Case Management Services for Iowans with Developmental Disabilities

A Study of Services Provided by the Iowa Department of Human Services

A Project of:
The Governor's Planning Council for Developmental Disabilities

STATE LIBRARY OF IOWA
DES MOINES, IOWA 50319

CASE MANAGEMENT SERVICES FOR IOWANS WITH DEVELOPMENTAL DISABILITIES: A Study of Services Provided By The Iowa Department of Human Services

Prepared for:
Governor's Planning Council for Developmental Disabilities

Submitted by:
The Service Coordination Task Force
Mary Ellen Imlau, Chairwoman

February, 1986

Project Director:
Thomas Fields
Iowa University Affiliated Facility
The University of Iowa

Project Associates:
Lawrence O. Johnsen
Jo Ann Sheeley
Iowa Department of Human Services
Bureau of Evaluations

STATE LIBRARY OF IOWA
DES MOINES, IOWA 50319

The Service Coordination Task Force
of the
Governor's Planning Council for Developmental Disabilities

Members:

Mary Ellen Imlau, Chairwoman
Manual Coordinator, Bureau of Policy Coordination,
Iowa Department of Human Services

Bill Callahan
Associate Professor, Department of Special
Education, University of Northern Iowa, and Board
Member, Exceptional Persons, Inc.

Phyllis Christensen
Member, Mental Health and Mental
Retardation Commission

JoEllen Dixon
Social Worker, Iowa Department of
Human Services, Polk County Office

Kathy Herring
Board Member, Iowa Head Injury Association

Eve Hickman
Manager of Program Resources, Association for
Retarded Citizens/Polk County

Ann Hoefer
Social Worker, Handicap Village

Karen Salter
Foster Parent of Handicapped Children

TABLE OF CONTENTS

Acknowledgments iii

Executive Summary iv

I. Introduction 1

II. Overview 3

The Service Coordination Task Force 3

The Service Coordination Model 5

Background 5
Process 6
Features 7
Utility 9

The Iowa Department of Human Services 9

Organizational description 9
Case management services to clients with developmental disabilities 12

III. Methodology 16

Approach 16

Probe Questions 16

Policy Review 18

Consumer Survey 18

Sample selection 18
Data collection 19

DHS Social Worker Survey 21

Sample selection 21
Data collection 21

DHS District Administrator Survey 22

Respondent selection 23
Data collection 23

Advocacy/Provider Group Survey 23

Respondent selection 23
Data collection 23

Data Analysis 24

DHS Key Administrative Staff Interviews 25

Respondent Profiles 25

IV. Findings and Discussion 31

Issue: System Responsiveness 31

Issue: Staffing 37

Issue: Role Definition 40

Issue: Client Satisfaction 44

Issue: Agency Responsibility for Case Management 46

Issue: Consumer Awareness 49

V. Summary 50

VI. Task Force Response 54

DHS Case Management Services to Iowans With Developmental Disabilities: Task Force Conclusions 54

Recommendations 55

References 59

Appendices 61

Appendix A: Case File Analysis Tool
Appendix B: Consumer Survey Questionnaire
Appendix C: DHS Social Worker Interview Questionnaire
Appendix D: Scoring Methodology for DHS Social Worker Training Needs Survey
Appendix E: DHS District Administrator Interview Quesionnaire
Appendix F: Advocacy/Provider Group Survey Questionnaire
Appendix G: Cover Letter to Advocacy/Provider Groups
Appendix H: Follow-up Post Cards
Appendix I: Definition Sheet
Appendix J: Service Coordination Model Schematic Diagram and Explanation
Appendix K: Data Analysis Matrix and Explanation

ACKNOWLEDGMENTS

The authors wish to acknowledge the time, thought and efforts of those who assisted us in completing this study. A special word of appreciation goes to the consumers and parents who took the time to meet with us for the interviews and showed considerable thought in responding to our many questions. The 16 DHS social workers also took time from their very busy schedules, and expressed great enthusiasm for improving Iowa's case management system. The advocacy group members and provider agency staff who answered our mailed questionnaire provided us valuable insight.

We appreciate the efforts of the DHS district administrators who gave their time for the interviews, and their cooperation in permitting us to conduct the client and social worker interviews in their districts. Assistant DHS Commissioners Larry Jackson, Charles Palmer and Sandra Scott discussed our findings with us at length, and shared their insights on case management.

Dr. M.C. Martinson, Director of the University Affiliated Facility at the University of Kentucky, provided us with valuable information on how he and his staff studied their state's case management system. Their study inspired our basic approach to the problem. The late Larry Askling of the Iowa UAF critiqued several drafts of our original methodology and offered helpful suggestions.

Eve Hickman of the Association for Retarded Citizens/Polk County graciously assisted us in setting up the field test of the client interview survey instrument. We appreciate the time and patience of the four clients of that agency who participated. JoEllen Dixon of Polk County DHS assisted in our design of the social worker survey instrument by explaining the intricacies of DHS policy and procedures.

Tom Throckmorton of DHS Bureau of Management Information made drawing the sample easier by his fast, efficient accessing of the SRS system, giving us precisely the information we needed in a readily-usable format. Gene Fitzsimmons of DHS Bureau of Evaluations lightened our load considerably in the tedious case file analysis by reviewing a lion's share of the cases.

Carol Galbraith of the Iowa UAF spent many hours typing and revising the document drafts and supporting materials, often meeting seemingly impossible deadlines. Tina Turnbaugh of DHS Bureau of Evaluations prepared the original data tables, and efficiently coordinated the lengthy case file analysis mailing process.

Thomas Fields
Lawrence O. Johnsen
Jo Ann Sheeley

EXECUTIVE SUMMARY

Introduction

This study examines case management services provided to clients of the Iowa Department of Human Services (DHS) who are developmentally disabled. Quality, accessibility and client satisfaction are reviewed and options to the present system are explored. Existing policy is compared with actual practice, then both are compared with a prescribed standard, the Service Coordination Model. This model has been designed, tested and implemented under the auspices of the federal Administration on Developmental Disabilities, and is considered "state-of-the-art."

The study was commissioned by the Governor's Planning Council for Developmental Disabilities in accordance with the goals expressed in its Three Year Plan. The Iowa University Affiliated Facility of the University of Iowa conducted the study with assistance from the Iowa Department of Human Services, Bureau of Evaluations. The Council's Service Coordination Task Force guided the project staff's efforts and formulated conclusions to the study's findings. The task force has also prepared recommendations for state policy, based on this study's findings and the group's other investigative activities to date.

Methodology

DHS case management services were examined from several perspectives:

Policy. Both explicit and implicit policy governing case management for developmentally disabled DHS clients were identified and reviewed. Sources were legislation, the DHS Employee's Manual and DHS staff persons.

Consumers. Field interviews were conducted with DHS clients in each of the eight DHS districts. The interviews focused on client satisfaction, system responsiveness to client need, and degree of client involvement. Additionally, eighty case files were examined for documentation of case management activity.

DHS Social Workers. Field interviews were conducted in all eight districts with DHS social workers who serve as case managers to clients with developmental disabilities. The interviews focused on the social workers' approach to the case management process, caseload, training needs, attitudes and opinions on systemic improvements.

DHS District Administrators. Field interviews were conducted with the eight district administrators or their designees, and focused on their perceptions of DHS's capability as a case management provider and their opinions on the viability, feasibility and desirability of the Service Coordination Model.

Advocacy Groups and Service Providers. A mail survey was conducted with 33 advocacy groups and service providers. The survey focused on the respondents' evaluation of DHS case management services and their perceptions of the viability and desirability of the Service Coordination Model.

DHS Key Administrative Staff. Interviews were conducted with the three DHS assistant commissioners who head the divisions with direct oversight in the administration and provision of case management services to clients with developmental disabilities. The interviewers sought the respondents' comments on the study's preliminary findings, the Service Coordination Model and proposed developments in DHS case management services.

Findings

The Service Coordination Task Force formulated five "probe questions" to define the parameters of this study and to direct the efforts of the project staff. The study's findings are summarized below, arranged by the probe questions.

Probe Question #1: To what degree are DHS's clients with developmental disabilities receiving the case management components mandated by the Iowa Administrative Code?

- Overall, DHS appears to be in compliance with the mandates of Iowa Administrative Code in the provision of case management services to Iowans with developmental disabilities.
- Many individual DHS caseworkers are going beyond what is mandated by the code in their provision of case management services.
- Three DHS Districts have initiated special projects which would appear to increase the effectiveness of case management services to clients with developmental disabilities.

Probe Question #2: Do inequities exist among the level of case management services received?

- DHS seems to be responding well to clients with developmental disabilities who have less complex or limited service needs. Among clients with more complex service needs, DHS response varies widely on a case-by-case basis.
- Most DHS caseworkers interviewed stated that their current caseloads are too large for them to provide the level of service they felt their clients with developmental disabilities required.
- Several workers with generic caseloads said that they often assign lower priority to their developmental disability cases due to more pressing needs of their other cases (e.g., child protective).
- Apparent gaps exist in case management provision to certain types of clients. Specifically, clients who are placed out of state do not receive regular visits by their caseworkers. In at least one district, clients who move from an SSBG-funded residential placement to a Medicaid-funded placement lose their case management service provided by DHS. Conversely, several workers questioned why State Hospital-School cases must be carried by field workers, when each client is assigned a caseworker at the institution.
- There are some groups which do not meet DHS eligibility guidelines whose advocates believe DHS should be serving them, notably, persons with brain injuries.
- The availability of service resources to case managers varied widely among the eight DHS districts.

- In some districts, DHS service plans were not individualized for the clients. There were also many instances of the service plan being developed from the provider plan, rather than the service plan governing the provider plan.
- Concern was expressed in some areas of the state that case management is "provider-driven," rather than driven by the needs of the clients. DHS district offices no longer have the resources to do community development, and clients must fit into existing services.
- Some developmentally disabled DHS clients have no legal guardian. There is no policy addressing such cases. This situation poses a particular dilemma in the provision of effective case management.
- Several caseworkers and some district administrative staff cited a lack of DHS staff's knowledge about developmental disabilities as a barrier to more effective case management.

Probe Question #3: To what extent are the components of the task force's Service Coordination Model already in place in DHS's case management system?

- The model represents a "client-centered" approach to case management--the system is designed to empower the client to play a controlling role in the case management process. While client self-determination is implied by DHS policies, the role of the client is mostly unclear.
- The model specifies the case manager as the leader of the inter-disciplinary team. DHS caseworkers are not currently designated as team leaders.
- The model employs a planning component to document unmet service needs. DHS documentation of unmet needs is not linked directly to case management, and ranges from none to inconsistent, unsystematic efforts.
- The model specifies immediate response to crisis and emergency situations. While DHS does respond to such situations, there is no specific policy governing this response.
- The model requires the service coordinator to describe the service coordination process to the client. While DHS social workers explain the case management process to their clients, in many cases these explanations are apparently not sufficient, given the number of observed misperceptions of roles.
- DHS clients have little choice of which social worker will be assigned to their case. This is partially dictated by staffing patterns, especially in rural areas. However, there appears to be little demand for this choice by the clients.
- The DHS service plan is not developed in a formalized, structured meeting, as the model requires.

Probe Question #4: To what extent do DHS clients, DHS case managers, DHS administrators and advocacy/provider groups representing Iowans with developmental disabilities view the Service Coordination Model as needed? How feasible do they perceive this model to be?

- The feeling was virtually unanimous that the Service Coordination Model was an improvement over the status quo. Particular aspects which respondents praised are: it is a more structured, systematized, comprehensive approach with clearer delineation of

roles and responsibilities; it is more clearly client-oriented; and service planning is linked directly to the case management process.

- The feeling was almost as strong that this model could not be implemented in Iowa given the current level of available resources. Some respondents thought that some components could be worked into the existing system.
- DHS district administrators felt that the provision of case management to persons who are developmentally disabled by an agency separate from DHS is unrealistic, citing a dearth or duplication of resources and unestablished legitimacy of a new agency as barriers.

Probe Question #5: How satisfied are DHS clients with developmental disabilities and advocacy/provider groups with the case management services currently available? If dissatisfaction exists, which changes need to be made?

- The collective response of clients could best be described as "not unfavorable." The unfavorable comments concerned direct services received or not received, not case management. However, the interviewers noted indifference and low expectation on the part of clients toward their DHS caseworkers. Client perceptions of caseworker roles varied widely, with some seeing their workers as true advocates, while others are unaware of their assigned DHS caseworkers.
- Less than half of the advocacy and provider groups contacted responded to a written survey, and among those who did, several answered "don't know" to many of the questions requesting their assessment of DHS services. This level of response may be attributed to lack of knowledge and/or interest in case management issues.
- Advocacy group respondents called for a sharpened focus of DHS case management services on the "transition" period which must link children's and adult's services.
- Advocacy groups felt that greater efforts should be made toward achieving a more equitable distribution of services throughout the state.

Task Force Response

Conclusions

The Service Coordination Task Force notes that the DHS case management system varies from the Service Coordination Model in some significant ways. For the DHS system to be brought into conformance with the Service Coordination Model, these major changes would need to be made:

1) Variance: Eligibility for case management from DHS is tied to the receipt of certain direct services. The Service Coordination Model dictates the provision of case management services at any or all times during the developmentally disabled individual's lifetime, regardless of whether other services are received, which other services are received, and the funding sources of any other services received.

Remedy: DHS would need to re-define case management as a service not tied to the receipt of other direct services.

2) Variance: Most DHS case management services are provided by social workers assigned to a variety of program areas in addition to developmental disabilities, with a variety of duties in addition to case management as defined by the model. The Service Coordination Model dictates the provision of case management by individuals whose sole function is service coordination to individuals with developmental disabilities.

   Remedy: DHS would need to identify its clients with developmental disabilities as a distinct group, served by personnel whose sole function is case management.

3) Variance: The roles of the client, case manager and direct service provider in the case management process are well-defined by the Service Coordination Model. DHS policy, as documented in the Employee's Manual, is limited in its definition of roles. These limitations were evident among the UAF report's sample of DHS cases.

   Remedy: DHS policy should be clarified and strengthened regarding role definition. The role of the case manager should be communicated to the case managers through the Employee's Manual. The service provider role would be expected to change considerably in many instances, as many are now performing some of the functions of the service coordinator. Agreements on the case manager and service coordinator's roles would need to be reached by DHS and the state's providers. The client's role is designed to be flexible according to the individual's abilities by both the Service Coordination Model and, implicitly, by DHS. By better defining the case manager and service provider roles, the client would be more able to effectively perform his/her role.

4) Variance: The Service Coordination Model contains a built-in planning component to document unmet needs. Clients whose service needs are not able to be met by the existing service array are still allowed to enter a tracking system. DHS does not have a statewide system to aggregate individual unmet service needs, and has no mechanism to track applicants whose needs cannot be immediately met because of service unavailability.

   Remedy: DHS would need to implement a statewide system to document unmet individual needs, possibly through the Services Reporting System (SRS). A tracking system, administered by DHS, would further address the planning focus of the Service Coordination Model.

Recommendations

Based on the culmination of the Service Coordination Task Force's analysis of case management issues, including the study of the DHS system, the task force makes the following recommendations to the Governor's Planning Council for Developmental Disabilities.

Recommendation I

A uniform, statewide system of case management (service coordination) employing the U.S. Department of Health and Human Services, Administration on Developmental Disabilities' Service Coordination Model should be made accessible to all Iowans with developmental disabilities.

Rationale:

Client-centered approach. The recommended approach promotes less client dependency on the system, while providing a life-long link with it, if desired by the client. The receipt of case management services would not be tied to receiving certain types of direct services.

Consumer awareness. Well-defined roles, the "service packages" proposed by the Bill of Rights committee and a uniform system of provision would make service coordination more tangible to consumers, fostering their increased ability to identify their own service needs and evaluate their own service.

Accountability. The explicit definition of roles of the service coordinator, the client, and the service provider articulated by the Service Coordination Model would foster a system of checks and balances.

Adaptability. The recommended approach can work well with a wide range of funding arrangements.

Integration. The recommended system would coordinate all services provided to a client regardless of the funding stream, unlike the current fragmented system. Funding streams would thus be tied together. Uniform service standards would promote a greater equality of services among the state's counties and providers.

Cost-effectiveness. The uniform statewide system concept would eliminate duplication of efforts in case management among the counties. The re-definition of roles would relieve the responsibility for case management from those service providers who currently assume this role, further reducing duplicated efforts.

Compatibility with the Bill of Rights. Implementing the recommended changes will support the needs of the county boards of supervisors and the state legislators for an

ongoing, coordinated source of reliable information on the service needs of Iowans with developmental disabilities. This information could be used to allocate funding among those areas of greatest service needs.

Recommendation II

Service coordination should be made available to all Iowans with developmental disabilities.

Rationale: Currently, many case management services are tied to the receipt of certain direct services: when the service ends, so does case management. A developmental disability is, by definition, a life-long condition. Therefore, the individual should be allowed to remain in the system throughout his/her lifetime, regardless of services received, age or other circumstances. Additionally, some case management services are available only to those who can pass a financial means test; however, the need for case management is independent of the individual's income status.

Recommendation III

Efforts should continue toward the identification of the most viable, effective means of implementing a statewide service coordination system.

Rationale: A thorough analysis of the options available to implement Recommendations I and II is needed. Some of the issues which should be addressed are:

1) Administration: What is the most viable, effective organizational structure: single agency vs. a network of agencies; public agency vs. private agency; existing agency vs. newly-created agency; an agency which provides other services vs. an agency whose sole function is service coordination.

2) Funding: What are the costs of each option? How will the chosen option be funded?

Case management continues to be a priority issue at both the federal level, as mandated by the Developmental Disabilities Act, and the state level, as promoted by the Bill of Rights.

I. INTRODUCTION

This study, commissioned by the Service Coordination Task Force of the Governor's Planning Council for Developmental Disabilities, examines case management services provided to clients of the Iowa Department of Human Services (DHS) who are developmentally disabled. Quality, accessibility and client satisfaction with the current system are reviewed, and options to the present system are explored. This study compares existing policy with actual practice, then compares both with a prescribed standard endorsed by the task force. A task force response to the study's findings and recommendations of policy direction are presented for the Council's consideration.

The study was conducted in accordance with Goal 3 of the Governor's Planning Council for Developmental Disabilities' Three Year Plan for FY 84-86 [1]:

> To put into place the components of a coordinated system of service delivery that appropriately provides services on an individual basis. [2]

The plan directed pursuit of the following objective as one means of attaining this goal:

> During FY1984, the Council, the Division of Mental Health, Mental Retardation and Developmental Disabilities and Commission on Mental Health and Mental Retardation in conjunction with appropriate agencies and groups will evaluate the provision of case management provided by the Department of Human Services and based upon findings formulate a policy statement. [3]

The University Affiliated Facility of The University of Iowa Division of Developmental Disabilities conducted this study with considerable assistance from the Iowa Department of Human Services, Division of the

Inspector General, Bureau of Evaluations. All recommendations were formulated by the Service Coordination Task Force of the Governor's Planning Council for Developmental Disabilities.

Work on this study commenced in February, 1985, when the task force selected the methodology and approach from three alternative methodologies prepared for them by the project staff. The study's findings were presented to the task force in December, 1985, and the final report with the task force response was presented to the Council in February, 1986.

This report presents a picture of the current state of the system through which DHS clients who are developmentally disabled receive case management services. The report does not attempt to analyze, evaluate or describe the total case management system used by all developmentally disabled Iowans. Such an attempt would be difficult at best, given the fragmented nature of Iowa's system: Iowa does not have a single, specific, state-level agency designated to serve developmentally disabled persons exclusively. There are approximately 220 [4] organizations, groups, and public and private agencies who describe themselves as providers of case management services to persons with developmental disabilities. While the exact distribution of clientele among these providers is unknown, it is the project staff's estimation that the Iowa Department of Human Services serves the greatest number.

II. OVERVIEW

The Service Coordination Task Force

The Federal legislation known as The Developmental Disabilities Assistance and Bill of Rights Act (P.L. 95-602), which established the current definition of developmental disability, identifies case management as a "priority service" area. [5] In accordance with this directive, the Iowa Governor's Planning Council for Developmental Disabilities formulated a major goal of their Three Year Plan for FY84-86 in the area of case management. In November, 1983, the Council established the Service Coordination Task Force to address its concerns in this area.

Much of this task force's earliest activities centered around definition. Through an examination of how case management is provided by Iowa's public and private agencies, and a review of case management service models employed in other states, it became evident to the task force that there exists a wide range of interpretation of the term "case management." For example, some case management models center around the management of the paperwork necessary to acquire and fund client services, while others focus on such activities as counseling, service delivery system planning, client advocacy and case finding.

As a means of identifying "good" case management, the task force identified those elements they believe are essential. Their list includes:

- communication
- crisis intervention
- information gathering
- assessment
- problem identification
- referral to services
- delineation of responsibilities

- individualized plan preparation
- ongoing information gathering
- conflict mediation. [6]

In subsequent sessions, the task force assisted the Council in developing their "Guiding Principles for Services." These principles were adopted as prescriptive measures for the provision of all services for Iowans with developmental disabilities, including case management. Following are these principles:

- The person with a developmental disability has the same fundamental rights as other persons, including the right to receive services needed to help achieve his or her maximum potential.
- The person with a developmental disability should be served within the context of a developmental model that acknowledges each person's capacity for learning, growing, and developing regardless of how disabled he or she may be.
- Services must be provided to meet the developmental needs of the person throughout his or her lifespan, so as to maximize the person's potential and enhance the persons ability to cope with his or her environment.
- Services must be provided in accordance with the principles of normalization (a manner of living that is as close as possible to what is considered normal in society) and least restrictive environment (services that intrude as little as possible on the person's life, while still effectively meeting needs).
- Standards for services for persons with developmental disabilities should emphasize the provision of appropriate individualized program plans, using an interdisciplinary approach (a team approach which pools information and resources to create a coordinated service plan). [7]

The Service Coordination Task Force, originally named the Case Management Task Force, chose their present name shortly after being convened. The members changed the name to reflect their concept of case management as a pro-active service based primarily on client needs, rather

than a means of processing "cases" through the system. The task force believes that improvements made in case management services should be designed with this concept in mind.

The Service Coordination Model

Background. Following a review of case management models employed in other states, the Task Force selected one model which they believe best articulates the features they identified as components of an effective case management system. This model, called the System of Individual Service Coordination for Persons with Developmental Disabilities (shortened to the Service Coordination Model in this report), would constitute a standard with which to compare current provision of case management services to persons with developmental disabilities by the Department of Human Services. Further elaboration of this process of comparison is found in the Methodology section of this report.

The Service Coordination Model is the culmination of several years of Federal effort, beginning in 1978 with the passage of PL 95-602, which designates case management as one of four priority areas of Federal developmental disabilities policy. In 1979, the Administration on Developmental Disabilities (A.D.D.) contracted with Rehab Group, Inc., a private consulting firm, to develop a case management model to assist states in meeting the Federally-mandated priority of PL 95-602.

The Serivce Coordination Model is based on research of the unique service needs of the developmentally disabled population, and utilizes the findings of an A.D.D.-sponsored national conference held in 1980. The conference, entitled "Case Management: State of the Art," convened, by invitation only, approximately 150 recognized experts in the field of developmental disabilities. The conference's purpose was to "provide the

opportunity for the exchange of ideas, and the sharing of knowledge, experience, problems and successes relating to the provision of case management services to the developmentally disabled." [8]

Upon completion of the model, the A.D.D. funded a second phase of the project to study the feasibility and demonstrate its effectiveness. This field test was conducted at three agencies of varying size in the states of California, Maryland and New Hampshire. During and after these field tests, the model was continuously reviewed and revisions were made to improve the model's effectiveness. The finalized version of the model was disseminated to the general public in 1984, and reviewed and accepted by the task force as the standard to be used in this study during the same year.

The Service Coordination Model is structured around the philosophy that the client's needs come first. Its primary mission is "to support and empower the individual clients in their search for the services they need and want." [9]

Process. The Service Coordination Model is designed to identify individuals with developmental disabilities who need and want assistance in selecting and obtaining appropriate services and, through an individualized planning process, provide eligible clients with such assistance. The client is matched with a "service coordinator" who procures information from the client and others in order to develop an individualized plan. This plan combines two components developed by two different teams, with each team including both the client and the service coordinator.

The "general service component" affirms the client's own plans and preferences, sets forth long-range goals and identifies the services needed and desired by the client. The "individual program component" specifies the short-term objectives and the ways the goals of the general service

component will be achieved and monitored. The service coordinator and client negotiate for the services and service modifications and monitors the services as the plan is implemented.

The plan is revised annually, or as needed. Throughout the individual planning, service coordination and monitoring process, the services that are needed but unavailable are documented. [10] The model process is presented in schematic form on the following page.

Features. Some of the Service Coordination Model's more distinctive features are:

- It views the client as a whole person, supporting and empowering him or her to exercise as much authority as possible in planning and shaping services.
- It is an ongoing process--not one-shot or periodic--which is vigilant to the interplay of the client's choices and to the providers' actions.
- It focuses primarily on the client's needs and secondarily on the service delivery system's structure: it is a personal service, not a management tool or paperwork chore.
- It features a built-in monitoring system which provides an ongoing source of data on client needs to policy makers and service planners.
- It is consciously designed to make the total service delivery system more accountable to the client and more responsive to his or her needs.

Service coordination, as defined by this model, differs from more traditional case management models in that, among the traditional models, the interaction between the client and case manager is short term and therapeutic, with the case manager providing intensive counseling. The goal is often to fill a gap, overcome a crisis or solve a problem. Service coordination, however, can be a long-term service, has continuity, is focused on the whole person and is oriented toward growth and the future. The service coordinator's role is facilitative, with the client controlling

SERVICE COORDINATION MODEL

PROCESS STEPS	MAIN ACTIVITIES
PROVIDE INFORMATION AND DETERMINE ELIGIBILITY	• Receive requests for assistance • Determine potential clients' needs for service coordination • Respond to crisis or emergency situations • Provide information to individuals who do not want service coordination • Describe the service coordination process to potential clients • Determine eligibility • Provide ineligible individuals with information on the reason(s) for their ineligibility and refer them to other appropriate services • Accept eligible persons as clients of service coordination system • Maintain records on the intake process
MATCH CLIENT AND SERVICE COORDINATOR	• Gather information needed to match the client with a service coordinator • Match the client with a service coordinator, involving the client in the selection • Develop a written agreement which governs the client-service coordinator relationship • Change the match on the request of the client or if the relationship is not working satisfactorily • Document information related to the matching process
GATHER EXISTING CLIENT INFORMATION	• Develop a profile of the client's strengths, needs, and personal goals • Procure existing assessment and service provision information, as specified in the written agreement • Review assessment and service data with the client and determine what other information is needed to fill existing gaps • Determine potential participants for the General Service Component development meeting and distribute information
PROCURE NEW ASSESSMENTS AS NEEDED	• Determine needed assessments and how they will be procured • Procure new assessments • Distribute results to appropriate people • Document unavailability of assessments
DEVELOP GENERAL SERVICE COMPONENT OF INDIVIDUAL PLAN	• Develop plans for the meeting and invite participants • Convene meeting within established time frame • Develop a total plan identifying long-range goals and service settings for the client • Assist the client to participate as fully as possible in the meeting • Identify direct service providers who will participate in developing the Individual Program Component and select a meeting chairperson or facilitator • Obtain signatures and agency commitment to provide services • Identify and document unavailable services
DEVELOP INDIVIDUAL PROGRAM COMPONENT OF INDIVIDUAL PLAN	• Gather meeting participants and convene meeting • Assist the client to participate in the meeting • Develop and document service plan which includes short-term objectives, strategies, and evaluation procedures • Negotiate and obtain agreement on the plan
MONITOR SERVICES AND REVISE PLAN	• Negotiate services as necessary • Monitor, review, and revise the individual plan • Cooperate with third-party monitors
DOCUMENT UNAVAILABLE SERVICES	• Identify unavailable and/or inaccessible assessments and services • Prepare report on unavailable/inaccessible assessments and services • Disseminate report to appropriate agencies

the planning and negotiation for service delivery. Counseling provided by the service coordinator is restricted to improving the client's ability to make personal choices, to advocate for and to obtain needed services. [11]

Utility. The Service Coordination Model has been selected by the task force to use as a standard with which to compare current case management provision. The model should be considered as an ideal standard, used to focus attention on those specific areas which need to be addressed to bring the system closer to the needs of persons with developmental disabililies. The task force and the project staff recognize that the current DHS system is not structured solely for developmentally disabled clients; the model is not used as a standard of compliance but represents instead an optimal approach to case management for persons with developmental disabilities. There are no plans at the time of this writing to implement the Service Coordination Model in its entirety anywhere in the state of Iowa.

The Iowa Department of Human Services

Organizational description. [12] The Department of Human Services (DHS) is the state agency mandated to oversee Iowa's major human services programs for children, adults and families in need. The department serves over 400,000 Iowans through the following program areas:

- Financial assistance
- Juvenile institutions
- Block Grant services (e.g., child and adult protection, transportation, adoption, case management)
- Veterans Home
- Institutions for persons with mental illness and mental retardation
- Services for persons with developmental disabilities. [13]

The projected DHS budget for fiscal year 1986 is approximately $895 million. [14]

The department states its mission as:

> . . .dedicated to improving the well-being of Iowa's poor, neglected, abused, ill and incarcerated. The primary responsibility of the Department is to help individuals or families become self-sustaining. Staff provide a "continuum of services" so that services are available to help clients at all levels and stages of their problems. DHS strives to maintain cooperative relationships with community-based providers to ensure that clients receive care close to their homes. [15]

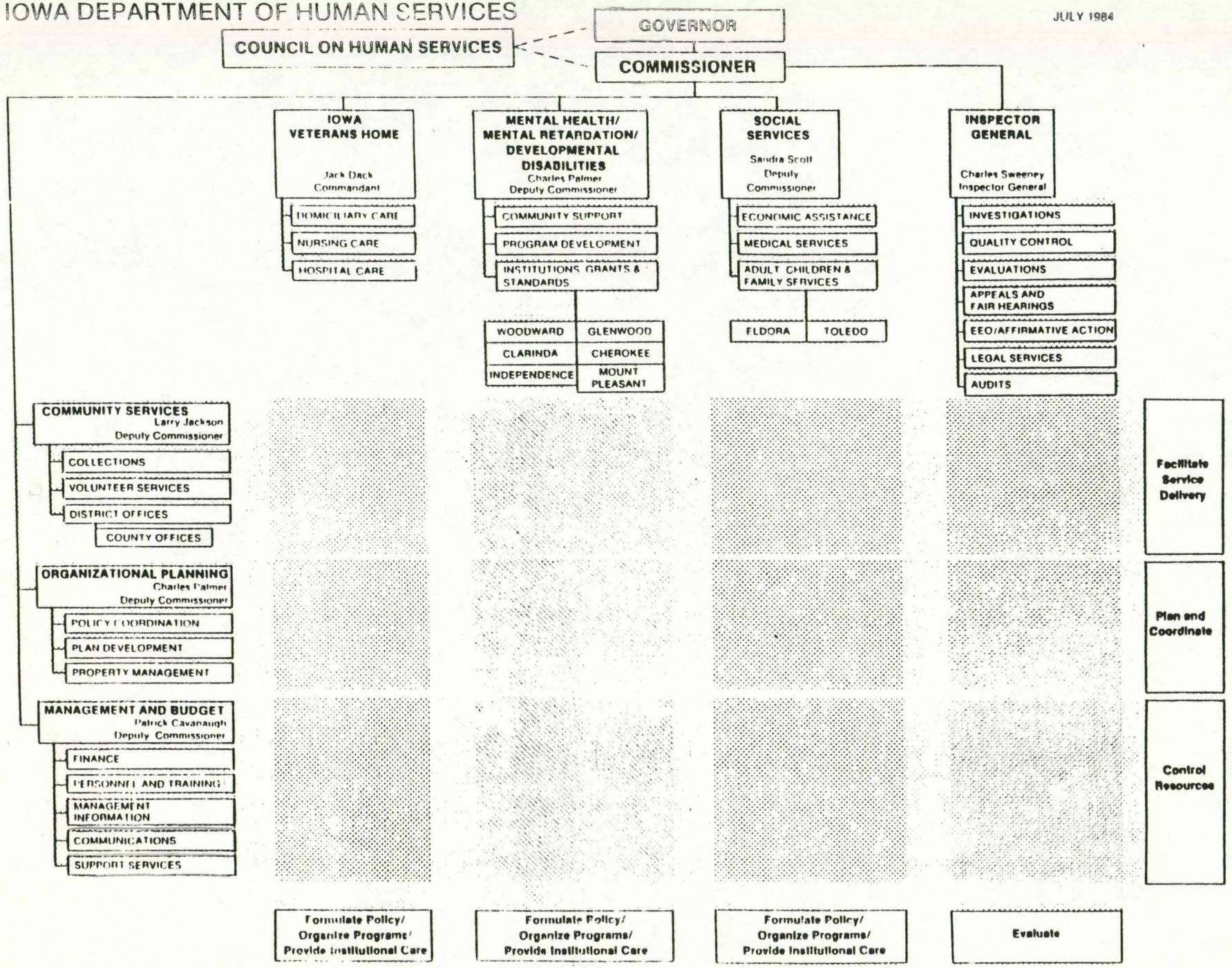
DHS is organized under the "umbrella agency" model of human services provision. Through this model, a broad range of human services are combined under one organizational structure which provides common planning, budgeting, administration and coordination of services to eliminate overlap and duplication. Policy-making for the department is carried out by the Council on Human Services, a legislated body appointed by the Governor.

There are six divisions which make up DHS, organized on a matrix structure (see diagram on next page). Three of these divisions are involved in the administration and provision of case management services to the department's clientele with developmental disabilities:

1) The mission of the Division of Mental Health/Mental Retardation/Developmental Disabilities is to "assure the continuing development of an integrated system of comprehensive mental health, mental retardation and developmental disabilities services, which furthers Iowans' opportunities to achieve their maximum level of functioning." [16] This division is responsible for statewide planning for the array of developmental disabilities services available through community-based providers and the state institutions administered by the division. The division administers the Federal Developmental Disabilities Basic

IOWA DEPARTMENT OF HUMAN SERVICES

JULY 1984



Grant Program funds for the state, and is responsible for staffing the Governor's Planning Council for Developmental Disabilities, a 24-member policy-making body.

2) The Division of Community Services is responsible for the delivery of all of the department's income maintenance programs, home-based social services and community-based social services, including case management. These programs are delivered through eight district offices, which oversee the services provided by the department's local (county) offices. Services are provided directly by DHS staff, or are purchased from other public and private agencies.

3) The mission of the Division of Social Services is to "define and develop financial, medical and social service programs for eligible Iowans and to deliver institutional services to youth." [17] The division is responsible for writing policy and developing service programs for adults, children and families, including case management. Among its goals are: "Utilize an integrated planning system for service delivery that explores alternative service delivery systems," and "structure programs to be more responsive to the needs of the changing population by shifting emphasis of programs and assuring a balance in the continuum of services." [18]

Case management services to clients with developmental disabilities. As an "umbrella agency," DHS does not classify clients categorically in their client data tracking system. All eligible clients must meet the department's service need criteria, which does not use the Federal definition of developmental disability. For this reason, the number of

clients served by DHS who have developmental disabilities is not able to be documented. However, the project staff places a gross estimate of this number at 6,298. [19]

DHS-provided case management services are dictated by a single, uniform policy, regardless of client disability status or program services received. The policy states:

> A Department social worker shall be reponsible for each client's case. These responsibilities include:
>
> A. Determining eligibility - financial and need for service.
>
> B. Ensuring that there is a Department case plan for each individual based on a comprehensive assessment of needs. Portions of the initial and updated case plans which are pertinent to the provider shall be sent to the agency. These portions shall serve as a basis of service provision by the provider agency. A copy of the case plan shall be provided to the client, or legal representative.
>
> C. Referrals to other workers, through proper channels, and coordination of all workers involved in a case.
>
> D. Input to the Service Reporting System and Case Data System.
>
> E. Oversee the case to ensure financial eligibility continues, the need for service continues, services are provided to the client, S.R.S. and Case Data reporting is correct, required documentation is included, and the case is cancelled when appropriate.
>
> F. Ensure that the client's needed services are not available elsewhere without charge to the client. [20]

The DHS Employees' Manual dictates that the DHS social worker is responsible for the planning, coordination, delivery and/or monitoring of all services to an individual or a family, including those provided by purchase of service agencies, volunteers or other community resources. [21]

DHS policy requires applicants to meet three eligibility tests to qualify for services: [22]

1) The applicant must be a resident of Iowa.

2) The individual service need must be established by the DHS service worker or ordered by the court.

3) The applicant must be eligible financially, i.e., one of the following criteria must be met:

   a) Income Maintenance Status: The applicant must be a recipient of Aid to Families with Dependent Children (AFDC), Supplemental Security Income (SSI), or State Supplemental Assistance (SSA); or a resident of medical institutions in the 300% Group, as defined by the Iowa Administrative Code.

   b) Without Regard to Income Status: The services must be court ordered, or directed toward the goal of preventing or remedying abuse, neglect or exploitation of children and dependent adults.

   c) Income Eligible Status: The applicant's gross monthly income must be at or below the following amounts:

Family Size	Gross Monthly Income
1	437
2	571
3	706
4	839
5	974
6	1108
7	1133
8	1158
9	1184
10	1209

Applicants who do not meet these eligibility criteria are eligible for information and referral service from the department. The duration of this service cannot exceed 96 hours. [23]

Case management is provided for the Department's clientele by the 475 Social Worker II's who staff the local offices located in each of the state's 99 counties. [25] These individuals are employed through the state's Merit Employment System. Minimum qualifications for the Social

Worker II classification are a Bachelor of Social Work degree, or a Bachelor's degree in any other discipline plus one year of social work experience. Additional years of social work experience can be substituted for each year of the required education. [25] DHS social workers are provided ongoing training largely by DHS personnel.

Until a major reorganization in April, 1982, each DHS district office (then numbering 16) was staffed by a Mental Retardation/Developmental Disabilities (MR/DD) Specialist who provided consultation and technical assistance to the districts' line staff. Most of the state's more populous counties had specialized MR/DD units with staff assigned solely to these clients. After the reorganization, the MR/DD Specialist positions and the specialized units at the county level were largely eliminated, with the caseloads reassigned on a "generic" basis. Under this staffing pattern, social workers are assigned cases from all program areas of the department (i.e., child protective, adult services, foster care, etc.)

III. METHODOLOGY

Approach

As stated above, the purpose of this project is to respond to Objective 3.1 of Goal 3 of the Governor's Planning Council for Developmental Disabilities' Three Year Plan for FY84-FY86. This objective states that the Council shall ". . . evaluate the provision of case management provided by the Department of Human Services and based upon the findings formulate a policy statement." [26] The Service Coordination Task Force determined that this objective would be addressed in the following manner:

1) A series of "probe questions" would be formulated by the task force to define the parameters of the evaluation.

2) A methodology would be developed by the project staff to address the probe questions, subject to the approval of the task force.

3) The findings would be presented to the task force by the project staff.

4) The task force, with the assistance of the project staff, would develop recommendations based on the findings for the consideration of the Council in formulating state case management policy.

Probe Questions

The task force developed a series of five probe questions to define the parameters of the evaluation and to direct the activities of the project staff. The questions were designed to address the issues the task force felt it needed to make recommendations for the formation of state case management policy. The probe questions were used by the project staff as a means to identify all necessary data and its sources for the implementation of this evaluation.

The probe questions are:

1) To what degree are DHS clients with developmental disabilities receiving the case management components mandated by the Iowa Administrative Code?

2) Do inequities exist among the level of case management services needed and the level of case management services received?

3) To what extent are the components of the task force's Service Coordination Model already in place in DHS's case management system?

4) To what extent do DHS clients, DHS case managers, DHS administrators and advocacy/provider groups representing Iowans with developmental disabilities view the Service Coordination Model as needed?

   a) How feasible do they perceive this model to be?

5) How satisfied are DHS clients who have developmental disabilities and advocacy/provider groups with the case management services currently available?

   a) If dissatisfaction exists, which changes need to be made?

To answer the probe questions, the following sources of data were identified:

- Case management policy (explicit and implicit)
- Consumers (i.e., developmentally disabled DHS clientele)
- DHS social workers
- DHS administration (field and Central Office levels)
- Advocacy groups
- Service providers

Through this approach, the task force hoped to examine case management from the perspective of every actor having a role in the service delivery system.

Policy Review

Explicit and implicit policy which defines and dictates the provision of case management services by DHS to its clients who are developmentally disabled was identified and reviewed. Sources of explicit policy were the Code of Iowa, [27] the Iowa Administrative Code, [28] the DHS Employees' Manual and the Iowa Comprehensive State Plan for Mental Health, Mental Retardation and Developmental Disabilities. Implicit policy was identified through field interviews with DHS officials at the local, district and state levels. Through this policy review, the project staff was able to establish the boundaries and structure of the current service delivery system.

Consumer Survey

The task force believed that DHS clients who are developmentally disabled, as consumers of case management services, were the most important source of input on program effectiveness. This group was surveyed in two phases, a case file analysis and a client interview field survey. This two-phase approach was chosen because the project budget allowed for only a small number of clients to be included in the field survey sample. The case file analysis was employed to provide a higher level of client input at a cost within the budget.

Sample selection. Selecting a consumer sample from among DHS's client caseload proved somewhat difficult, since the department's client data tracking system, the Service Reporting System (SRS), does not maintain developmentally disabled client cases as a separate category. To resolve this difficulty, a system was devised to identify a representative sample of clients with developmental disabilities using the available SRS data. This system follows:

1) The total number of clients identified by the SRS system as having a "handicap/disability" listed as mentally retarded, emotionally handicapped, physically handicapped (orthopedic), physically handicapped (non-orthopedic), visually handicapped, hearing impaired, and/or a "special problem area" listed as mental retardation, disabled, communication disability, hearing impaired, physical disability and/or multiple handicap was drawn (N=11,997).

2) From this group, a random sample of 50 clients from each of the eight DHS districts was drawn (N=400).

3) Lists of the 50 clients were sent to each respective district, along with the Federal definition of developmental disabilities. Appropriate DHS staff were instructed to identify every client on the list who met the definition (N=210, statewide).

4) From this pool of 210 developmentally disabled client cases, the project staff drew a random sample of ten clients per district for the case file analysis (N=80).

5) From this case file analysis sample, a sub-sample was drawn to serve as the client interview sample (i.e., all subjects included in the field survey were also included in the case file analysis). Two client cases were randomly drawn from each DHS district (N=16). This sample was stratified to include one case from each district's most urban county and one case from one of the district's rural counties.

Data collection. The instrument used for the case file analysis (see Appendix A) was designed to collect the following information from each case file in the sample:

1) Eligibility determination. Documents establishing client eligibility (i.e., the application/reapplication form and the notice of decision) were examined for presence in file, proper completion and timeliness.

2) DHS service plan. The case plan document was examined for presence in file, quality of documented client assessment, addressing of national goals, quality and specificity of objectives, delineation of worker/client/provider responsibilities and evidence of client involvement in the case planning process.

3) Provider service plan. The provider plan document was examined for presence in file (if required), consistency with DHS service plan and quality.

4) Narrative. The narrative was examined in terms of clarity of documentation of case activity and evidence of case plan monitoring and implementation.

The casefiles in the sample were called in from the field and read in Des Moines by the three members of the project staff and an additional DHS staff person during July and August, 1985.

The instrument used in the client interview phase of the consumer survey (see Appendix B) focused on the following:

- client satisfaction
- client involvement in case management process and case planning
- accessibility
- availability
- system responsiveness to client-perceived needs.

Interviews were conducted during August and September, 1985, by the project staff in each of the eight DHS districts. The interviews took

place in private homes, residential and vocational facilities and local DHS offices, with the subjects choosing the sites.

Due to the nature of the population being surveyed, it was anticipated that some clients would be unable to respond to an interview. In those cases where it appeared that the client's functioning level might not permit a valid interview, the project staff contacted the client's DHS case worker and asked if the worker believed the client could respond to the survey. In cases where the worker did not believe it was possible, the worker was asked to identify a parent, guardian or other person who could best respond from the client's point of view. As an additional means to insure response validity, the interviewers probed for the respondent's understanding of certain key concepts included in the interview schedule before the interview was begun.

DHS Social Worker Survey

The DHS social workers who staff the state's local offices were chosen to be surveyed for their perspective as case managers to DHS clients with developmental disabilities. Positioned at the clients' singular point of entry to the DHS case management system, these individuals play a crucial role in the case management process.

Sample selection. This sample consisted of the sixteen social workers who were assigned, as of April, 1985, to the clients in the field survey sample in phase two of the consumer survey. This approach assured a random sample, stratified in the same manner as the client interview sample.

Data collection. While each worker in this sample was paired with a subject in the client interview sample, the interviews did not focus solely on those particular cases. Instead, workers were queried on the total

extent of their involvement as case managers to clients with developmental disabilities. The client interview cases did, however, serve as examples which the interviewers could use to focus in on generalities with the social workers.

Data was gathered in the following areas (see Appendix C for survey instrument):

- worker demographics
- case management process
  a) client involvement
  b) handling unmet needs
  c) case planning procedure
  d) provider relations
  e) transferring cases
- worker attitudes toward developmentally disabled clients
- worker training needs
- caseload
- worker opinions on systemic improvements.

Interviews were conducted in each DHS district by the project staff during August, September and October, 1985. All interviews took place in the social worker's offices, except for a small portion of the sample, which was interviewed via mail and telephone due to scheduling conflicts. All social workers interviewed were guaranteed confidentiality.

DHS District Administrator Survey

The Department of Human Services' eight district administrators are responsible for the provision of all Social Services Block Grant (SSBG) services at the local level, including case management. From this perspective, the Task Force felt that this group of people could provide valuable insights into the workings of the case management process as currently practiced by the Department, and could serve as informed critics of the Service Coordination Model.

Respondent selection. Since clients and social workers were to be interviewed in all eight districts, it was decided to approach all eight district administrators for interviews, rather than select a sample.

Data collection. The interview schedule consisted of ten open-ended questions focusing on the respondents' perceptions of DHS's capability to provide case management services to persons with developmental disabilities, and their opinions on the viability, feasibility and desirability of the Service Coordination Model. (See Appendix E for survey instrument.) The interviews took place at the district administrators' offices during August and September, 1985.

Advocacy/Provider Group Survey

Advocacy groups which have been organized to represent Iowa's citizens with developmental disabilities were chosen to provide the consumer's point of view, yet with a comprehensive perspective. Provider agencies are an integral part of case management--as providers of services, they furnish the "raw materials" of the system. Advocacy and provider groups were included in the same survey, since similar data was requested from each. Furthermore, the distinction between advocates and providers is often blurred, as most providers consider themselves client advocates, and some advocacy groups also provide direct services.

Respondent selection. The task force was provided with a list of several of Iowa's advocacy groups and providers by the Governor's Planning Council for Developmental Disabilities' staff. From the list, the task force identified 33 groups they wished to survey.

Data collection. Data was collected by mail. Each subject received a packet containing a letter explaining the survey and this study (see Appendix G), a questionnaire to be filled out by the respondent (see

Appendix F), the DHS definition of case management, the federal definition of developmental disability (see Appendix I), a one-page summary of the Service Coordination Model (see Appendix J) and a stamped return envelope. Due to the variation in size among the groups surveyed, the task force instructed the project staff to send one to five packets to each group, depending on its size. Each group was requested to distribute the packet(s) to any member(s) they chose as representative of the group's viewpoint.

The data requested focused on demographics, the groups' evaluation of DHS case management services, and the respondent's perceptions of the viability and desirability of the Service Coordination Model. The questionnaires were mailed to the subjects on July 29, 1985. Follow-up post cards were mailed August 13 and August 30 as reminders to those who had not yet responded to the survey (see Appendix H).

Data Analysis

Due to the relatively small number of persons surveyed, the project staff was able to use a large number of open-ended questions in the survey instruments. However, as typical with the open-ended format, a large amount of non-categorical data was generated which was not amenable to computer analysis.

To organize and synthesize this accumulated data, the project staff constructed a matrix (see Appendix K). The matrix facilitated the gathering of the data from each of the five survey instruments, and the arrangement of it in a meaningful way. Each response was analyzed by the members of the project staff as a group, and assigned by consensus to the salient probe question(s). After the data was grouped by probe question, the

project staff analyzed each grouping for emergent issues. Each of these issues is presented in the Findings section of this report.

DHS Key Administrative Staff Interviews

Upon completion of the policy review, the consumer, social worker, district administrator and advocacy/provider group surveys, and the data analysis phases of the study, interviews with key DHS administrative staff of the agency's Central Office were conducted. The project staff and the task force chairwoman selected top administrators who oversee the provision of case management to DHS clients who have developmental disabilities as the survey's respondents.

The purpose of these interviews was to present the preliminary findings of the earlier surveys to these administrators, and solicit their reactions. The respondents were also asked to comment on future developments in case management and offered the opportunity to react to the Service Coordination Model.

The project staff and the task force chairwoman interviewed three individuals. The respondents were the DHS assistant commissioners who direct the divisions identified in the policy review as having direct oversight in the administration and provision of case management services to clients with developmental disabilities: the Division of Mental Health, Mental Retardation and Developmental Disabilities; the Division of Community Services; and the Division of Social Services. The interviews were conducted at DHS Central Office in late fall, 1985.

Respondent Profiles

Consumer survey. Data was gathered on the Social Services Block Grant (SSBG) services which are provided or monitored for each client in the sample (N=79). A total of 163 services were listed for the group. The

most frequently provided or monitored services were client assessment/case management (82.3% of cases), work activity (34.2% of cases) and sheltered workshop (15.2% of cases). The following table elaborates.

Services	No. of Cases	% of Cases
Adoption Services	1	*
Adult Residential Care	7	8.8
Family Life Home	1	*
Child Protection	1	*
Licensed Center - Daycare - Child - Half-day	1	*
Adult Daycare	1	*
Employment/Education	1	*
Foster Family Home	1	*
Foster Group Care	10	12.6
Adult Residential Treatment	8	10.1
Court-ordered Client Oversight	4	5.0
Health Related Service	8	10.1
Home Management Services	4	5.0
Mental Health Service	6	7.6
Work Activity	27	34.2
Sheltered Workshop	12	15.2
Transportation	4	5.0
Client Assessment/Case Management	65	82.3
In-home Health Care	1	*
TOTAL	163	

* less than 1%

SERVICES PROVIDED/MONITORED BY DHS
FOR CONSUMER SURVEY SAMPLE CLIENTS

According to federal mandate, SSBG services must be directed toward one of five SSBG national goals in the client case planning process. The following table lists the goals assigned to the consumer survey sample.

Additional descriptive data was obtained from the sub-sample of the 14 clients who participated in the client interview phase of the survey. The table on the page 28 describes these individuals' age and sex, and designates the actual interviewee (as stated above, some clients' functioning level did not permit a valid interview, so a parent or guardian was substituted). The SSBG goals are listed (see previous table for explanation of coding numbers), as well as the SSBG services.

Goals	No. of Cases	% of Cases
#1 Achieving or maintaining economic self-support to prevent, reduce or eliminate dependency	1	1.3
#2 Achieving or maintaining self-sufficiency, including reduction or prevention of dependency	25	31.6
#3 (1) Preventing or remedying neglect, abuse or exploitation of children and adults unable to protect their own interests; (2) preserving, reuniting or rehabilitating families	3	3.8
#4 Preventing or reducing inappropriate institutional care by providing for community-based care, home based care, or other forms of less intensive care	28	35.4
#5 Securing referral or admission for institutional care when other forms of care are not appropriate, or providing services to individuals in institutions	22	27.8
TOTALS	79	100.0%

SSBG GOALS ASSIGNED TO
CONSUMER SURVEY SAMPLE CLIENTS

DHS Social Worker Survey. The social workers (N=16) had caseload sizes ranging from 30 to 159 cases, with an average of 74 cases.

Perhaps a truer reflection of social worker work assignments is "case weighting." Case weighting is a system used by DHS to assign values to individual cases reflective of the case's degree of difficulty and level of effort required of the worker to service the case adequately. The sum of the case weights of each social worker's assigned cases is a standard with which caseloads can be compared. DHS's current ideal case weight is 130 per social worker. Among the social workers in the sample, the average case weight was 149.6, with a range of 92.8 to 238.8.

Regarding educational levels, 2 of the 16 social workers had master's degrees, 13 had bachelor's degrees, and one had neither. Nine of the 15 graduates took their degree in social work, while the remaining 6 had degrees in other fields.

Client	Age	Sex	Interviewee	Goal	Services Provided/ Monitored by DHS
A	34	Male	Client	2	Work Activity Case Management
B (1)	—	--	--	—	—
C	30	Male	(2)	4	Adult Residential Treatment Case Management
D	30	Female	Parent	5	Health Related Service
E	33	Male	Client	5	Adult Residential Care Mental Health Ser. Sheltered Workshop Case Management
F	30	Female	Sister	5	Adult Residential Treatment Case Management
G	42	Female	Client	2	Mental Health Ser. Home Management Service
H	24	Male	Client	2	Sheltered Workshop Case Management
I	8	Female	Guardian	3	Court Ordered Client Oversight
J	65	Female	(2)	4	Work Activity Case Management
K	35	Female	Client	5	Adult Residential Treatment
L	70	Male	Client	4	Work Activity Transportation Case Management
M	30	Female	Parent	5	Health Related Service Case Management
N	36	Male	Client	4	Work Activity Case Management
O	43	Female	Client	4	Work Activity Home Management Services Case Management
P (3)	—	—	—	—	—

DEMOGRAPHIC CHARACTERISTICS OF
CLIENT INTERVIEW SAMPLE CLIENTS
(N=16)

NOTES: (1) It was determined during the interview that this client does not meet the federal definition of developmental disability. The case was therefore eliminated from the sample.

(2) Client was unable to participate in interview, due to functioning level, and had no guardian or other advocate to speak for him/her. A partial interview was completed with residential facility staff.

(3) Client moved from state prior to interview.

Regarding work experience, the average social worker in the sample had 9.3 years as a social worker, with a range of 1.5 years to 20 years. The social workers had an average of 6.2 years experience in working with clients with developmental disabilities, with a range of 1.5 years to 18 years.

The majority of the social workers had mixed (generic) caseloads, with only one having 100% clients with developmental disabilities, and another with all but one client with a developmental disability.

The following table provides elaboration of this data.

Social Worker	Case-load Size	Case Weight	Educ.	# Yrs. Soc. Wk. Exper.	# Yrs. Dev. Dis. Exper.	% Dev. Dis. Clients	Other Types of Cases Assigned
1	65	101.4	MSW	20.0	10.0	50	generic
2	91	152.6	BSW	7.0	6.0	100	none
3	55	125.7	BSW	5.5	5.5	20	foster care, fost. hm. licensure, child prot. trtmt.
4	75	188.3	high schl.	4.0	4.0	75	generic
5	60	92.8	BSW	7.0	3.0	75	daycare, child protective
6	97	173.2	BSW	6.0	4.0	50	adult services
7	81	177.6	BSW	6.5	2.5	60	adult services
8	159	283.8	BA	10.5	2.0	85	adult protective, mental hlth., brain-injured
9	30	142.0	BSW	4.0	1.0	2	child protective
10	70	151.2	BA	13.0	3.5	2	generic
11	71	147.2	BA	6.0	6.0	10	mental health
12	67	140.3	MSW	15.0	9.0	56	generic (except foster care)
13	95	116.1	BS	18.0	18.0	94	adult services
14	60	165.2	MA	10.0	8.0	70	adult prot., child prot. trtmt., foster care
15	59	123.9	BSW	1.5	1.5	99	adult services
16	50	112.6	BA	15.0	15.0	10	foster care, in-home health
averages	74	149.6		9.3	6.2	53.6	

SELECTED CHARACTERISTICS OF
DHS SOCIAL WORKER SURVEY SAMPLE

DHS District Administrator Survey. Of the eight DHS district administrators, five participated directly in the interviews, while the remaining three appointed other district staff members to represent them for the interviews.

Advocacy/Provider Group Survey. Sixteen of the 33 groups surveyed responded by returning at least one questionnaire, for a return rate of 48.5%. A total of 28 questionnaires was returned (as described above, the larger groups were given proportionally more questionnaires). The sixteen groups responding claimed to represent 9,295 members.

The groups described themselves as concerned with the following disabilities (some gave multiple responses):

- all disabilities (3 groups)
- all developmental disabilities (2 groups)
- mental retardation (3 groups)
- physical disabilities (2 groups)
- hearing impairments (1 group)
- autism (1 group)
- muscular disabilities (1 group)
- geriatric-related disabilities (1 group)
- learning disabilities (2 groups)
- epilepsy (1 group)
- mental illness (2 groups)
- brain injuries (1 group)

Eight of the sixteen respondent groups (50%) described themselves as "providers of direct services to persons with developmental disabilities."

IV. FINDINGS AND DISCUSSION

The findings of this study are presented below, grouped according to major issue areas. These groupings are structured to facilitate the making of recommendations by the task force. Several of these findings cut across issue areas; efforts have been made to cross-reference where appropriate.

Issue: System Responsiveness

To the needs of clients with developmental disabilities. The majority of DHS clients with developmental disabilities are assigned to "generic" rather than specialized caseloads. Most DHS workers reported that they are sometimes forced to put their developmentally disabled clients' needs on the "back burner" due to more pressing needs of other cases, e.g., court-ordered child protective services. Workers complained of caseload sizes in excess of what they felt was reasonable for them to adequately meet the needs of all of their clients, including clients with developmental disabilities. See Staffing, below, for further elaboration of this issue.

The consumers interviewed were asked how often they felt that the services they received through the efforts of their DHS social worker helped them reach their goals. Their responses: Never - 1; Sometimes - 4; Usually - 2; Always - 0.

One factor which has an impact on the effectiveness of case management services is the availability of resources such as programs, agencies, facilities, funding, etc. The respondents to the district administrator and the advocacy/provider group surveys described resource availability as one of the more common barriers faced by the DHS case management system.

To ineligible clients. The majority of workers interviewed said they encounter few ineligible applicants who are developmentally disabled; i.e., few are "slipping through the cracks." The workers routinely referred those ineligible for DHS services to their County Board of Supervisors, who were usually able to meet the immediate need to some degree.

To unmet needs. Currently, identified client service needs which are unable to be met due to unavailability or other reasons are not dealt with in a consistent manner throughout the state. Some social workers said they report these needs to their supervisors, while others lobby directly with their county board. In one district, a county agency conducts a bi-annual needs assessment among the social workers, while policy in another district requires the social worker to document the unmet need in the casefile.

The concept of tying service delivery system planning to the case management system was discussed with the survey respondents. Through the proposed system, each unmet need identified by the case manager is entered into the client data tracking system, which allows these needs to be aggregated for planning purposes. All but one of the social workers surveyed gave favorable responses to the idea. Some comments: "It would give more direction to planners," "I would welcome the opportunity to deal more directly with those who plan," "I wouldn't mind the extra paper work--it would be worth it to get better input."

All of the district administrator survey respondents like the idea: "Our system is currently unstructured and informal--I like this better," "It would improve the case management system and the quality of services," "If we do it, I'd like to see the data made available to local groups, not just state-level."

The majority of advocacy groups and providers surveyed were in favor of the concept, but a minority felt otherwise. Some favorable comments:

"Services could be developed to meet client needs rather than making clients 'fit' existing services," "The more information, the better for everyone involved in developing or even eliminating services," "Availability varies by counties and special efforts are needed to make the programs more equal throughout the state." A provider wrote: "This would be a tremendous benefit to see changes, gaps, etc., and respond accordingly. Currently, it costs us time and money to gather such information."

Among the negative responses, one respondent wrote that the current DHS data base system is "unsophisticated and unreliable. . .If data was timely, relevant and accurate, it would be a good idea, but DHS's track record indicates it wouldn't be." Another wrote: "If funding is not provided after all the facts are documented, then it is useless to spend badly needed (staff) time on extra documentation."

To out-of-county placements. There are two types of out-of-county placements which pose particular dilemmas to the social workers assigned. The first type is that of DHS clients who reside in facilities outside the state. DHS has a policy of not allowing social worker visits to out-of-state placements, while still requiring the worker to provide case management. One of the cases in the client survey sample involved a profoundly retarded adult who currently resides at a private residential facility in another state. A DHS social worker is assigned to her case in the county of the client's legal residence. Case management consists of monitoring the placement by receiving reports from the facility, assuring that the facility's bill is paid by DHS, and visiting the client each Christmas when she is at her parents' home. The worker has never been to the facility.

A similar situation reported by several social workers is the requirement that DHS workers in county offices are assigned to the cases of clients from their counties who are now residents of the State Hospital-Schools at Woodward and Glenwood. Workers complained that they were only peripherally involved in case planning because the institutional staff took the lead. The demands of their caseloads and limited departmental travel budgets did not permit visits to these clients more than once or twice a year. One district assigns all such cases to the local workers but has one district office social worker make all institutional visits. The county worker complained that it was difficult to monitor her institutional cases with this arrangement. Several workers questioned why these cases were assigned to the county offices, given the minimal nature of their involvement.

Guardianship. Guardianship emerged as a case management issue during the course of conducting the client interview phase of the consumer survey. In identifying the interviewees for those clients in the sample who were unable to respond to the survey questions, the project staff identified two adults, both profoundly mentally retarded, as having no legal guardians.

While these individuals represent two of the sixteen clients in the sample, it is unknown how many DHS clients are without guardians. There is no departmental policy regarding the management of such cases. One of the DHS officials interviewed believed that some DHS social workers work toward getting guardians for their clients, but the practice is not uniform. A further barrier involves funding to pay the legal fees for having a guardian appointed.

Effective case management requires a level of consumer awareness and involvement in the process. Clients of low functioning levels who have no guardian or other advocate are more vulnerable to inappropriate case

management. This dilemma poses a particular challenge to the case management system.

Local efforts to improve case management services. In spite of the current dearth of resources available to DHS, there are local efforts of note currently underway in three of the eight DHS district offices. In one district, social workers are instructed to conduct their case planning in a way similar to the case planning process defined by the Service Coordination Model. This procedure involves the conscious identification of client needs in an individualized manner, without regard to existing services. While the needs must be met with the existing services, the services needed but unavailable are documented in a systematic manner for planning purposes.

Another district has enacted a policy requiring the staffing of all adult clients who are being placed in residential facilities and day programs. A multi-disciplinary approach is taken to assess client needs. These staffings are convened at three locations in the district, and include the client, local DHS representatives, and community-based client representatives.

In a third district, staff members have taken an initiative improve communication between DHS field staff and the staff of the State Hospital-Schools (SHS). The district staff have convened a "panel of experts" consisting of DHS field staff, SHS staff and other professionals from the community to facilitate the movement of more SHS residents to community placements.

Feasibility of the Service Coordination Model. The Service Coordination Model was presented in summary form to the district administrators and the advocacy/provider group survey respondents for their review. The feeling was virtually unanimous that the model was an

improvement over the status quo. Particular aspects which the respondents praised were:

- it is a more structured, systematized, comprehensive approach with clearer delineation of roles and responsibilities;
- it is more clearly client-oriented;
- service planning is linked directly to the case management process.

However, few of the DHS district administrator respondents thought that the model could be implemented in Iowa, mainly because of the current lack of available funding. Specific changes they see as needed to implement the model are:

- a "working" client data tracking (SRS) system
- a return to specialized caseloads
- more flexibility in the format of the DHS Service Plan document
- clarification of the case management function in the Employee's Manual
- the sanction of the community
- re-training of the social workers involved
- more congruity among DHS Divisions (Community Services, Social Services and MH/MR/DD) with consensus on and coordination of policy
- a "matrix" relationship between District Administrators and State Hospital School superintendents: the superintendents need to take a lead role in the development of community services
- a common agreement among the professionals involved regarding terminology
- greater expertise in developmental disabilities among DHS social workers.

Transferred cases. Workers in all districts reported receiving very few cases involving clients with developmental disabilities transferred

from other counties. With minor exceptions, the few they did receive presented no problems in their provision of case management services. Cases transferred within counties also presented no problems.

Issue: Staffing

Caseloads. While there is no single, commonly-agreed upon ideal caseload size for case managers serving clients with developmental disabilities, participants at a national case management conference identified 60 cases as a maximum. [29] The caseloads of the DHS social workers interviewed were somewhat higher than this, with an average caseload of 74, and a range of 30 to 159 cases. However, the vast majority of the sample respondents had "generic" caseloads, which included cases other than developmental disabilities: the average caseload consisted of 53.6% developmental disabilities cases.

DHS uses a "case weighting" system to monitor and assign cases in an efficient manner. The case weight is an index which represents the total relative workload for a particular social worker. The current ideal standard case weight for DHS social workers is 130. [30] The average case weight of the social worker sample is considerably higher: 149.6, with a range of 92.8 to 283.8.

The issue of generic vs. specialized caseloads was of concern to the majority of the social worker respondents. Many felt that they were not able to give their clients with developmental disabilities the attention they'd like because of the demands of their other cases (see System Responsiveness, above). Among the sample, one respondent had a specialized (100% of cases) developmental disabilities caseload; four had a specialized adult services (including adults with developmental disabilities) caseload; one had a specialized mental health caseload; one had a specialized child

protective caseload; and eleven had generic caseloads, providing a variety of services to most or all of DHS's client populations.

Training. One district administrator emphasized that a lack of training in developmental disabilities was a significant problem among the generic caseworkers. This concern was echoed by some of the respondents of the advocacy/provider group survey, one of whom stated that DHS social workers' lack of training renders them incapable of doing an adequate job of client needs assessment and individual plan development.

The social workers surveyed were given a list of 19 training competency areas and asked to identify and prioritize those in which they felt a need for more training. Following are the competencies, ranked by strength of response:

Rank	Competency	Score*
1	How to identify client's personal goals, preferences, strengths and needs.	34
2	Methods for creative problem solving and for helping others to think innovatively.	29
3	Legal rights of clients and steps necessary to protect those rights.	27
4	How to assist clients in becoming their own service coordinators.	24
(5)**	How to monitor quality of service to individual clients.	19
(5)	General information on developmental disabilities.	19
7	Methods for negotiating with clients and service providers when client disagrees with individual plan.	16
(8)	How to participate effectively in the individual planning process.	11
(8)	Methods for procuring accurate information related to service options to meet individual client needs.	11

*See Appendix D for scoring methodology.
**Parentheses indicate ties.

(8)	Methods to assist and refer clients in crises or emergency situations.	11
11	Methods to facilitate the team consensus process.	10
12	The values and attitudes required to actualize the case management system's service mission, its goal of client self-determination, and its advocacy for quality services.	7
(13)	How to relate to and work with participating agencies.	4
(13)	How to function as a broker of service.	4
15	How to procure and analyze intake data to determine client eligibility for service coordination.	3
(16)	How to identify all pertinent information related to the client.	2
(16)	How to analyze initial client information and develop a formal agreement with the client.	2
18	How to interpret the jargon of various disciplines.	1
19	How to participate in periodic client reviews.	0

Attitudes. In spite of the high caseloads carried by most of the social workers interviewed, the attitudes of this group toward their clients with developmental disabilities were extremely positive. When asked what the ideal make-up of their caseload would be, 7 of the 16 respondents chose a caseload of 100% developmental disability clients; 8 of the 16 chose some, but not all clients with developmental disabilities; and 1 of the 16 preferred no clients with developmental disabilities (this particular worker is a child protective specialist and prefers not to have this type of client because he knows little about their specialized needs).

The social workers were also polled on their attitudes toward the degree of control the client may exert in the case management process. The Service Coordination Model specifies that the client should be in complete control of the case plan development process, but all but one respondent felt this was unrealistic. The vast majority of the respondents believed

that, while the interests of the client should always be incorporated into the planning process, reality dicates that many persons with developmental disabilities and their parents or guardians do not know what is "best" for themselves, and that the professionals on the team should maintain some veto power.

The social workers were polled on their perceptions of their current responsibilities as a case manager and what they feel should be their responsibility to make their efforts more effective. Following are the results:

1) Ensuring that the service plan review meeting is held: 8 of 16 workers feel it is their responsibility; 11 of 16 believe it should be.

2) Ensuring that the resulting plan update is developed jointly by those invited: 14 of 16 believe it is their responsibility; 15 of 16 believe it should be.

3) Ensuring that the client's views are heard and integrated into the plan: 16 of 16 believe it is their responsibility; 15 of 16 believe it should be.

4) Advocating for the client when he/she disagrees with the rest of the team: 15 of 16 believe it is their responsibility; 15 of 16 believe it should be.

5) Writing the plan document and distributing it to client and team members: 13 of 16 believe it is their responsibility; 13 of 16 believe it should be.

Issue: Role Definition

The issue of role definition was examined from several perspectives. The roles of the actors in the case management process--the client, the social worker and the provider--were identified through the policy review and the survey phases of the study, then analyzed through the perspective of the Service Coordination Model.

The role of the client. The Service Coordination Model was designed to be "client centered." The advocacy/provider group sample was asked to comment on their perception of DHS in this regard. In answer to the question, "Would you describe the case management services provided to developmentally disabled persons by DHS as focusing on those persons' overall needs?," 6 of the 16 respondents answered unequivocally yes. One respondent stated that clients' needs are met "because DHS's system insures it." Six others cited inequities in the system, including inconsistent service varying by region and by individual social worker. Other inequities cited were that "easy" clients get the service they need, but clients with specialized needs do not. One respondent said that these clients often must rely on the advocacy of service providers to get what they need from DHS. Another said that the current system is "too splintered" and called for "greater coordination of efforts among the state's agencies so that one agency cannot pass the luck."

Four of the sixteen respondents to this question answered "no." Two of these said DHS does not really provide case management at all. "It's just a paper function," wrote one. Another stated that DHS focused on available services, not individual client needs.

The district administrators were also asked to respond to this issue. Three of the eight described DHS service delivery as "client centered." Said one, "The client and his family is in control of the system, not DHS, not the providers." Another said that the social workers are willing and able to "bend" the system to get what the client needs. Some of those dissenting said that the system was designed for the client, but the realities of limited DHS resources have compromised it. Some of their comments: "We just can't do community development (for new services) anymore."; "We don't have the expertise in developmental disabilities that

we should."; "If we had more funding, we'd have a range of services to fit all client needs, but, in reality, the client gets what's available regardless of need."; "Our system is provider-driver, not client-centered; we use existing services, not fund new ones."

Training for the client (or parent/guardian) to be their own case manager is currently available in a few areas of the nation. The DAs and advocacy/provider groups were polled on this idea as a potential improvement in Iowa's system. The majority of DAs had favorable comments: "It would certainly strengthen client advocacy;" "I'd be willing to try it in this district;" "It might permit (DHS) to cut some clients from our caseloads." The dissenting DAs stated, "We need checks and balances--if DHS is responsible for oversight of these cases, we should provide the service. Our workers have the experience parents lack and can't easily get;" and "Our social workers are already functioning as effective advocates for their clients."

The majority of the advocacy/provider group respondents were favorable to this idea also. Some comments: "Very feasible, provided back-up and support is available to the client;" "It sounds cost-effective." A representative of a learning disabilities advocacy group and a representative from an autism group both thought the idea had particular merit for their constituencies. One of the negative responses was, "It's not feasible for parents to be effective advocates."

The role of the provider agencies. As noted above, some district administrators and advocacy groups are concerned about the role providers play in some areas of the state. One DA stated, "Right now the tail wags the dog. We (DHS) need to control the case management process, not the providers." Another respondent said, "Since we can no longer do community

resource development, we have to wait for the providers to develop new services on their own." An advocacy group member said, "DHS has built its system around existing services, not developing new ones to meet client needs."

While policy dictates that the DHS service plan is developed before the provider plan is written, a few instances of DHS service plan development based on the provider plan came to light. Some workers admitted they followed this practice because demands of their caseload did not always permit them to do a proper plan update.

Although, "on paper", DHS has oversight responsibility for every case, many of the functions of the case manager specified by the Service Coordination Model are actually carried out by the staff of one or more of the client's provider agencies. In several of the cases reviewed, the clients identified provider staff as their primary service contacts and relied on them, sometimes to the total exclusion of the DHS worker, for advocacy, problem-solving, brokering and case coordination. A few of the DHS workers in the sample had very low visibility. Their clients were unable to describe what the social worker's function was and, in one case, didn't acknowledge knowing who their worker was.

The role of the DHS social worker. Many of the clients interviewed had very limited purviews of what their DHS social workers were supposed to do for them in terms of case management. These clients described their workers' roles in such terms as, "He's going to find me a job," or "She makes sure the bills get paid (to the facility)." When asked whom they'd call if they had a problem or if they needed additional services, these respondents most frequently answered that they'd notify a staff person at one of the provider agencies from which they receive services.

Generally, the social workers themselves wanted to exert more control over the case management process, but often complained of high caseloads and demands from other types of cases as preventing them from taking a more active role. One worker observed, "We've been given the responsibility but not the authority to accomplish what we're mandated to do as case managers."

Most social workers were satisfied with their roles in the individual case planning process. However, one type of case, residents of the State Hospital-Schools at Woodward and Glenwood, caused concern for some respondents. They complained that their input into the planning process is often negligible, since they are not able to have frequent contacts with these clients, and the institutional staff sometimes formulates plans in the social workers' absence, before the formal meetings are held.

Some of the survey respondents felt that the case management process, as spelled out in the DHS Employee's Manual, is vague. They suggested the need for a clearer definition of the social worker's role. Several of the district administrators commented that the the Service Coordination Model (p. 8, above) provides was a clearer format in delineating this role.

Issue: Client Satisfaction

The majority of clients interviewed were generally satisfied with their DHS case management services. Seven of the eleven clients who responded to the question, "Are you satisfied with the way your DHS worker helps you?," answered yes, with four answering no. However, as noted in a previous section, most clients had low expectations of the system and made few demands on it. A few clients relied exclusively on the staff of provider agencies for their case management, acknowledging little or no contact with the DHS social worker assigned to their case.

In the consumer survey, respondents were asked to rate case management quality according to the following dimensions:*

- Accessibility
- Timeliness
- Coordination
- Advocacy
- Service Planning Process

1) Accessibility: Can the client access case management services with minimal inconvenience to him/herself? Seven of the ten respondents to this question were satisfied, with three not satisfied. An example of a non-satisfied client was an institutionalized woman who said she sees her DHS worker only at staffings and then doesn't speak with her. She did admit she never initiated telephone calls to her worker when she had a concern.

2) Timeliness: Can the client get a new service promptly when he/she feels it is needed? Only five clients felt qualified to answer this question: three responded positively, two negatively.

3) Coordination: Does the client who needs many services at the same time receive them in a coordinated manner? Again, only five clients' circumstances were addressed by this question. Two responded positively, three negatively.

4) Advocacy: Does the case management system advocate for the client? Clients were asked if they felt their DHS worker was "on their side." Four clients responded: two, yes; two, no. Clients were also asked if they felt their DHS worker helps them solve their problems. Of nine responses, five were positive, four negative.

*Two of the clients in the sample were unable to respond to these questions, since they were non-verbal and had no parent or guardian to speak for them.

5) The Service Planning Process: Is the client satisfied with the way in which his/her individual plan is developed? The client sample was asked a series of questions on issues related to this process:

a) Client Input. Question: "When you express your ideas at the staffing, do the other people there listen to what you have to say and take it into consideration when writing up the plan?"

Response: Never - 1, Sometimes - 2, Usually - 3, Always - 2.

b) Outcome. Question: "After the staffing is over, are you satisfied with what has taken place?"

Response: Never - 0, Sometimes - 2, Usually - 6, Always - 1.

c) Timeliness. Question: "Are your service plan review meetings held as often and when they should be?"

Response: Never - 2, Sometimes - 2, Usually - 2, Always - 2.

d) Goal Achievement. Question: "How often are the goals in your service plan met?"

Response: Never - 0, Sometimes - 6, Usually - 3, Always - 0.

Question: "How often do the services you receive help you reach the goals in your plan?"

Response: Never - 1, Sometimes - 4, Usually - 2, Always - 0.

Issue: Agency Responsibility for Case Management

Several questions on the district administrator and advocacy/provider group survey questionnaires centered on DHS's capability as a provider of case management to persons with developmental disabilities, and explored alternative means of providing this service. The following summarizes their response to this issue.

All of the district administrators (DA) felt that DHS should continue to provide case management to clients with developmental disabilities, that

this function should not be taken over by another agency. The strength of this response varied from one person who replied, "If it ain't broke, don't fix it," denying there was any room for improvement, to several others who had specific criticisms but felt that DHS was still the most viable vehicle to serve this group. One of the assistant commissioners interviewed summed up the responses of this group: "Give us an equal amount of resources, and we (DHS) would do just as well as a new agency."

The majority of the DA respondents felt DHS was doing a good job of providing this service, in spite of the admittedly high caseloads of the DHS social workers (see Staffing, above). Several stated that DHS plays an integral role in the overall service delivery system for Iowans with developmental disabilities. One mentioned the close relationship the agency has with the county governments: "We (DHS) are in the best position to help the clients get what they need from their counties." Another cited close ties with providers: "In our district we've worked long and hard to develop a broad variety and high level of services for developmentally disabled clients." This district has two line staff assigned to develop developmental disabilities services, a feature no longer found in most other districts. One respondent believed the strongest reason to retain DHS as the provider of case management is, "We (DHS) provide the funding for it."

Most of the respondents felt that a separate agency to provide case management to Iowans with developmental disabilities was not desirable because it runs contrary to the "umbrella" concept of human services delivery, which they believe is the most efficient organizational model. As one respondent noted, a separate agency would "isolate" clients with developmental disabilities from the mainstream of service provision, resulting in diminished services. One respondent asked, "How would

multi-problem families be served?" Another believed that a new agency would simply be "another layer of bureaucracy" added to the system.

Other potential problem areas with a new agency which are foreseen by the DA respondents include a lack of legitimacy and a tendency toward "turf protection". One person commented, "It's just not politically feasible at this time to start a new state agency."

A minority of DA respondents believed that DHS's generic approach to caseload assignments (also discussed under System Responsiveness, above) has been detrimental to clients with developmental disabilities, as the over-burdened caseworkers direct most of their attention to the "crisis" cases, e.g., child protection. However, another respondent did not believe developmentally disabled clients received inequitable service from DHS, because, of all the client groups DHS serves, they are the most "protected" by their "very strong advocacy groups."

The response rate was low among the advocacy groups and providers surveyed (see Consumer Awareness, below). However, among those who responded to the question, "Should DHS continue to provide case management to Iowans with developmental disabilities?" 17 respondents answered affirmatively, 6 answered "don't know," and 1 answered "no." The negative respondent felt that DHS was "inadequately staffed, with no real leadership," and cited "inadequate training" of DHS field staff as a problem. The respondent concluded that, "DHS either needs to provide adequate field staff or get out of the business."

Among the affirmative responses, those who elaborated on their response cited the fact that DHS is already the provider as the most frequent reason for keeping case management responsibility with DHS. One respondent cited DHS's need for "more resources" so they could do a "better job" of case management. Another felt that DHS was the appropriate agency

for case management, but that their efforts should be better coordinated with the educational system.

Issue: Consumer Awareness

The consumer survey and the advocacy/provider group survey respondents appeared to have a low level of awareness of case management. As noted above, clients made few demands on the system, and a substantial number of them had very limited views of what they could expect of their case managers. This is in spite of the fact that every social worker interviewed (16) said they explain the case management process to their clients upon initiating services with the client. Their explanations include definition of the roles and responsibilities of both worker and client.

The low response rate to the advocacy/provider group survey (48.5%, despite measures taken to increase survey participation described in the Methodology section) can be interpreted as a low level of interest in, or understanding of, case management issues. Even among those who did respond to this survey, many left questions blank or answered "don't know". For example, to the question, "Do you feel that DHS's eligibility requirements for case management services currently exclude some persons with developmental disabilities who truly need this service?," 12 of the 27 respondents answered "don't know", left the question blank, or otherwise did not respond to the question. Another question asked the respondents to comment on the concept of providing training to persons with developmental disabilities, their parents or guardians, to be their own case managers. Ten of the twenty-seven respondents did not respond to this question. This level of response may suggest a lack of initiative among consumers and their representatives in shaping case management policy.

V. SUMMARY

This section summarizes the major findings of this study. Each of the five probe questions which guided the study are addressed.

Probe Question #1: To what degree are DHS's clients with developmental disabilities receiving the case management components mandated by the Iowa Administrative Code?

- Overall, DHS appears to be in compliance with the mandates of Iowa Administrative Code in the provision of case management services to Iowans with developmental disabilities.
- Many individual DHS caseworkers are going beyond what is mandated by the code in their provision of case management services.
- Three DHS Districts have initiated special projects which would appear to increase the effectiveness of case management services to clients with developmental disabilities.

Probe Question #2: Do inequities exist among the level of case management services received?

- DHS seems to be responding well to clients with developmental disabilities with less complex or limited service needs. Among clients with more complex service needs, DHS response varies widely on a case-by-case basis.
- Most DHS caseworkers interviewed stated that their current caseloads are too large for them to provide the level of service they felt their clients with developmental disabilities required.
- Several workers with generic caseloads said that they often assign lower priority to their developmentally disabled cases due to more pressing needs of their other cases (e.g., child protective).
- Apparent gaps exist in case management provision to certain types of clients. Specifically, clients who are placed out of state do not receive regular visits by their caseworkers. In at least one district, clients who move from an SSBG-funded residential placement to a Medicaid-funded placement lose their case management service provided by DHS. Conversely, several workers questioned why State Hospital-School cases must be carried by field workers, when each client is assigned a caseworker at the institution.
- There are some groups which do not meet DHS eligibility guidelines whose advocates believe DHS should be serving them, notably, persons with brain injuries.

- The availability of service resources to case managers varied widely among the eight DHS districts.

- In some districts, DHS service plans were not individualized for the clients. There were also many instances of the service plan being developed from the provider plan, rather than the service plan governing the provider plan.

- Concern was expressed in some areas of the state that case management is "provider-driven," rather than driven by the needs of the clients. DHS district offices no longer have the resources to do community development, and clients must fit into existing services.

- Some DHS clients with developmental disabilities have no legal guardian. There is no policy addressing such cases. This situation poses a particular dilemma in the provision of effective case management.

- Several caseworkers and some district administrative staff cited a lack of DHS staff's knowledge about developmental disabilities as a barrier to more effective case management.

Probe Question #3: To what extent are the components of the task force's Service Coordination Model already in place in DHS's case management system?

- The model represents a "client-centered" approach to case management--the system is designed to empower the client to play a controlling role in the case management process. While client self-determination is implied by DHS policies, the role of the client is mostly unclear.

- The model specifies the case manager as the leader of the inter-disciplinary team. DHS caseworkers are not currently designated as team leaders.

- The model employs a planning component to document unmet service needs. DHS documentation of unmet needs is not linked directly to case management, and ranges from none to inconsistent, unsystematic efforts.

- The model specifies immediate response to crisis and emergency situations. While DHS does respond to such situations, there is no specific policy governing this response.

- The model requires the service coordinator to describe the service coordination process to the client. While DHS social workers explain the case management process to their clients, in many cases these explanations are apparently not sufficient, given the number of observed misperceptions of roles.

- DHS clients have little choice of which social worker will be assigned to their case. This is partially dictated by staffing patterns, especially in rural areas. However, there appears to be little demand for this choice by the clients.

- The DHS service plan is not developed in a formalized, structured meeting, as the model requires.

Probe Question #4: To what extent do DHS clients, DHS case managers, DHS administrators and advocacy/provider groups representing Iowans with developmental disabilities view the Service Coordination Model as needed? How feasible do they perceive this model to be?

- The feeling was virtually unanimous that the Service Coordination Model was an improvement over the status quo. Particular aspects which respondents praised are: it is a more structured, systematized, comprehensive approach with clearer delineation of roles and responsibilities; it is more clearly client-oriented; and service planning is linked directly to the case management process.

- The feeling was almost as strong that this model could not be implemented in Iowa given the current level of available resources. Some respondents thought that some components could be worked into the existing system.

- DHS district administrators felt that the provision of case management to clients with developmental disabilities by an agency separate from DHS is unrealistic, citing a dearth or duplication of resources and unestablished legitimacy of a new agency as barriers.

Probe Question #5: How satisfied are DHS clients with developmental disabilities and advocacy/provider groups with the case management services currently available? If dissatisfaction exists, which changes need to be made?

- The collective response of clients could best be described as "not unfavorable." The unfavorable comments concerned direct services received or not received, not case management. However, the interviewers noted indifference and low expectation on the part of clients toward their DHS caseworkers. Client perceptions of caseworker roles varied widely, with some seeing their workers as true advocates, while others are unaware of their assigned DHS caseworkers.

- Less than half of the advocacy and provider groups contacted responded to a written survey, and among those who did, several answered "don't know" to many of the questions requesting their assessment of DHS services. This level of response may be attributed to lack of knowledge and/or interest in case management issues.
- Advocacy group respondents called for a sharpened focus of DHS case management services on the "transition" period which must link children's and adult's services.

- Advocacy groups felt that greater efforts should be made toward achieving a more equitable distribution of services throughout the state.

VI. TASK FORCE RESPONSE

DHS Case Management Services to Iowans With Developmental Disabilities: Task Force Conclusions

Based on the findings of the Iowa University Affiliated Facility study of the Department of Human Services' case management service, the Service Coordination Task Force notes that the DHS system varies from the Service Coordination Model in some significant areas. Following is a summary of the major variances of the two systems, and the changes which would need to be implemented to bring the DHS system in conformance with the Service Coordination Model.

1) Variance: Eligibility for case management from DHS is tied to the receipt of certain direct services. The Service Coordination Model dictates the provision of case management services at any or all times during the developmentally disabled individual's lifetime, regardless of whether other services are received, which other services are received, and the funding sources of any other services received.

   Remedy: DHS would need to re-define case management as a service not tied to the receipt of other direct services.

2) Variance: Most DHS case management services are provided by social workers assigned to a variety of program areas in addition to developmental disabilities, with a variety of duties in addition to case management as defined by the model. The Service Coordination Model dictates the provision of case management by individuals whose sole function is service coordination to individuals with developmental disabilities.

   Remedy: DHS would need to identify its clients with developmental disabilities as a distinct group, served by personnel whose sole function is case management.

3) Variance: The roles of the client, case manager and direct service provider in the case management process are well-defined by the Service Coordination Model. DHS policy, as documented in the Employee's Manual, is limited in its definition of roles. These limitations were evident among the UAF report's sample of DHS cases.

   Remedy: DHS policy should be clarified and strengthened regarding role definition. The role of the case manager should be communicated to the case managers through the Employee's Manual. The service provider role would be

expected to change considerably in many instances, as many are now performing some of the functions of the service coordinator. Agreements on the case manager and service coordinator's roles would need to be reached by DHS and the state's providers. The client's role is designed to be flexible according to the individual's abilities by both the Service Coordination Model and, implicitly, by DHS. By better defining the case manager and service provider roles, the client would be more able to effectively perform his/her role.

4) Variance: The Service Coordination Model contains a built-in planning component to document unmet needs. Clients whose service needs are not able to be met by the existing service array are still allowed to enter a tracking system. DHS does not have a statewide system to aggregate individual unmet service needs, and has no mechanism to track applicants whose needs cannot be immediately met because of service unavailability.

   Remedy: DHS would need to implement a statewide system to document unmet individual needs, possibly through the Services Reporting System (SRS). A tracking system, administered by DHS, would further address the planning focus of the Service Coordination Model.

Recommendations

Since November, 1983, the Service Coordination Task Force has examined ways of improving the case management services available to Iowans with developmental disabilities. Efforts have included the identification of the components necessary for effective case management for persons with developmental disabilities; development of the Guiding Principles for Service Delivery, currently used by the Governor's Planning Council for Developmental Disabilities; the study of the Iowa Department of Human Services' case management services (included in this document); and a review of state-of-the-art case management systems and models proposed or in use in other states. Based on the culmination of these efforts, the task force makes the following recommendations to the Governor's Planning Council for Developmental Disabilities.

Recommendation I

A uniform, statewide system of case management (service coordination) employing the U.S. Department of Health and Human Services, Administration on Developmental Disabilities' Service Coordination Model should be made accessible to all Iowans with developmental disabilities.

Explanation: The statewide system would be administered by a single agency or a group of agencies. Options include existing agencies or newly-created agencies; state or local agencies; profit or not-for-profit agencies; public or private agencies. The system would be bound together by adherence to a uniform set of service standards, policies and procedures, regardless of the number and characteristics of the administering agency(ies).

Rationale: Several significant improvements would result from the adoption of this recommendation. They are:

Client-centered approach. The recommended approach promotes less client dependency on the system, while providing a life-long link with it, if desired by the client. The receipt of case management services would not be tied to receiving certain types of direct services.

Consumer awareness. Well-defined roles, the "service packages" proposed by the Bill of Rights committee and a uniform system of provision would make service coordination more tangible to consumers, fostering their increased ability to identify their own service needs and evaluate their own service.

Accountability. The explicit definition of roles of the service coordinator, the client, and the service provider articulated by the Service Coordination Model would foster a system of checks and balances.

Adaptability. The recommended approach can work well with a wide range of funding arrangements.

Integration. The recommended system would coordinate all services provided to a client regardless of the funding stream, unlike the current fragmented system. Funding streams would thus be tied together. Uniform service standards would promote a greater equality of services among the state's counties and providers.

Cost-effectiveness. The uniform statewide system concept would eliminate duplication of efforts in case management among the counties. The re-definition of roles would relieve the responsibility for case management from those service providers who currently assume this role, further reducing duplicated efforts.

Compatibility with the Bill of Rights. Implementing the recommended changes will support the needs of the county boards of supervisors and the state legislators for an ongoing, coordinated source of reliable information on the service needs of Iowans with developmental disabilities. This information could be used to allocate funding among those areas of greatest service needs.

Recommendation II

Service coordination should be made available to all Iowans with developmental disabilities.

Explanation: Eligibility for service coordination should be tied solely to the fact of an individual having a developmental disability.

Rationale: Currently, many case management services are tied to the receipt of certain direct services: when the service ends, so does case management. A developmental disability is, by definition, a life-long condition. Therefore, the individual should be allowed to remain in the system throughout his/her lifetime, regardless of services received, age or other circumstances. Additionally, some case management services are available only to those who can pass a financial means test; however, the need for case management is independent of the individual's income status.

Recommendation III

Efforts should continue toward the identification of the most viable, effective means of implementing a statewide service coordination system.

Explanation: The Service Coordination Task Force has adopted, after extensive review, the Service Coordination Model as an ideal system to work toward. The task force has also critically examined the state's largest provider of case management services, and has reviewed many other service delivery systems. At this point, a thorough analysis of the options

available to implement Recommendations I and II is needed. Some of the issues which should be addressed by this anlaysis are:

1) Administration: What is the most viable, effective organizational structure: single agency vs. a network of agencies; public agency vs. private agency; existing agency vs. newly-created agency; an agency which provides other services vs. an agency whose sole function is service coordination.

2) Funding: What are the costs of each option? How will the chosen option be funded?

Rationale: The task force has determined through its research to date that there is much room for improvement in meeting the case management needs of Iowans with developmental disabilities. Case management continues to be a priority issue at both the federal level, as mandated by the Developmental Disabilities Act, and the state level, as promoted by the Bill of Rights.

REFERENCES

1. Iowa Department of Human Services, Division of Mental Health, Mental Retardation and Developmental Disabilities, Iowa's Comprehensive State Plan for Mental Health, Mental Retardation and Developmental Disabilties for the Period July 1, 1983 Through June 30, 1986, Iowa Department of Human Services, Des Moines: 1983.

2. Ibid., p. VI-6

3. Ibid.

4. Bacon, Bob and Alfred Healy (eds.), Iowa Directory of Services for Persons with Developmental Disabilities, 1983-84, The University of Iowa, Iowa City: 1983, pp. 337-341.

5. P.L. 95-602: The Amendment to the Developmental Disabilties Services and Facilities Reconstruction Act, sec. 601 (8) (c), 1978.

6. Minutes of meeting, Service Coordination Task Force, December 8, 1983.

7. Governor's Council on Developmental Disabilities, (leaflet), Iowa Department of Human Services, Des Moines: 1985.

8. National Conference on Social Welfare, Case Management: State of the Art, Final Report, Adminstration on Developmental Disabilities, U.S. Department of Health and Human Services, Washington: 1981, p. 4.

9. Andreasen, Lesa and Carolyn Mercer-McFadden, Specifications for a System of Individual Service Coordination for Persons with Developmental Disabilities, Rehab Group, Inc., Falls Church, VA, 1984, p.7.

10. Ibid., pp. 12-17.

11. Ibid., p. 5.

12. Iowa Department of Human Services, An Overview of Responsibilities, Programs, Funding and Initiatives, Des Moines: 1984.

13. Ibid., p. 3.

14. Iowa Department of Human Services, Division of Management and Budget and Division of Organizational Planning, DHS Projected Budget and Legislative Mandates: FY 1986, May, 1985.

15. Iowa Department of Human Services, Overview, p. 4.

16. Ibid., p. 14.

17. Ibid., p. 28.

18. Ibid.

19. Extrapolated from DHS Services Reporting System data using methodology outlined on p. 18, above.

20. Iowa Department of Human Services, Employees' Manual, Des Moines: 1982, pp. XIII-A-26 to XIII-A-27.

21. Ibid.

22. Ibid., 1984, pp. XIII-A-9 to XIII-A-11.

23. Ibid., p. XIII-A-10b.

24. Iowa Department of Human Services, Office of Personnel, Clarification Report #075-N463B, December 4, 1985.

25. Interview, State of Iowa, Merit Employment Department, November 8, 1985.

26. Iowa Department of Human Services, Division of Mental Health, Mental Retardation and Developmental Disabilities, p. VI-6.

27. State of Iowa, Code of Iowa, Des Moines: 1985.

28. Ibid., Iowa Administrative Code, Des Moines: 1985.

29. National Conference on Social Welfare, p. 11.

30. Interview with DHS official, October 25, 1985.

APPENDICES

APPENDIX A

CASE FILE ANALYSIS TOOL

I. Eligibility Determination

a) Applications/re-applications

1) present in file?

2) filled out properly?

3) timely?

Comments:

b) Notice of Decision

1) present in file?

2) filled out properly?

3) timely?

Comments:

II. Caseplan

a) present in file?

b) assessment documented?

c) are National goals addressed? _____ Yes _____ No

(1) which National goal is specified?

d) are objectives (1) specific?

(2) measurable?

(3) time frames stated?

(4) individualized for client?

e) responsibilities/action steps stated?

f) copies sent to provider agencies?

g) evidence of client involvement in planning process?

h) are services being provided consistent with SRS?

Comments:

III. Provider Service Plan (if applicable)

a) present in file?

b) consistent with service plan?

Comments:

IV. Narrative

a) clearly documents case activity?

b) evidence that caseplan is being monitored and implemented?

Comments:

V. General Comments

APPENDIX B

CONSUMER SURVEY

Worker Name: _____

Probe for definitions of:	Client Understands Yes	No
Service Worker	_____	_____
Staffing	_____	_____
Satisfaction	_____	_____

1) Why is the Department of Human Services involved in helping you? What do they do for you? (1)

2) What is (name of DHS worker) supposed to do to help you? What are you supposed to do? (1)

3) Are you satisfied with the way (name of DHS worker) helps you? (2,5)

_____ Yes

_____ No

a) If yes, why?

7) Do you help decide who will attend your service plan review meetings? (Circle one.) (3)

Never/Occasionally/Often/Always

8) When new information or appointments are needed, do you help make any of the arrangements? (3)

_____ Yes

_____ No

a) If yes, describe; if no, would you like to be involved?

_____ Yes

_____ No

9) Does (DHS worker name) prepare you for your staffings? (3)

_____ Yes

_____ No

a) If yes, how? If no, go to next question.

1) Talks about the purpose of the meeting. _____ Yes _____ No

2) Tells me what will happen at the meeting. _____ Yes _____ No

3) Tells me what I will be expected to do at the meeting. _____ Yes _____ No

b) If no, what problems are you having?

4) Could you get another service worker assigned to help you if you were not satisfied with the one you have? (3)

_____ Yes

_____ No

_____ Don't know

5) When you first applied for case management services from DHS, did you have an emergency need? (3)

_____ Yes

_____ No

_____ Don't remember

a) If yes, describe: (If no, go on to question #6.)

b) Was your emergency need met adequately by your service worker?

_____ Yes

_____ No

6) When your service worker wrote up your case plan, were you given the opportunity to present your own ideas and goals? (3)

_____ Yes

_____ No

10) At the staffing, do you feel that (name of DHS worker) is "on your side"? (3)

_____ Yes

_____ No

a) If yes, how? If no, why do you feel this way?

11) When you express your ideas at the staffing, do the other people there listen to what you have to say and take it into consideration when writing up the plan? (Circle one.) (3,5)

Never/Sometimes/Usually/Always

12) After the staffing is over, are you satisfied with what has taken place? (Circle one.) (5)

Never/Sometimes/Usually/Always

13) Are your service plan review meetings held as often and when they should be? (Circle one.) (1,5)

Never/Sometimes/Usually/Always

18) When I need new services, (name of DHS worker) sees that I get them promptly. (5)

Comments:

_____ Yes

_____ No

_____ Does not apply

19) When I need many services at the same time, (name of DHS worker) sees that I get them all at the same time. (5)

Comments:

_____ Yes

_____ No

_____ Does not apply

20) When I have any problem with the services I receive, (name of DHS worker) helps me solve the problem. (5)

Comments:

_____ Yes

_____ No

_____ Does not apply

21) Is there anything that DHS <u>does</u> <u>not</u> do for you now in meeting your service needs that you think they should be doing for you? If yes, what are those things? (4)

14) How often are the goals in your service plan met? (Circle one.) (5)

Never/Sometimes/Usually/Always

15) How often do the services you receive help you reach the goals in the plan? (Circle one.) (5)

Never/Sometimes/Usually/Always

16) Are the goals in your plan changed as needed? (1,5)

_____ Yes

_____ No

_____ Don't know

Questions 17-21 deal with your satisfaction with the case management services you are receiving from the Department of Human Services. For each statement, please say whether it applies to your situation. For each statement which does apply, please say whether you are very satisfied, satisfied, dissatisfied or very disatisfied. We're interested in any comments you may have about these statements, also.

17) I can reach (name of DHS worker) by telephone or by going to his/her office without too much inconvenience. (5)

Comments:

_____ Yes

_____ No

_____ Does not apply

APPENDIX C

DHS SERVICE WORKER INTERVIEW

1) When orienting a new D.D. client, their parent, or guardian to DHS services, do you specifically explain the case management process to them? (1,3)

____ Yes

____ No

2) What action do you take with ineligible applicants for case management services? (1)

3) Do your D.D. clients have the opportunity to request another case manager if he/she is not satisfied with the services you are providing? (2,3)

____ Yes

____ No

4) Is the current procedure for transferring cases adequate in terms of enabling you to provide effective case management services to your clients? (2)

____ Yes

____ No

a) How could the transfer process be improved? (4)

5) Do you contact your clients prior to their service plan review meeting for the purpose of discussing the upcoming meeting with them? (If yes, explain process.) (1,3)

____ Yes

____ No

6) Are you satisfied with the way service plan review meetings are currently conducted? (If yes, proceed to question #7.) (4)

____ Yes

____ No

a) If no, what are the major problems with the process?

b) How can these problems be solved?

7) Please circle the letter of the response below which most closely represents your opinion: (3)

A. The client always knows what is best for him/herself, so his/her wishes should always prevail when the service plan is written.

B. The client generally knows what is best, but he/she should have no more say than the members of his interdisciplinary team in developing the service plan.

C. The service plan should be developed solely by the members of the client's interdisciplinary team, regardless of what the client wishes.

If none of the above represent your view, write your own statement on this subject.

8) How often is consensus reached at the end of the service plan reviews you participate in? (Circle one.)

Never/Sometimes/Frequently/Always

a) How can this system be improved? (3)

9) How can DHS case management services for D.D. clients be made more client-centered? (3)

10) How important do you feel it is for the client to participate in the service plan review meeting? (Circle one.) (3)

Not important/Somewhat important/Very important

11) For each of the following statements, put a check in the first column if you feel it reflects a current responsibility of yours as a D.D. case manager. In the second column, put a check for each statement you feel should be your responsibility as a D.D. case manager (both columns may be checked for each statement, if appropriate): (1,3)

	is my responsibility	should be my responsibility
A. Ensuring that the service plan review meeting is held		
B. Ensuring that the resulting plan update is developed jointly by those invited		
C. Ensuring that the client's views are heard and integrated into the plan		
D. Advocating for the client when he/she disagrees with the rest of the team		
E. Writing the plan document and distributing it to client and team members		

12) Do you encourage the clients/parents/guardians who are able to do so to take an active role in procurring, adapting and arranging the services identified in the service plan? (3)

____ Always

____ Sometimes

____ Never

13) Explain how you monitor the progress of the service plan. (1,2,3)

a) How can this process be improved?

14) What do you do when you've identified a service need for your D.D. client, but the needed service is unavailable? (1,3)

15) Do you have any input into the planning of the D.D. service delivery system in the area you serve? If yes, please describe the nature of your input. (2,3)

____ Yes

____ No

16) One proposal to improve Iowa's D.D. case management system involves the case manager documenting each client need which is unmet due to service unavailability. This information would be transmitted periodically to policy makers, service planners and providers, advocacy groups and others with a direct influence on the service delivery system. Would such a system improve your ability to serve your clients as a case manager? Why/why not? (4)

a) In your opinion, is such an idea a realistic one? Why/why not?

17) What is your educational background?

18) How many years of direct social work experience do you have?

19) How many years of experience in working with individuals with D.D. do you have?

20) Approximately what percentage of your current caseload is D.D.?

21) Which other types of clients, if any, do you serve (e.g., child protective, adult services, WIN/IETP, etc.)?

22) If you were able to choose the makeup of your caseload, which would you choose? (Circle one.)

A. 100% developmentally disabled clients

B. Some, but not all, developmentally disabled clients

C. No developmentally disabled clients

23) Thinking of your role as case manager for D.D. clients, in which of the following topics do you feel you have a current need for more training? Circle the letter of all of the topics which apply.

____ a. The values and attitudes which are required to actualize the system's service mission, its goal of client self-determination, and its advocacy for quality services.
____ b. How to identify client's personal goals, preferences, strengths, and needs.
____ c. Methods for creative problem solving and for helping others to think innovatively.
____ d. Legal rights of clients and steps necessary to protect those rights.
____ e. How to assist clients in becoming their own service coordinators.
____ f. How to relate to and work with the various participating agencies.
____ g. How to interpret the jargon of various services.
____ h. Methods to assist and refer clients in crises or emergency situations.
____ i. How to procure and analyze intake data to determine client eligibility for service coordination.
____ j. How to identify all pertinent information related to the client.
____ k. How to analyze initial client information and develop a formal agreement with the client.
____ l. How to function as a broker of service.
____ m. Methods to facilitate the team consensus process.

____ n. How to participate effectively in the individual planning process.
____ o. Methods for procuring accurate information related to service options to meet individual client needs.
____ p. Methods for negotiating with clients and service providers when the client disagrees with individual plan components.
____ q. How to participate in periodic client reviews.
____ r. How to monitor quality of service to individual clients.
____ s. General information on developmental disabilities.

Now, go back over the list and select from the items you have circled the three areas you believe it is most important that you receive training in. Place a "1" to the left of the item which is the most important of the three, a "2" to the left of the second-most important, and a "3" to the left of the third-most important.

24) Please list any comments, suggestions, etc., not already listed above, which you may have on how to improve case management services to developmentally disabled DHS clients.

APPENDIX D: Scoring Methodology for DHS Social Worker Training Needs Survey

The method used to determine scores and assign rankings among the training competencies listed in the DHS social worker survey (Appendix C, question #23) is as follows: Values were assigned to the competencies in the following manner:

- A score of five points was assigned to each competency for every "first priority" response it received.
- A score of four points was assigned to each competency for every "second priority" response it received.
- A score of three points was assigned to each competency for every "third priority" response it received.
- A score of one point was assigned to each competency circled, but not prioritized, by the respondents.

The total scores were summed for each of the competencies, then rankings were assigned.

APPENDIX E

DHS DISTRICT ADMINISTRATOR INTERVIEW

1) To what extent is DHS able to provide adequate case management services to its developmentally disabled clients in your district? (1,2)

2) To what extent do you believe that the current system employed by DHS social workers to develop the caseplan meets the needs of developmentally disabled clients? (2)

3) In some states, developmentally disabled persons and/or their parents can receive training to become their own case managers, if they wish to do so. Please comment on this idea. (4)

7) To what extent does the current DHS provision of case management services mirror/fit this Model? (3)

8) Do you believe that this Model can improve case management services to developmentally disabled Iowans? Why?/Why not? (4)

9) How feasible do you believe it would be to implement this Model? (4)

10) Which major organizational changes, if any, would need to be made to implement this Model? (4)

4) Should DHS continue to provide case management services to persons with developmental disabilities? Why?/Why not? If no, which agency or group should be providing this service? Why? (1,4)

The following questions pertain to the Service Coordination Model developed for the U.S. Department of Health and Human Services, Administration on Developmental Disabilities. (A summary of this Model has been enclosed with this questionnaire.)

5) The Model requires each case manager to document every service need which is unmet because of unavailability. This information would be transmitted periodically to policy makers, service planners and providers, advocacy groups and others with an influence on the service delivery system. Would such a system improve the quality of services to developmentally disabled persons? Why?/Why not? (4)

6) The Model is based on the premise that case management services should be "client centered". Do you feel that DHS case management services are "client centered"? Why?/Why not? (4)

APPENDIX F

ADVOCACY GROUP/PROVIDER GROUP SURVEY

Questions 1-7 address the case management services provided by the Iowa Department of Human Services to persons with developmental disabilities. The definition of case management which DHS uses has been enclosed with this questionnaire. Please answer these questions based on this definition of case management.

1) Do you feel that the Department of Human Service's (DHS) eligibility requirements for case management services currently exclude some persons with developmental disabilities who truly need this service? If yes, please elaborate, using instances with which you are familiar. Do not identify persons by name. (5)

2) Are those whom DHS finds ineligible for case management services able to get this service from another agency? (2)

3) Is the intake process (eligibility determination and needs assessment) for DHS case management services adequate? If no, please elaborate and state how you feel this process can be improved. (5)

4) Do you feel that the current system DHS social workers use to develop the service plan meets the needs of developmentally disabled clients? If no, please elaborate and suggest how improvements can be made. (5)

5) One proposal to improve Iowa's D.D. case management system requires the helping professional to document each service need which is unfilled because of unavailability. This information would be transmitted periodically to policy makers, service planners and providers, advocacy groups and others with an influence on the service delivery system. Would such a system improve the quality of services to developmentally disabled persons? Why/why not? (4)

6) Would you describe the case management services provided to developmentally disabled persons by DHS as focusing on the disabled person's overall needs? Why/why not? (3)

7) Should DHS continue to provide case management services to Iowans with developmental disabilities? Why?/Why not? (5)

Questions 8-10 pertain to the Service Coordination Model developed for the U.S. Department of Health and Human Services, Administration on Developmental Disabilities: (A summary of this Model has been enclosed with this questionnaire.)

8) Which aspects of this Model do you consider to be improvements over the current means of providing case management services to developmentally disabled Iowans? (4)

9) Which changes, if any, would you make in this Model to improve its effectiveness in meeting the needs of developmentally disabled Iowans? (4)

10) How feasible do you believe it would be to implement this Model in Iowa? (4)

11) In some states, developmentally disabled persons and/or their parents can receive training to be their own case managers, if they wish to do so. Please comment on this idea, relative to the needs of your group. (4)

12) Some states currently operate D.D. information and referral telephone "hotlines". Disabled persons, their family members and the professionals who serve them can call from anywhere in the state and are connected to a person with access to information on the state's services and resources for developmentally disabled persons. Please comment on the desirability and feasibility of such a program for Iowa.

Please describe your organization by answering questions 13-15.

13) Does your organization provide direct client services (other than advocacy) to developmentally disabled persons?

_____ Yes

_____ No

If yes, please list them.

14) Which disabilities does your organization concern itself with?

15) How many members does your organization currently have?

16) Please list any further comments on DHS case management services to persons with developmental disabilities you may have (strengths, weaknesses, suggestions for improvement, etc.).

May we telephone you if we wish to discuss your responses with you?

_____ Yes

_____ No

Telephone number where you can be reached during daytime:

( )_____

The University of Iowa
Iowa City, Iowa 52242

APPENDIX G

Iowa University Affiliated Facility
University Hospital School

July 29, 1985

Dear Advocacy or Provider Group Representative:

The Governor's Planning Council for Developmental Disabilities is currently working toward the improvement of case management services to Iowans with developmental disabilities. As a part of that effort, the Council has commissioned the Iowa University Affiliated Facility (UAF) to study the case management services of one of the state's largest providers, the Iowa Department of Human Services (DHS). To accomplish this task, the UAF is seeking input from those who are most directly involved in DHS's case management system: DHS administrators, case workers and clients. The UAF is also interested in hearing from the groups who advocate for and/or provide services to developmentally disabled Iowans.

You can provide input for your group by completing the enclosed survey questionnaire. Before doing so, please take a few minutes to review the accompanying information, which includes the current federal definition of developmental disabilities, and DHS's definition of case management. Also enclosed is a brief description of a "service coordination" model, which the Governor's Planning Council for Developmental Disabilities service coordination task force has identified as an ideal to compare with current case management practice.

We are most interested in receiving your input. Please include comments on case management based on your knowledge and experiences as an advocate or provider to developmentally disabled Iowans. Return the questionnaire in the enclosed stamped envelope by August 12, 1985. All responses will be held in strictest confidence. If you would like a copy of the results of this survey, please indicate on the last page of your questionnaire and include your name and address. The results should be available by late autumn.

If you have any questions about this survey, please contact Mary Ellen Imlau, Chairwoman, Governor's Planning Council for Developmental Disabilities Service Coordination Task Force, 515/281-6379.

Thank you in advance for your time and effort in giving us this valuable information.

Sincerely,

Thomas Fields

Thomas Fields
Community Services Specialist

TF/cg

Enclosures

APPENDIX H

REMINDER

Approximately two weeks ago, the Service Coordination Task Force of the Governor's Planning Council for Developmental Disabilities sent you a questionnaire for a study of case management services for persons with developmental disabilities. As of the date of this mailing, we have not yet received a response from you. We would find your input most valuable, since you have been identified as a provider of services to, or as an advocate for, developmentally disabled Iowans.

If you have questions or concerns, please call our Task Force staff person, Dee Schieffelbein, at 515/281-3988. If you need another copy of the questionnaire, call Tom Fields, 319/353-5406. Thank you.

Mary Ellen Imlau, Chairwoman
Service Coordination Task Force

LAST CALL!

As of the date of this mailing, we still have not received your completed questionnaire for our study of case management services for Iowans with developmental disabilities. If it's in the mail, thank you. If not, there is still time to get your organization's input into our study and recommendations. The closing date is September 6, 1985. If you wish to have your group's concerns represented, please return your questionnaire postmarked no later than that date.

If you need another copy of the questionnaire, please call the Iowa University Affiliated Facility, 319/353-5406. Thank you.

Mary Ellen Imlau, Chairwoman
Service Coordination Task Force
Governor's Planning Council for
Developmental Disabilities

APPENDIX I

DEVELOPMENTAL DISABILITIY DEFINED

As defined by Public Law 95-602, a "developmental disability" is a "severe, chronic disability of a person which:

- is attributable to a mental or physical impairment or combination of mental and physical impairment;
- is manifested before the person attains age 22;

  and

- is likely to continue indefinitely;

  and

- results in substantial functional limitations in three or more of the following areas of major life activity:
  - self care,
  - receptive and expressive language,
  - learning,
  - mobility,
  - self direction,
  - capacity for independent living, and
  - economic sufficiency;

  and

- reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of life-long or extended duration and are individually planned and coordinated.

CASE MANAGEMENT DEFINED
(IOWA DEPARTMENT OF HUMAN SERVICES DEFINITION)

The Iowa Department of Human Services defines "client assessment/case management" as:

> The direct casework service component provided to eligible clients by Department workers.
>
> Client Assessment includes:
>
> 1. Determining eligibility
> 2. Assessing client service needs with the client
> 3. Developing the case plan with the client
> 4. Providing referral to community resource
> 5. Arranging for service provision
>
> Case Management includes:
>
> 1. General oversight and supervision of the case
> 2. Ongoing contact with the client as determined by specific program guidelines
> 3. Coordination with the provider to assure service provision in accordance with the Department case plan
> 4. Review and reassessment of the client's timely progress toward goal achievement as outlined in the Department case plan.

(DHS Employee's Manual, p. XIII-A(2)-2.)

APPENDIX J

SERVICE COORDINATION MODEL

PROCESS STEPS	MAIN ACTIVITIES
PROVIDE INFORMATION AND DETERMINE ELIGIBILITY	• Receive requests for assistance • Determine potential clients' needs for service coordination • Respond to crisis or emergency situations • Provide information to individuals who do not want service coordination • Describe the service coordination process to potential clients • Determine eligibility • Provide ineligible individuals with information on the reason(s) for their ineligibility and refer them to other appropriate services • Accept eligible persons as clients of service coordination system • Maintain records on the intake process
MATCH CLIENT AND SERVICE COORDINATOR	• Gather information needed to match the client with a service coordinator • Match the client with a service coordinator, involving the client in the selection • Develop a written agreement which governs the client-service coordinator relationship • Change the match on the request of the client or if the relationship is not working satisfactorily • Document information related to the matching process
GATHER EXISTING CLIENT INFORMATION	• Develop a profile of the client's strengths, needs, and personal goals • Procure existing assessment and service provision information, as specified in the written agreement • Review assessment and service data with the client and determine what other information is needed to fill existing gaps • Determine potential participants for the General Service Component development meeting and distribute information
PROCURE NEW ASSESSMENTS AS NEEDED	• Determine needed assessments and how they will be procured • Procure new assessments • Distribute results to appropriate people • Document unavailability of assessments
DEVELOP GENERAL SERVICE COMPONENT OF INDIVIDUAL PLAN	• Develop plans for the meeting and invite participants • Convene meeting within established time frame • Develop a total plan identifying long-range goals and service settings for the client • Assist the client to participate as fully as possible in the meeting • Identify direct service providers who will participate in developing the Individual Program Component and select a meeting chairperson or facilitator • Obtain signatures and agency commitment to provide services • Identify and document unavailable services
DEVELOP INDIVIDUAL PROGRAM COMPONENT OF INDIVIDUAL PLAN	• Gather meeting participants and convene meeting • Assist the client to participate in the meeting • Develop and document service plan which includes short-term objectives, strategies, and evaluation procedures • Negotiate and obtain agreement on the plan
MONITOR SERVICES AND REVISE PLAN	• Negotiate services as necessary • Monitor, review, and revise the individual plan • Cooperate with third-party monitors
DOCUMENT UNAVAILABLE SERVICES	• Identify unavailable and/or inaccessible assessments and services • Prepare report on unavailable/inaccessible assessments and services • Disseminate report to appropriate agencies

copy reduced 65%

THE SERVICE COORDINATION MODEL*

The Service Coordination Model has been identified by the Service Coordination Task Force of the Governor's Planning Council for Developmental Disabilities as an exemplary system of providing case management services to persons with developmental disabilities. The Task Force sees the Model as containing the basic components necessary for effective, client-centered case managment. The Model is being used by the Task Force as a standard with which to compare present case management practices employed in this state. The Model will not necessarily be implemented.

The Service Coordination Model is summarized graphically on the reverse side of this page. The Process Steps (left side of page) are the eight basic components of the system. Because the Model is designed to be sensitive to the needs of the individual client, not all clients would need to progress through all eight steps, nor would the steps necessarily be followed in each case in the sequence shown on the chart. The Main Activities (right side of page) are action-oriented statements which detail what needs to happen within each Process Step to achieve effective service coordination.

Some of the more distinctive features of the Service Coordination Model are:

- It views the client as a whole person, supporting and empowering him or her to exercise as much authority as possible in planning and shaping services for him- or herself.
- It is an ongoing process which is vigilant to the interplay of the client's choices to the providers' actions.
- It is focused primarily on the client's needs and secondarily on the service delivery system's structure: it is a personal service, not a management tool or paperwork chore.
- It features a built-in monitoring system which provides an ongoing source of client needs data to policy makers and service planners.
- It is consciously designed to make the total service delivery system more accountable to the client and more flexible to his or her needs.

*Developed by Rehab Group, Inc., Falls Church, VA, under contract with the U.S. Department of Health and Human Services, Administration on Developmental Disabilities, 1984.

APPENDIX K: Data Analysis Matrix and Explanation

	Probe Question #1	Probe Question #2	Probe Question #3	Probe Question #4	Probe Question #5
Case File Analysis Tool	1,2,3,4,5	1,2,3,4,5			
Consumer Survey Schedule	1,2,13,16	3	4,5,6,7,8,9, 10,11	21	3,11,12,13,14,15,16, 17,18,19,20
DHS Service Wrkr. Interview Schedule	1,2,5,11,13,14	3,4,13,15	1,3,5,7,8,9,10,11, 12, 13,14,15	4,6,16	
DHS District Administrator Interview Schedule	1,4	1,2	7	3,4,5,6,8,9,10	
Advocacy/Provider Group Survey Questionnaire	16	2,16	6,16	4,5,8, 9, 10, 11,16	1,3,4,7,16

Explanation: This matrix was used to synthesize the study's findings from the results of the case file analysis and client interview phases of the consumer survey, the DHS social worker survey, the DHS district administrator survey and the advocacy/provider group survey. The columns represent the five probe questions which defined the study's parameters (p. 5, above). The rows represent the survey instruments (Appendices A, B, C, E and F). The numbers in each cell refer to the questions from the survey instruments represented by the rows. Blank cells indicate that there were no questions from the survey instruments (rows) pertaining to the probe questions represented by their columns.

STATE LIBRARY OF IOWA
DES MOINES, IOWA 50319

STATE LIBRARY OF IOWA
DES MOINES, IOWA 50319