depending on the interests and knowledge of the respondent, could elicit quite specific and elaborate responses.

The results of the interviews are organized to first address systems-level issues pertaining to what organizations bear or should bear, responsibility for assuring the quality of the services provided to developmentally disabled persons in Colorado. These systems level issues are addressed in subsection II. A. Most of the responses related to the mechanics of different quality assurance procedures, i.e. to the efficacy of different quality assurance mechanisms. These responses are organized according to four basic components of quality assurance procedures: standards, measures, feedback and control. This discussion is presented in subsections II B - E.

The interview summary focuses on the perspectives of the respondents on particular issues, not on the structure of the existing service delivery or quality assurance system(s) or on other descriptive information obtained. The positions of the following interests are distinguished where possible:

- o individual client advocates (parents, citizen advocates, case managers and the clients themselves)
- o advocacy organizations (ARC, UCPA, CEPA, NSAC, DDC, and

- Legal Center for the Handicapped)
- o service providers (most Community Centered Board's, regional centers, residential program providers, day program providers, and case managers)
 - o system administrators (Department of Institutions, Division for Developmental Disabilities; Community Centered Boards; Department of Education; Department of Health; Department of Social Services, Office of the State Auditor);
 - o policy makers and budget makers (state legislators, legislative staff, gubernatorial staff, and budget office staff.

A list of respondents is attached. Note: in some cases respondents represented more than one interest (e.g., community centered boards can play system administrative as well as service provider roles).

On many issues it was not possible to find clearly discernible positions for these interests as the opinions of the respondents, chosen by the Steering Committee to represent each interest, were not always convergent; moreover, the sampling was purposive and not random. It was designed not to yield statistically representative results but to yield a diversity of perspectives.

Generally speaking the results of the interviews were very encouraging. There appears to be a surprising degree of consensus of the strengths and weaknesses of existing quality assurance mechanisms, and on the areas needing improvement. Even more encouraging is the fact that many of the points agreed upon by most respondents are the same points agreed upon by members of the steering committee.

II. RESULTS

A. System Level Issues -- Locus of Quality Assurance Responsibilities

Most respondents felt that the ultimate quality assurance responsibility should logically rest with that state agency responsible for funding the developmental disabilities services in question. The logic of this argument was punctuated by several respondents who noted that the Division of Rehabilitation's plans to require CARF accreditation for VR funding might well result in some providers electing to give up the VR funding as it is so small a part of their funding picture relative to the funds provided by the Division for Developmental Disabilities.

Other respondents felt that in view of the client-oriented nature of the services, the ultimate responsibility should be vested in a group independent of program agencies such as the Developmental Disabilities Council or a special commission established for this purpose.* A few respondents looked favorably upon a quality assurance agency independent of the Division for Developmental Disabilities only because they felt the Division for Developmental Disabilities hadn't demonstrated the commitment to police the providers. This perception of the Division for Developmental Disabilities was viewed as inaccurate

* It was suggested by one staff member that this same group might have ultimate control over the eligibility of developmentally disabled persons for service as well. This individual feels that there is an inherent conflict of interest when the agency responsible for providing service also has control over the service eligibility and service quality determination processes.

by most members of the Division for Developmental Disabilities who explained that enforcement was accomplished through negotiation and fiscal pressures quite undramatic in nature and often not apparent to persons outside of the Division. A few providers expressed the opinion that the Division for Developmental Disabilities would better serve as it has in the past in more of a training and technical assistance mode than in an enforcement mode. Several respondents felt that policing provider compliance with minimum standards might better be done by another agency, or insofar as Title XIX services are concerned, by the Department of Health.

B. Standards

A number of providers, both private and public, felt that some of the existing standards were not reasonable or equitable. Many providers (including two regional centers) were of the opinion that the same set of standards applied to the community should be applied to the regional centers to the extent possible. They also felt that many of the standards should be more ends-oriented than means-oriented. For instance, instead of surveys requiring that windowsills be no more than 32 inches from the floor for ease of evacuation, they should simply require that the facility has to be evacuable in five minutes. The most common concerns of providers were that the standards, applied in the Department of Health and Department of Education surveys were too medically oriented or facility oriented, and were often inappropriate and unreasonable in view of individual situations.

1. Residential Programs

Developmental Disabilities residential program standards are embodied in the checklist for monitoring community residential services. These standards were generally viewed as reasonable and beneficial by the residential providers interviewed though some felt that they could be made more comprehensive and thorough.

2. Day Programs

Vocational rehabilitation program standards exist as part of the code of federal regulations, Rehabilitation Services Manual, and case review procedure recently developed by the Division of Rehabilitation. Additionally, the Division of Rehabilitation intends to require that all vocational rehabilitation providers be CARF accredited thus endorsing the CARF standards. Most of the rehabilitation service providers interviewed favored the CARF standards. Their concerns were that the CARF standards were perhaps too "paper" oriented and costly to implement, and for this reason might be a prohibitive burden on smaller providers in rural areas.

Largely for this reason, the DDD staff and other advocates oppose the adoption of the CARF standards. They are not convinced that the CARF standards would be cost beneficial. A few respondents while not opposing the CARF standards believe the ideology embodied in the ACMR/DD standards to be stronger and more reflective of the Colorado system ideology than that reflected in the CARF standards. A number of providers and several advocates viewed the CARF standards as "better than

nothing" or a "good place to start". They pointed to the fact that the state had failed many times to develop the its own standards, and they so no reason why another state effort would end any differently.

3. Other Programs

Several respondents reported that there were no program standards existing that applied to the following specialized services to persons with developmental disabilities: follow along services, respite care programs, host homes, and case management services. The Division for Developmental Disabilities is reportedly developing standards to cover all of these programs.

One person noted that there were no established standards or guidelines for child screening and diagnostic evaluation services being provided by the Department of Education as part of the child finding program, by the Department of Health as part of the EPSDT program, and by community centered boards as part of their facility review committees procedures. Work in developing such guidelines was begun several years ago by the Division for Developmental Disabilities but has been discontinued.

C. Measures

When asked to identify those service dimensions that they would look at to satisfy themselves that the services provided were quality services respondents mentioned the following dimensions:

Inputs

- o staff qualifications
- o facility and equipment condition and aesthetics
- o staff training (preparedness) to do the job
- o record keeping
- o financial stability

Process

- o staff attitudes
- o IHP, IEP, and IPP documentation
- o IHP, IEP and IPP implementation
- o existence of internal program evaluation and monitoring procedures
- o existence of program plans and objectives
- o general atmosphere
- o client/staff interaction, nature of
- o meaningfulness of client activities
- o client rights
- o openness or ease of access to program by outside visitors

Outputs

- o number of clients served

Outcomes

- o client adjustment to setting
- o client development
- o client movement
- o family/client satisfaction

There were few discernible differences between the interests in terms of the dimensions of quality favored. The universally agreed upon dimensions that respondents said they would look at

in order to satisfy themselves that the services were (by their own definition) quality services, were the existence of the IHPs, IPPs, IWRP's and/or IEPs, and the competency of the staff providing the services.

Providers, and state and local administrative staff in particular emphasized the importance of the IHP process and staff competency.

The central concern of budget makers, members of the Governor's Office, and legislators interviewed was program efficiency and productivity. In this connection, some Division for Developmental Disabilities' staff expressed concern that the Program Management Information System (PMIS) developed under contract for the Department of Institutions imposes uniform output measures which effectively slant the cost/benefits picture in favor of mental health programs. They fear that legislative staff policy and budget makers might be misled by these figures. However the legislative staff interviewed, professed to understand these differences, and felt that the Division for Developmental Disabilities' staff concerns were needless. Legislative staff also expressed some desire for measures of the appropriateness of the services provided.

Providers, advocates and administrative staff were asked directly how desirable, practical, and useful they believed client outcome measures to be. Adult training service providers frequently mentioned the importance of client outcomes, particularly client movement. Some Department of Institutions staff, and some parents and advocacy groups also placed heavy

emphasis on client outcomes. While most staff of state agencies, Community Centered Boards, and private providers acknowledged the importance of individual client outcomes, particularly for purposes of internal management and quality control, they questioned the reliability and utility of such information. Many strongly opposed attempts to hold providers individually accountable for outcomes, particularly client movement, as they believe that such outcomes depend on too many factors outside of the providers' control (e.g., service availability, client propensity to improve, family support). They were also concerned that the setting of "movement" standards or objectives could lead to production (throughput) -oriented as opposed to individualized behavior- and development-oriented programs. A number of case managers interviewed, like the providers, were concerned that their performance not be evaluated in terms of client outcomes, specifically client movement, as they felt that client movement is affected by too many factors outside of their control. They were less concerned about providing aggregate figures on changes in client levels of functioning or movement, just so long as the reporting burden would not be prohibitive and the information would not be used to sanction them.

D. Feedback

Feedback on provider performance may be obtained through self reviews and reports, or onsite reviews. The onsite reviews may be periodic or continual. Most providers said they have little use for the information they compile for the CORE and other ongoing state reporting requirements, though they did not

question the state's need for the information.

Most providers volunteered that the Division on Developmental Disabilities' recent use of self-reviews and reports in lieu of onsite reviews was a waste of everyone's time -- a paper exercise of no perceivable benefit insofar as improving the quality of services and accountability are concerned. Questioned about this practice, Division for Developmental Disabilities' staff acknowledged as much, but said they have little choice given the loss of Developmental Disabilities Council funds and the legislature's unwillingness to pick up the funding needed to continue the on-site residential reviews.

On the contrary all providers saw some value in the onsite reviews in terms of providing needed direction, quality control, and spreading new ideas. Some felt that the reviews could serve these purposes far better than they were currently. The Department of Education's reviews were generally viewed as the most substantive and beneficial. Although often times were seen as unreasonable in that they applied standards more appropriate to school environments than to community centered board environments and regional center environments.

The Health Department reviews were generally seen as the least beneficial though several providers observed that the health surveys had recently improved. Most respondents maintained that the program part of the surveys were not thorough enough, and that the the surveys would be far more beneficial were the surveyors more experienced and better trained, and

thereby equipped to provide helpful suggestions. A number of providers questioned the value of the survey team's reviewing each and every client from head to foot as part of their "Inspection of Care." One respondent suggested that surveyors and regulation writers be required to serve for some period of time at the provider level, possibly on a rotating basis, in order to "help them keep their feet on the ground."

Providers were particularly concerned with the excessive paperwork required to document formal plans and procedures. They were quick to point out that such formal procedures may or may not reflect what actually goes on. They commented candidly on the mounds of paperwork which must be prepared just prior to onsite reviews. Members of the reviewing agencies in the Department of Health, Department of Institutions, and Department of Social Services, acknowledged this problem. However, several Division for Developmental Disabilities staff pointed to the statewide success of the IPP reviews in getting the IPP process instituted. They cited these reviews as evidence that "paper-driven" requirements can work. A number of providers admitted that the IPP reviews had prompted them to initiate and eventually institutionalize the IPP process.

Several Community Centered Boards and providers pointed to the fact that many of the review processes covered the same standards, and expressed the hope that the reviews could be designed to be more complimentary, and that they could possibly be done at the same time order to lessen the burden.

Most providers expressed dismay that the feedback from the

Department of Health and Department of Education surveys took months, and that after filtering down through the state bureaucracy often ended-up lacking substance. The reviewing agency staff interviewed recognized this problem and said they plan to provide more immediate feedback as part of the surveys.

The universal judgment of the provider agencies was that to have any influence, the review should be positive and constructive in tone, should be linked with technical assistance and training, and should preferably include peers. The review agency personnel interviewed concurred; however, most stated that the reviews needed to assure that the providers meet minimum standards as well. Providers also expressed the hope that the survey teams would be more consistent from year to year in their interpretations of the standards. They suggested that this might be accomplished by keeping the same compliance survey team staff from year to year, or requiring more rigorous surveyor training.

The program oversight function of case managers, parents, and other client advocates was recognized by most everyone. However the extent to which and the manner in which case managers, parents, and client advocates monitor the quality of client services varies considerably from area to area. In some areas parents, advocates, and case managers were reported to be actively involved in monitoring program performance; in other areas this was not so.

At one regional center, residential staff have been trained to perform as case managers although their effectiveness is reportedly diminished by their lack of confidence in dealing with

the "better educated" program staff. However, even at this center there was a recognized need for case managers independent of the regional center.

More than any other issue, there was disagreement among the providers on the ways in which these advocates should be involved and the value of their involvement. Most felt that such monitoring should necessarily be informal in nature and best kept at that level; some would like to see the advocate and case manager roles as program monitors more formalized.

Most all of the advocacy organizations and individual advocates interviewed felt that they should play a pro-active monitoring role; however, not everyone was sure that it would be possible to recruit, train, and maintain a sufficient number of advocates to do such monitoring particularly in areas where relatively inactive local advocacy organizations, or where no local advocacy organizations existed. A number of persons involved in the Division for Developmental Disabilities' on-site reviews of adult residential services pointed to the difficulty of getting DDC and ARC representatives to participate.

Similarly, while nearly all respondents recognized that the case manager was in a unique position to play a pro-active monitoring role, they expressed doubt that the legislature would see fit to fund enough case managers to do the job. They pointed to past failures to obtain legislative support for implementing the Colorado case management model.

F. Control

Most respondents agree that the state should exercise the ultimate control over the quality of services provided. However, a number of the Division for Developmental Disabilities staff and Community Centered Board directors interviewed would like to see more Community Centered Board involvement in the quality monitoring and control of services to developmentally disabled clients in ICF/MRs and Class I facilities.

1. Licensure and Regulation

Several respondents noted that respite homes, host homes, and individual apartments were not presently licensed; they believe that these programs should at least be certified prior to receiving state support. This is reportedly under consideration by the Division for Developmental Disabilities and the Department of Health.

At present the ARS program standards and other administrative and programmatic requirements for Division for Developmental Disabilities funded programs such as those pertaining to client rights and admission procedures are established by administrative directive and enforced through specification in community center board contracts. In order to comply with the provisions of the Title XIX waiver, the residential and case management standards are being tightened and included in regulatory form. Most Division for Developmental Disabilities staff, while acknowledging the need to move to more systematic procedures for establishing and updating standards for Division for Developmental Disabilities funded programs, hoped

that the Division would not become a regulatory agency stifling innovative program initiatives and encouraging program mediocrity.

2. Performance Contracting

A number of individual advocates and members of the State Auditor's Office were of the general opinion that the Community Centered Board's performance contracts and enforcement procedures should be strengthened. Of particular concern was the inability of the Division for Developmental Disabilities to assure that Community Centered Boards expended funds for the purposes for which they were received. This was not mentioned as an issue of concern by the Division for Developmental Disabilities, Community Centered Boards or private providers.

3. Fiscal Sanctions and Incentives

At least one provider felt that the private providers and regional centers should be held to the same rates of reimbursement. Several Community Centered Board directors felt that the rate setting process was too inflexible and should be simpler. Several client advocates believe that provider payments should be tied to performance, specifically client outcomes.

4. Accreditation

As noted earlier, most of the rehabilitation service providers interviewed favored the CARF standards. Most also favored the idea of the state's requiring CARF accreditation as a condition of funding. However, because of the high cost of CARF accreditation, several CCB directors felt that the state should underwrite this cost. Several, too, expressed concern that the

smaller rural providers would be unable to achieve CARF accreditation as the CARF standards and paperwork burden would be too great. Concern was also expressed that deeming of the CARF standards by the state might be used as an excuse for the state to bow out of the quality assurance picture. They believed that the state should participate in the CARF accreditation process if only as an observer. Finally, the concerns among advocates and some members of the Division for Developmental Disabilities office was that the CARF accreditation might induce providers to spend too much time "papering" the process rather than engaging in services to clients.

5. Training and Technical Assistance

As already noted there was universal agreement among the respondents that the state should support more technical assistance and training as an adjunct of the performance reviews. The general feeling is that staff are well motivated and want to improve but need to know how. The general concern seems to be that the rapid growth of community programs, while something to be proud of, may have outstripped the state's capacity to manage and assure the quality of these services.

In-service training in some community centered boards (e.g., Pueblo) and at regional centers is being done. Many of the respondents favor in-service training and on-site technical assistance; they do not favor what one person called "road shows", that is one-shot seminars, workshops and conferences. However, a number of other respondents felt that such "road shows" were important as well as they kept Colorado providers and

administrators informed of the latest developments in other areas of the country.

6. Investigation and Complaint Mechanisms

The staff interviewed at one regional center believe that external incident and complaint investigation procedures should be established to supplement or even supplant the existing internal procedures. They believe that the internal procedures alone are not enough to satisfy outside interests and leave them particularly vulnerable to outside criticism.

A number of advocates and advocacy organizations were concerned that the Community Centered Boards "grievance and due process" procedures were too burdensome and time consuming.

They strongly support the development of a more uniform procedure providing for the channeling of unresolved complaints to the Department of Institutions, and providing for the expediting of urgent and critical problems.

7. Case Management

The case managers were recognized by many as the cog in the developmental disabilities service wheel and in a particularly advantageous position to assure the quality of services particularly insofar as they affect the well-being of their clients. The majority of the persons interviewed believe that in order to promote good communication and to be effective the case manager should sit within the Community Centered Board or regional centers but must somehow be organizationally independent of the program staff. Some Community Centered Board directors

disagreed with the need for case managers independent of the programs.

A number of respondents, the advocacy organizations in particular, would like to see the case management and integrally related quality assurance functions located apart from the CCB's possibly at regional offices like those in California and other states. Such offices are independent of the service providers. These regional offices exercise control over client access to services and over the quality of these services through purchase-of service contracting.

Interviewees:

Date

organization

INTERVIEW SCHEDULE

1. Service Quality Dimensions

a. What are the dimensions of DD service quality of most concern to you/your organization? (check only those volunteered)

_____ Staff qualifications	_____ Client health and safety
_____ Facility and equipment/condition	_____ Client rights
_____ Provider stability	_____ Client satisfaction
_____ Fraud	_____ Provider efficiency
_____ Client welfare	_____ Other (specify)
_____ Client development	_____
_____ Service accessibility	_____

2. Roles and Responsibilities

a. What organizations or individuals (self-included) do you believe have a role to play in assuring the quality of services provided to developmentally disabled persons in Colorado? (check only those volunteered, but introduce all)

_____ Parents	_____ Citizens
_____ Colorado Developmental Disabilities Council	_____ Providers
_____ Clients	_____ Community centered board

_____	Case managers	_____	Legislature
_____	Dept. of Institutions, Divison of Developmental Disabilities	_____	UCP
_____	Dept. of Social Services	_____	CEPA
_____	Dept. of Social Services Rehab Div.	_____	NSAC
_____	Dept. of Health	_____	ARC
_____	Dept of Education	_____	other (specify)
_____	Legal center for the handicapped (P&A)	_____	

- b. Please describe the roles of each party identified.
- c. To what extent are these roles presently fulfilled?
- d. Are any of these organizational roles overlapping or duplicative? How so?

3. Existing Quality Assurance Mechanisms

- a. Please identify those quality assurance activities in which you or/your organization is currently involved.
- b. To what extent do you believe each of these activities have an impact on service quality?
- c. Is it worth continuing?
- d. Could it be improved? If so, how?

4. Alternative Mechanisms

- a. Do you believe there are other things that could be done to better assure service quality?
- b. If so, please explain.

5. Quality Information Detail

- a. What information do you receive reflecting the quality

of DD services?

- b. Do you use it?
- c. If not, why not?
- d. If so, how?
- e. What information would you like to have that you do not currently receive?
- f. How would you use it?

6. Positions -- Our charge is to make recommendations for improving the DD quality assurance efforts in the state of Colorado as appropriate.

a. Are there any recommendations you feel strongly that we should make? Please explain.

b. Are there any recommendations you feel strongly that we should not make? Please explain.

7. Draft Final Report

a. Would you like to have the opportunity to comment on the final report to be completed in July?

b. Address.