systems, instruments and programs

strategies for evaluation of developmental disabilities services

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University of North Carolina at Chapel Hill, Fall 1975.

Strategies for Evaluating Developmental Disabilities Services: Systems, Instruments, and Programs

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Introduction

During the last few years, the interest in evaluating systems which provide services to handicapped and developmentally disabled people has increased significantly. This interest is a result of growing needs for accountability data which will satisfy both governmental officials and consumers who are concerned with services and service gaps. The climate generated by these needs has sponsored a variety of systems and strategies for evaluating services and institutions including client tracking, instrumentation, and program evaluation. It is the purpose of this paper to review and classify some of the more established strategies in order to provide some understanding of the current state of the art. It is not our purpose to endorse or evaluate these strategies but merely to document and highlight them so that interested readers will be guided in their consideration of them.

To accomplish this purpose,we have chosen to present a classification system and status report of evaluation components capable of providing useful information on the developmentally disabled population. Because this paper is a follow-up to The Developmental Disabilities Formula Grant Program and Evaluation Systems by Bruninghaus and Pelosi (DD/TA, April 1975), the philosophy of that paper bears repeating. This study of evaluation components is not an exhaustive one; systems, instruments, and programs are presented because they have either demonstrated or potential usefulness for developmental disabilities planners. No particular strategy is being advocated. What is being advanced is the caution that many strategies which appear similar in design are, in fact, constructed for different

purposes. Any decision to choose any one of them should therefore include an investigation of as many of them as is possible. And at the basis of that investigation the writers believe should lie a single question: what decisions will be made with the evaluation data, whatever kind will be collected? The answer to this question can provide a rational basis for determining which strategies will provide the most reliable and valid information relevant to the decisions. Perhaps none of the systems, instruments, and programs described in this paper can meet the evaluation needs of the developmental disabilities programs. If this is the case, it is suggested that the answer to the question raised above can provide a rational basis for designing an evaluation mechanism which will meet this need.

In line with this thinking, the major characteristics of the evaluation strategies catalogued in this paper are outlined. It is important to note, however, as the status report indicates, that these strategies are generally in a state of continuous development and that new components are being developed around the country. Keeping track of the trackers is no easy task.

PART 1

Brief
Descriptions, Classification, and Status Report
of
Systems, Instruments, & Programs

Evaluation Systems

Twelve evaluation systems are briefly described below. These systems either track clients, and/or catalogue service programs and agencies. Some of the systems provide data on client progress through the service system; some provide information on the client's developmental progress and service needs. Others provide information on service programs and agencies, or they provide qualitative information on service programs and the management practices of agencies involved in human service delivery. The systems are arranged in alphabetical order by acronym. (See Part 2 for complete descriptions and contact persons)

(ALERT) Alternative Life Environments Rating and Tracking System:

ALERT is being developed to deal specifically with top management evaluation questions related to deinstitutionalization and service alternatives. It identifies various educational, occupational, and living environments and measures individual flow through the various alternatives. It contains two components: the Management Information System (MIS) and the Living Environments Classification System. (LECS).

(CAI-CIS) Client Assessment Instrument/Client Information System:

The Client Assessment Instrument is administered every year to determine client change in service needs and service utilization. This information is incorporated into the Client Information System which has been designed to focus on cost effectiveness and is primarily a client tracking/client progress system.

(CDHS) Comprehensive Developmental Health Services: A Concept and a Plan on Mental Retardation, Chapel Hill, North Carolina:

This report describes a system for providing Comprehensive Developmental Health Services (CDHS) in North Carolina. It conceptualizes a service delivery system focused on prevention, early detection of health and developmental problems, in-depth evaluation and planning for children with special needs, and access to an array of health intervention alternatives.

(CERIS) Client Eligibility and Resource Information System:

This system was developed to assist the Massachusetts Bureau of Developmental Disabilities achieve a more adequate local service delivery system of care for current and prospective developmentally disabled citizens by developing a plan for institutional reform and a range of community based domiciliary options through the vehicle of Title XIX, ICF/MR. This system consists of: a client financial assessment form that captures all of the key financial eligibility information on a client, behavioral assessment forms (including social, psychological and medical evaluations which generate eligibility and management information and a treatment plan), an encyclopedia of the principal Federal/State authorizations relevant to the developmentally disabled, and a directory of public and private service providers.

(CPS) Client Progress System:

The purpose of this system is to assess client progress towards "normalization" in an effort to improve the effectiveness of the service programs. The client's progress is periodically reassessed on a number of developmental tasks. This intensive evaluation of client progress is then used to evaluate a program's effectiveness. The system monitors residents of institutions or participants in services (mostly children).

(IDB) Individualized Data Base Project:

The major objective of this project is to develop a model system to identify retarded individuals, to collect information regarding living plans

and services being utilized, and finally, to track the individuals through a continuum of service and living plans in order to monitor and evaluate developmental progress over time. As of August, 1975 the project involved eleven states.

(IMPACC) Information and Management Procedures for Accountability:

IMPACC is a management system used primarily to measure the "cost-effectiveness" of multiple services. Its foci are planning for multiple services impact, measuring that impact, and calculating the cost of that impact.

(MSIS) Multi-State Information System:

This system objectifies, systematizes and makes available significant information concerning the mentally retarded from their identification in the community, through inpatient course and treatment, to their reintegration back into the community.

(Ohio) Client Tracking System:*

The Client Tracking System is designed to: track client movement through all the different services, facilitate deinstitutionalization, access client progress and identify needs, facilitate the selection and evaluation of care programs, and provide a basis for an advocacy system.

(PLACE) Program Listing and Client Evaluation:

The PLACE Program is a computer-based data system in which each developmentally disabled client is assigned a unique identifying case number. Comprehensive information about each client is coded and serves as "input" to the Client Data Bank of the computer. This system provides

*proposed (See Table 2)

a systematic approach to: (1) placing developmentally disabled clients in appropriate programs, (2) periodic evaluation of client progress, (3) isolating gaps in services throughout the state, and (4) marshalling the state's staff resources to focus on specific problem areas.

(SCRIP) Statewide Computerized Referral Information Program:

The SCRIP system is basically a resource tracking program. All programs, facilities and services available for the developmentally disabled are included in a computer resource bank. Persons seeking appropriate placement for clients access the computer by requesting referral information relative to the characteristics of the client. SCRIP provides monthly print-outs of: requests for services by geographic area, number of people involved per program area, capacity of facilities vs. client's being served, as well as other reports.

(SSIS) Special Services Information System:*

This system has received attention because of its comprehensive computerization. All referral information is combined with all special services utilization for nine state health service agencies. One unique characteristic is the collection of data on early identification systems and institutional status, so population movement can be monitored.

Evaluation Instruments

Five evaluation instruments are briefly described below. The PAC evaluates client developmental progress. PASS evaluates service programs and agencies. ACFMR is a set of standards for agencies and residential facilities. REAL scales evaluate client development and environment. SPEC is a program planning package which has built-in program evaluation criteria. These instruments are listed in alphabetical order by acronym. (See Part 2 for complete descriptions and contact persons)

*Formerly called Data System for the Handicapped.

(AC-FMR) Accreditation Council for Facilities for the Mentally Retarded (Agencies):

These standards were adopted as a basis for voluntary accreditation of community agencies which provide non-residential programs and services to developmentally disabled people. The standards deal with the following "essential characteristics" of each individual agency within a service delivery system: responsiveness; availability, which includes comprehensiveness, completeness, balance, and the cross disciplinary approach; accessability; individuation, which includes participation and acceptability; records; quality control; and accountability.

(AC-FMR) Accreditation Council for Facilities for the Mentally Retarded (Residential Facilities):

These standards were first adopted in 1971 as a basis for voluntary accreditation of residential programs for mentally retarded children and adults. The standards deal with the following general areas of program concern: (1) resident-living or domiciliary services that all residential facilities must themselves provide; (2) the sound organizational and administrative practices that are applicable to many types of programs, in addition to those providing residential services; and (3) the professional and special services and programs that may be required by the residents of facilities, in addition to domiciliary services--whether or not such services and programs are provided by the facility itself, and whether or not such services and programs are provided only to residents of facilities.

(PAC) Progress Assessment Chart:

PAC is an instrument designed to assess the social functioning of the mentally handicapped child or adult and to provide information relating to the individual's achievement compared to that of other children or adults with a similar mental handicap. Use of the instrument over time makes it

possible to monitor the progress an individual achieves while involved in a program of social education and to consider whether what has been learned can be applied in real-life situations.

(PASS) Wolf Wolfensberger and Linda Glenn, Program Analysis of Service Systems: A Method for the Quantitative Evaluation of Human Services, National Institute on Mental Retardation (Canada), 1973.

PASS is a device for the objective quantification of the quality of human service programs, systems, and agencies already in operation or in the planning stage. A program's total score is based on ratings in two large areas, one concerned primarily with administrative matters and the other ideological ones. Two major purposes are cited for PASS: (1) to provide a means of quantitatively evaluating the quality and adequacy of a human service program and to make it possible to compare it with other programs, and (2) to utilize the specification of the normalization principle as a teaching tool for service personnel.

(REAL) Resident-Environment Analysis by Levels Scales:

The scales are used to outline ways to measure and interpret relationships between individual behavior and environments of retarded adults and the sufficiency of administrative support mechanisms. The scales result in a numerical degree of fit between a retarded person and an environment and can measure change quantitatively in that relationship. The manner of data collection is observational. Areas evaluated are: feeding, protecting, moving, physical environment, staff qualifications, money, goods, energy, work performance, value orientation, and social boundaries.

(SDDS) Status of Developmental Disability Services:

SDDS is an instrument which has been developed to assess service needs geographically within states by regions. It can assess who gets served, who does not, and who gets duplicated services. It is concerned with collecting four types of information: demographic, disability, service and environmental. SDDS is a field instrument, and it should be used in coordination with other evaluation efforts.

(SPEC) Systematic Planning and Evaluation Criteria:

Though basically a program planning package, SPEC contains specific criteria for evaluation. It is designed specifically for DD service administrators and service providers. Its focus is comprehensive planning at all levels and across sixteen service areas. With formats and step by step procedures, it focuses on the development of a feasible plan that contains built in evaluation criteria.

Evaluation Programs

Two evaluation programs are included below. Both programs are designed to evaluate clients in order to ascertain whether early intervention is required and what the intervention should be.

(EPSDT) Early and Periodic Screening, Diagnosis and Treatment

W. K. Frankenburg, A. F. North, Jr., A Guide to Screening for the Early and Periodic Screening, Diagnosis and Treatment Program under Medicaid. This is a manual written to assist public officials, physicians, nurses and others in planning and implementing an Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program under medicaid that will effectively meet certain health care needs of children who are eligible for the program.

(RIP) Regional Intervention Program: State Department of Mental Health, Nashville, Tennessee

The Regional Intervention Program (RIP) was developed to provide training for families with children under five years of age whose behavior is so disturbing because of developmental or other disabilities that there is a serious family disruption and whose behavior makes them a high risk for eventual long-term institutionalization. The program is unique in that it is directed by, and accountable to, the families served. Families are admitted to the program at no expense and are expected to provide one parent to participate in the program six to ten hours a week for six months after work with their own child is making significant progress. Child progress is monitored by daily data collection and by an Evaluation Committee consisting of parents and consultants.

Classification

There are a number of ways to classify the evaluation strategies currently available.* The approach outlined in the Bruninghaus-Pelosi paper (April 1975) is continued in order to provide decision makers involved in the Developmental Disabilities Formula Grant Program with a ready reference to the kinds of evaluation strategies that are available and the functions they serve.

The strategies have been classified according to whether they are systems, instruments, or programs. They have also been classified according to their primary functions. Table 1 summarizes the classification of the following evaluation systems, instruments, and programs:

*See H. Baker and R. Surles, Client Tracking and Case Registry Systems: Introduction and Annotated Bibliography Working Paper 3, DD/TAS, 1974.

Systems

1)	ALERT	Alternative Life Environments Rating and Tracking System
2)	CAI-CIS	Client Assessment Instrument/Client Information System
3)	CDHS	Comprehensive Developmental Health Services
4)	CERIS	Client Eligibility and Resource Information System
5)	CPS	Client Progress System
6)	IDB	Individual Data Base Project
7)	IMPACC	Information and Management Procedures for Accountability
8)	MSIS	Multi State Information System
9)	Ohio	Ohio Client Tracking System
10)	PLACE	Program Listing and Client Evaluation
11)	SCRIP	Statewide Computerized Referral Information Program
12)	SSIS	Special Services Information System

Instruments

1)	ACFMR	Accreditation Council for Facilities for the Mentally Retarded
2)	PAC	Progress Assessment Chart
3)	PASS	Program Analysis of Service Systems
4)	REAL Scales	Resident-Environment Analysis by Levels Scales
5)	SDDS	Status of Developmental Disability Services
6)	SPEC	Systematic Planning and Evaluation Criteria

Programs

1)	EPSDT	Early Intervention Program
2)	RIP	Regional Intervention Program

Status Report

Tables 2, 3, and 4 indicate the developmental status of the systems, instruments, and programs described in this paper as of August, 1975. It is important to reiterate that these components are generally in a state of continuous development; these charts may be very quickly outdated.

TABLE 1

Classification of Evaluation Components

	Description			Primary Functions					
Name	System	Instrument	Program	Client Assessment	Client Tracking	Agency Assessment	Agency Tracking	Service Program Assessment	Service Program Tracking
ACFMR		•				•			
ALERT	•				•			•	
CAI-CIS	•	•		•	•				
CDHS	•			•	•			•	
CERIS	•			•			•		•
CPS	•			•					
EPSDT			•	•					
IDB	•			•	•			•	
IMPACC	•					•		•	
MSIS	•			•	•		•		•
Ohio	•			•	•		•	•	•
PAC		•		•					
PASS		•				•			
PLACE	•			•	•				•
REAL Scales		•		•		•			
RIP			•	•				•	
SCRIP	•						•		•
SDDS		•		•				•	
SPEC		•						•	
SSIS	•							•	•

*Proposed

TABLE 2

Present Status of Evaluation Systems*

NAME	Being Developed	Developed but not Field Tested	Field Tested but not Implemented	Implemented (state wide)	Being Revised	STATES
ALERT		•	(Aug.-Sept., 1975)			KS
CAI-CIS				•	•	FL
CDHS		•				NC
CERIS				•		MA
CPS				•	•	NB, WA
IDB				•		LA, NV, AL, AK, NM, VA, CA, AZ CO, HI, IL
IMPACC		•				KS
MSIS				•	•	NY, VT, KN
Ohio			•		•	OH
PLACE				•		CT
SCRIP				•	•	NJ
SSIS				•	•	MD

*Fall, 1975

TABLE 3

Present Status of Evaluation Instruments *

NAME	Being Developed	Developed but not Field Tested	Field Tested but not Implemented	Implemented	Being Revised	STATES/COUNTRIES
ACFMR				•		USA
PAC				•		England & USA
PASS			USA	CANADA		Canada & USA
REAL Scales			•			TN
SDDS			•			KS , NB
SPEC					•	KS

TABLE 4

Present Status of Evaluation Programs*

NAME	Being Developed	Developed but not Field Tested	Field Tested but not Implemented	Implemented	Being Revised	STATE/COUNTRIES
EPSDT				•	•	USA
RIP				•		TN

*Fall, 1975

Conclusion

The current state of the art is clearly a morass of evaluation strategies with various purposes, components, and states of development. Each serves its own purposes and provides data for decision making. Whether any produces results equal to the costs in terms of resources, is unclear from current information. There is a growing need, nevertheless, for reliable information as a basis for planning and decision making.

During the next few years, these evaluation strategies may get a serious review as a result of the Developmental Disabilities Act of 1975. This Act calls for HEW to develop a nationwide strategy for evaluating the Developmental Disabilities Program. Such a strategy will, by necessity, need to include some aspects of the evaluation strategies reviewed here: client characteristics, service characteristics, client tracking, standards, etc. Such a nation-wide strategy will most likely include flexibility for individual states to utilize the best components of these current evaluation strategies.

In any case, a review of the Developmental Disabilities Program is most needed. Are gaps being filled and are services improving? Are community alternatives being successfully developed and is deinstitutionalization working satisfactorily? And at what cost, to whom? These questions need to be answered. The strategies presented in this paper will provide a basis for thinking about cost effective ways to answer these questions.

Part 2

Complete Descriptions of Systems, Instruments, and Programs

Evaluation Systems

(ALERT) ALTERNATIVE LIFE ENVIRONMENTS RATING AND TRACKING SYSTEM

Contact: Warren D. Schoomaker
ALERT Project Director
Haworth Hall
University of Kansas, Lawrence, Kansas

ALERT is being developed to deal specifically with top management evaluation questions related to deinstitutionalization and service alternatives. It identifies various educational, occupational, and living environments and measures individual flow through the various alternatives. It contains two components: the Management Information System (MIS) and the Living Environments Classification System. (LECS).

The management information system measures the rate of movement or change across the environmental continua. Pre and post measures will provide base-line data and quantify the amount of impact. Two types of data forms are used - the data collection type done for the number of DD individuals in a certain environment and a data representation type to display the findings. This component's main focus is individual flow.

Secondly, the Living Environments Classification system is a classification system that provides criteria for planning alternatives or improving present alternatives. It is a means of classifying a program or service delivery system in terms of type and level of environment they provide.

ALERT's obvious strengths are its simplicity, ease of use, and cost. Its forms are short and concise. ALERT focuses on the life environments of DD consumers - primarily where they live, where they attend school, where they work (from the highest degree of institutionalization to the most general population norms). Criticisms of ALERT include its lack of attention to personal (physical, mental) well-being, e.g. recreation, civil rights, community awareness, etc. of DD consumers.

This system will be field-tested in August, 1975. The manual will be rewritten by October 1, 1975. Reliabilities will be checked during October, 1975.

(CAI-CIS) CLIENT ASSESSMENT INSTRUMENT/CLIENT INFORMATION SYSTEM

Contact: Kingsley Ross/James Ansley/Chris Polivka
DD Staff
Department of Health, Division of Retardation
1211 Winewood Blvd.
Tallahassee, Florida

This system has been in the developing stages for two years and is presently in operation statewide in Florida. The Client Assessment Instrument is administered every year to determine client change in service needs and service utilization. This information is incorporated into the Client Information System which has been designed to focus on cost effectiveness and is primarily a client tracking/client progress system.

This System is now in the revision stages. Two areas of revision are being concentrated on: product expectation and sensitivity to change. Some observations on this system in its present state:

- This system has the uniqueness of a staff evaluation component.
- It is not comprehensive even when utilized as a two-part scheme.
- It offers good demographic, health, developmental and vocational data organization.
- It is rather expensive to administer (about $25 per head) mostly due to the use of outside interviewers. However, Ansley doubts if staff administration will cut costs much.
- Reliability checks on 700 readministration (Summer, 1975) produced an average 7.80.

(CDHS) COMPREHENSIVE DEVELOPMENTAL HEALTH SERVICES

T. D. Scurletis, M. Headrick-Haynes, C. D. Turnbull, R. Fallon. Comprehensive Developmental Health Services: A Concept and A Plan. Read before President's Committee on Mental Retardation, Chapel Hill, North Carolina, May 6, 1974.

This report describes a system for providing Comprehensive Developmental Health Services (CDHS) in North Carolina. It conceptualizes a service delivery system focused on prevention, early detection of health and developmental problems, in-depth evaluation and planning for children with special needs, and access to an array of health intervention alternatives.

The model for CDHS includes the following components:

1. A data system--to identify children needing services, monitor provided services, and identify failures in the system. The data system directs the outreach component of the system.

2. The outreach component--includes casefinding, early and periodic screening for developmental health problems, on-going personal contact with people in the system, and follow-through.

3. The community services component--including medical services, preschool and public education programs, generic social services, and the wide range of community-based family support systems.

4. The regional service component lies beyond the community, but relates to the system in providing interdisciplinary and specialized diagnostic and treatment centers, specialized educational centers, consultative and professional education services, and other program resources.

5. The central services component includes large medical centers and training centers for professionals needed to sustain the system.

All components are linked by a data system which tracks a child and his family throughout the developmental period, summarizing his service needs, use of service and effectiveness of those services.

(CERIS) CLIENT ELIGIBILITY AND RESOURCE INFORMATION SYSTEM

Contact: Jonathan Leopold
Bureau of DD Office of Planning & Programs
Executive Office of Administration & Finance
Room 909, 100 Cambridge St.
Boston, Massachusetts

This system was developed under a grant from the Massachusetts Developmental Disabilities Council to develop the necessary client management and program administration tools to assist the Bureau of Developmental Disabilities in achieving a more adequate local service delivery system of care for current and prospective developmentally disabled citizens by developing a plan for institutional reform and a range of community based domiciliary options through the vehicle of Title XIX, ICF/MR. This system consists of the following components:

(1) a client financial assessment form that captures all of the key financial eligibility information on a client;

(2) behavioral assessment forms including social, psychological and medical evaluations which generate eligibility and management information and a treatment plan meeting the requirements of DMH periodic review, Title XIX, Ch. 766 and Social Services;

(3) an encyclopedia of the principal Federal/State authorizations relevant to the developmentally disabled;

(4) a directory of public and private service providers.

The system provides for more effective client intake and management by identifying and establishing client eligibilities for a variety of services and benefits and matching clients with appropriate service providers. CERIS also provides for more effective program administration by coordinating the intake process of different agencies and providing administrators with comprehensive data on clients' needs and eligibilities in order to plan programs around actual needs and to identify the most cost effective way to

fund those programs under current funding restrictions. CERIS information has been used to:

(1) mass process the state school population for Supplemental Security Income (SSI) and Medicaid,

(2) to document $18 million claims for reimbursements for Social Services under Titles IVA and VI of the SSA,

(3) to provide planning data for the Division of Mental Retardation, DMH for developing plans for the deinstitutionalization of the state institution population.

These two projects focused on 6,200 developmentally disabled persons currently served in the state schools for the mentally retarded. The projects have significantly improved the quality and scope of services and benefits for this population.

(CPS) CLIENT PROGRESS SYSTEM

Contact: J. Alan Hansen
Community/Regional Services Inc.
2525 Sumner
Lincoln, Nebraska

The purpose of this system is to assess client progress towards "normalization" in an effort to improve the effectiveness of the service programs. The goal is normalization of the clients, or an increase in those behaviors most needed/helpful in functioning in the community or residence. The client's progress is periodically reassessed on a number of developmental tasks. This intensive evaluation of client progress is then used to evaluate a program's effectiveness.

The system monitors residents of institutions or participants in services (largely children). The system requires extensive testing and requires funds for many qualified testers.

(IDB) INDIVIDUALIZED DATA BASE PROJECT

Contact: Alan Boroskin, Director
IDB - Pacific State Hospital
Pomona, California

The major objective of this project was to develop a model system for identifying retarded individuals, to collect information regarding living plans and services being utilized, and finally, to track the individuals through a continuum of service and living plans in order to monitor and evaluate developmental progress over time. As of August, 1975 the project involved eleven states.

The model uses a client-evaluation approach. It does not focus on identifying all clients who are developmentally disabled. Instead, it focuses on those seeking or receiving services and collects data on the basis of service-providing agencies. The project seeks to evaluate the effectiveness of the service(s) to the client. The main criterion for measuring service effectiveness is the developmental outcome of the client receiving it. A series of behavioral and developmental instruments have been prepared for use toward measuring service effectiveness.

The individualized data base system provides the capability for varied feedback to the service providing network. Examples of periodic statistical reports include: profiles of individuals receiving specified services; profiles of services provided, frequency of services, and comparative costs; cost benefit ratios for alternative paths of placement and services; correlation of changes in developmental status of clients with living arrangements and services received.

The IDB is currently shifting from experimentation to service support and evaluation of these services. Among the changes now being made are the following:

1. An emphasis will be placed on individualized progress reports which may be included in client records.

2. Standardized caseload reports will be issued regularly to managers and administrators of services.

3. Intake and individual background data will be modularized so that there is greater statistical versatility in caseload analysis.

4. A pool of new behaviors will be offered as an option to states so that outcome measurements are more appropriate to the clients being served.

(IMPACC) INFORMATION AND MANAGEMENT PROCEDURES FOR ACCOUNTABILITY

Contact: James Budde
UAF Unit
Kansas Center for MR and Human Development
University of Kansas, Lawrence, Kansas

IMPACC is a management system used primarily to measure the "cost-effectiveness" of multiple services. Its foci are planning for multiple services impact, measuring that impact, and calculating the cost of that impact.

IMPACC contains a procedures manual and a computerized data processing system. Some noteworthy advantages to its hardware are that data processing can also be done by hand and the data collection and evaluation process is not time consuming (UAF in house use required 2% of staff time). The system can be used to evaluate internally the operations of an organization like a DD Council. Its strong cost orientation and its concise, easy computer programming abilities are particularly practical.

Presently IMPACC's procedures manual is being revised. Nebraska has volunteered to pilot this system. Its lack of DD specificity is being reviewed.

(MSIS) MULTI-STATE INFORMATION SYSTEM

Contact: Claire Moonen
Liaison Representative
Rockland Research Institute
Orangeburg, New York

This system objectifies, systematizes and makes available significant information concerning the mentally retarded from their identification in the community, through inpatient course and treatment, to their reintegration back into the community. The data gathered and incorporated into the data system provides for comprehensive program evaluation studies, allows clinicians to choose the most efficient treatment modalities in relation to specific behavioral objectives, and provides administrators with information needed to make the kinds of decisions necessary for efficient allocation of resources and to establish a data base for research in mental retardation.

The mental retardation information system consists of 10 subsystems: (1) the admission/census system, (2) the clinical system, (3) the physical examination system, (4) the drug system, (5) the staffing system, (6) the service scheduling system, (7) the incident reporting system, (8) a client personal property system, (9) an inventory control system and (10) a community resource directory . Each subsystem contributes information that adds to the habilitation and management of mentally retarded citizens.

(Ohio) CLIENT TRACKING SYSTEM

Contact: Anne Paschall, Project Supervisor
Department of Mental Health and Mental Retardation
Columbus, Ohio

The Client Tracking System was designed for the mentally retarded and developmentally disabled population to:

1) track client movement through all the different possible services that may be needed and all the different possible living arrangements,

2) facilitate de-institutionalization; the moving of this population from warehouse type institutions to more humane community located facilities,

3) assess client progress and identify needs of the client,

4) facilitate the selection and evaluation of care programs,

5) identify where the client is not receiving needed services,

6) provide a basis for a true advocacy system and insure the legal rights of the mentally retarded and developmentally disabled people,

7) facilitate the information sharing between different private and public organizations serving the developmentally disabled population, and

8) provide data for client support payments and other cost accounting reports.

After a feasibility study was completed, in April 1974, a survey of other statewide systems across the country was conducted to determine if Ohio could adapt any of these systems to meet its tracking and information needs. None of these systems had all the necessary capabilities of Ohio's proposed system. Ohio will, however, borrow as much as it can from these systems to minimize costs and eliminate duplication of effort, if the necessary funds to implement the proposed system can be found.

(PLACE) PROGRAM LISTING AND CLIENT EVALUATION

Contact: Program Listing and Client Evaluation (PLACE)
Connecticut State Department of Health
Office of Mental Retardation
Hartford, Connecticut

The PLACE Program is a computer-based data system that incorporates the following general methodology in which each developmentally disabled client is assigned a unique identifying case number. Computer terminals are located in each Training School and Regional Center, as well as the Central Office of Mental Retardation, for direct "on-line interaction" with a time-shared computer.

Comprehensive information about each client is coded and serves as "input" to the Client Data Bank of the computer. Information on all programs of each Regional Center and Training School, as well as all other known programs in the region, is coded and serves as "input" to the Program Data Bank. Information on all known persons having special skills/abilities potentially useful to clients or programs is coded and serves as "input" for the Special Human Resources Data Bank.

The PLACE Program Manual describes organizational assignments relative to system maintenance. It includes built-in training arrangements for staff at different levels of the program.

This system provides a variety of capabilities, including: a systematic approach to placing developmentally disabled clients in appropriate programs, periodic evaluation of client progress, isolating gaps in service throughout the state, and marshalling the state's staff resources to focus on specific problem areas relative to the developmentally disabled.

(SCRIP) STATEWIDE COMPUTERIZED REFERRAL INFORMATION PROGRAM

Contact: Claude W. Doak
DD Council, 169 W. Hanover St.
Trenton, N. J.

The SCRIP system is basically a resource tracking program. All programs, facilities and services available for developmentally disabled people are included in a computer resource bank. Each resource is described relative to its capacity for handling clients and the type of programs and services provided.

Access to the resource data bank is accomplished through four terminals located geographically throughout the state. Persons seeking appropriate placement for clients access the computer by requesting referral information relative to the characteristics of the client, including age, sex, primary and secondary disabling conditions, needs for services and special circumstances. The computer resource tracking program then responds by listing the available programs contiguous to the geographic location of the client.

The SCRIP system avoids problems of maintaining confidentiality by not listing clients in any manner. Information sent to the computer about clients does not include client name or code number. Instead, the name of the person requesting resource information for the client is used, thereby placing accountability for confidentiality on that person.

SCRIP is described as having good planning capabilities. It keeps track of all resources in the state, and maintains continuous up-dating relative to resource capacity. Information about needed additional services can be derived from requests for services not met. SCRIP provides monthly printouts of: requests for services by geographic area, number of people involved per program area, capacity of facilities vs. clients being served, as well as other reports.

(SSIS) SPECIAL SERVICES INFORMATION SYSTEM*

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Maryland's system has received attention because of its comprehensive computerization. All referral information is combined with all special services utilization for nine state health service agencies. One characteristic is the collection of data on early identification systems and institutional status, so population movement can be monitored. The data management device is tape decks, and a manual for the storage and retrieval of these data is available.

This Special Services Information System is in the process of being revised.

*Formerly called Data System for the Handicapped

Evaluation Instruments

(AC-FMR) ACCREDITATION COUNCIL FOR FACILITIES FOR THE MENTALLY RETARDED (Agencies)

Joint Commission on Accreditation of Hospitals, Accreditation Council for Facilities for the Mentally Retarded, Standards for Community Agencies Serving Persons with Mental Retardation and Other Developmental Disabilities, 875 North Michigan Ave., Suite 2201, Chicago, Illinois.

These standards were adopted as a basis for voluntary accreditation of community agencies which provide non-residential programs and services to developmentally disabled people. They were developed by a committee composed of parents, practitioners, program directors, state agency and university personnel, and representatives of national organizations concerned with such services. The committee was assisted by expert consultants, and the final draft was reviewed by representatives of community agencies and consumer groups.

The standards are based on a view of developmental disabilities within a "developmental model" which emphasizes each person's capability for learning, growing, and developing no matter how severely disabled he is. Thus, they focus on the need for individual programs designed to elicit and maintain behavior that is as culturally normative as possible, with consumer and parent participation in all decisions when feasible. Given this focus, the standards deal with the following "essential characteristics" of each individual agency within a service delivery system: responsiveness; availability, which includes comprehensiveness, completeness, balance, and the cross-disciplinary approach; accessibility, individuation, which includes participation and acceptability; records; quality control; and accountability.

Several uses of the standards are contemplated by the Accreditation Council: (1) to guide the administrators and staffs of agencies in upgrading programs; (2) to inform members of the various professions that provide services to mentally retarded and other developmentally disabled people; (3) to assist

agencies in planning and developing systems of community services; (4) to provide concrete information for legislators, consumers, and the general public; (5) to assist consumers and consumer representatives in evaluating and monitoring the services that are made available to meet their needs, and in initiating change when necessary; (6) and to serve as a basis for the evaluation and accreditation of community agencies.

Specific program areas covered by the standards are enumerated in the Table of Contents as follows: Provision for an Overall Individual Support System, Agency Service Components, Community Organization, Program Evaluation, Research and Research Utilization, Records, and Administration.

In June, 1974, the Accreditation Council published the Survey Questionnaire designed for use with the Standards document in the accreditation process. This recent document specifies the information necessary to determine whether an agency's program complies with each standard. It could be used by an individual, consumer group, planning group, etc., in reviewing existing programs as well as by agencies themselves in seeking accreditation.

(AC-FMR) ACCREDITATION COUNCIL FOR FACILITIES FOR THE MENTALLY RETARDED (Residential Facilities)

Joint Commission on Accreditation of Hospitals, Accreditation Council for Facilities for the Mentally Retarded, Standards for Residential Facilities for the Mentally Retarded, February, 1974, 875 North Michigan Ave., Chicago, Illinois.

These standards were first adopted in 1971 as a basis for voluntary accreditation of residential programs for mentally retarded children and adults. They were developed by committees representing the various disciplines and interests involved in providing adequate programs for the retarded. The document deals with the following general areas of program concern: (1) resident-living or domiciliary services that all residential facilities must themselves provide; (2) the sound organizational and administrative practices that are applicable to many types of programs, in addition to those providing residential services; and (3) the professional and special services and programs that may be required by the residents of facilities, in addition to domiciliary services--whether or not such services and programs are provided by the facility itself, and whether or not such services and programs are provided only to residents of facilities.

A more detailed view of program areas covered by the standards can be found in the document's Table of Contents: Administrative Policies and Practices, Resident Living, Professional and Special Programs and Services, Records, Research, Safety and Sanitation, Administrative Support Services.

The Accreditation Council cites several potential uses for the standards: (1) to guide the administrators and staffs of residential facilities in upgrading programs; (2) to assist agencies in planning and developing systems of residential services; (3) to provide concrete information for legislators, consumers, and the general public; and (4) to serve as a basis for the evaluation and accreditation of residential facilities.

(PAC) PROGRESS ASSESSMENT CHART

H. C. Gunzburg, Progress Assessment Chart of Special and Personal Development (PAC), 3rd edition, 1974. Aux Chandelles, PAC Department, Box 398 Bristol, Indiana.

PAC is an instrument designed to assess the social functioning of the mentally handicapped child or adult and to provide information relating to the individual's achievement compared to that of other children or adults with a similar mental handicap. Use of the instrument over time makes it possible to monitor the progress an individual makes while involved in a program of social education and to consider whether what has been learned can be applied in real life situations. Five PAC forms list inventories of skills which make it easier for mentally handicapped children/adults of various age levels to adjust smoothly to their immediate environments. The account of each individual's achievements and failures is given by using a diagram which "charts" his/her situation rather than by compressing information into a quantitative test score. Using the individual's chart, the Progress Evaluation Index (PEI), makes it possible to determine whether a child/adult is backward, average, or superior when compared to others with a similar handicap.

The PAC forms are designed for use with the following clients:

The P-PAC (Primary PAC) refers to the early development of a very young normal child and is suitable for mentally handicapped children to approximately 7 years of age and sometimes older.

The PAC-1 contains a selection of skills which are part of normal childhood development, but are particularly relevant to the social development of children of school age. This is the standard form suitable for mentally handicapped children aged 6 years to 16 years, but will also be used for older age groups.

The PAC-1A is an extension of the PAC-1 and contains additional social skills which are particularly relevant to the social education of the mentally handicapped.

The PAC-2 has been designed for the mentally handicapped adolescent and adult and describes "parcels of behavior" (the combination of various skills of different types) which will help the mentally handicapped person in his social adjustment.

(PASS) PROGRAM ANALYSIS OF SERVICE SYSTEMS

Wolf Wolfensberger and Linda Glenn, Program Analysis of Service Systems: A Method for the Quantitative Evaluation of Human Services, National Institute on Mental Retardation, 1973, York University Campus, Toronto, Canada, M3J1P3.

PASS is a device for the objective quantification of the quality of human service programs, systems, and agencies already in operation or in the planning stage. Each service program is rated on forty-one major characteristics by a team of qualified raters who have thoroughly familiarized themselves with all aspects of the program. A program's total score is based on ratings in two large areas: one concerned primarily with administrative matters and the other with ideological ones. The most important concept with respect to ideological ratings is the principle of normalization; this principle calls for the use of means which are as culturally normative as possible in order to elicit and/or maintain in clients behaviors which are also as culturally normative as possible. PASS is based on the belief that this principle has implications for every element of a program--structure and identity, facility location and design, manpower and program details.

Two major purposes are cited for PASS:

(1) to provide a means of quantitatively evaluating the quality and adequacy of a human service program and to make it possible to compare it with other programs, and to utilize the specification of the normalization and (2) to provide principle as a teaching tool for service personnel.

PASS raters do not have to be professionals or highly educated; they do have to be intimately familiar with the principle of normalization and PASS itself. It is contemplated that many knowledgeable non-professionals, such as consumer representatives and members of self-help action groups, can become skilled in the perusal and interpretation of written program materials, site

visiting, and rendering of rating judgements which are required for use of PASS. A detailed Field Manual is provided for use by raters.

Elements of a service program which are covered by PASS ratings are arranged hierachically as follows:

I. Ideology

A. Normalization Related

1. Integration (physical and social)
2. Appropriate interpretations and structures (age and culture appropriate)
3. Specialization
4. Developmental growth orientation
5. Quality of setting

B. Administration Related

1. Comprehensiveness
2. Utilization of generic services
3. Consumer and public participation
4. Innovativeness

C. Various

1. Ties to academia
2. Research climate

D. Regional Priorities

1. Deinstitutionalization
2. Age group priorities

II. Administration

A. Manpower Considerations

1. Staff development
2. Manpower development

B. Operational Effectiveness

1. Internal administration
2. Finance

(REAL) Scales RESIDENT-ENVIRONMENT ANALYSIS BY LEVELS SCALES

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In August 1974 with the help of a DD grant the draft of the REAL Scales was developed. The use of the scales is to outline ways to measure and interpret relationships between individual behavior and environments of retarded adults and the sufficiency of administrative support mechanisms. The REAL Scales accept the notion that optional adequacy of behaving and supporting occurs when the balance between a person's behavior (whether normal, advanced, or retarded) and access to resources is sufficient for a normal daily life. Like the new ALERT system (UAF, Kansas), this instrument is sensitive to the issue of deinstitutionalization.

The mechanics of the REAL scales are simple though not as clear and concise as that simplicity might suggest. The scales result in numerical degree of fit between a retarded person and an environment and can measure change quantitatively in that relationship. The manual provides an interpretive outline for that data. The manner of data collection is observational (direct, subject as informant, other as informant, and records search) requiring a minimum of 24 hours of observation per observer. Areas evaluated are: feeding, protecting, moving, physical environment, staff qualifications, money, goods, energy, work performance, value orientation and social boundaries.

The plans for the REAL Scales project include more validation and reliability research this year. An extension of the focus to populations other than DD (such as mental patients and geriatric patients) will begin this year, and a variation to the scales is proposed. This project is still in its experimental phase.

(SDDS) STATUS OF DEVELOPMENTAL DISABILITY SERVICES (Nebraska, Kansas)

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James Budde
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Kansas Center for MR and HD
Univ. of Kansas, Lawrence, Kansas

SDDS is an instrument which has been developed to assess service needs geographically within states by regions. It can assess who gets served, who does not, and who gets duplicated services. It is concerned with collecting four types of information: demographic, disability, service and environmental. The system contains three basic components which include: (1) a procedure and training manual, (2) a standard information form, and (3) a computerized data processing system.

Presently, SDDS is in the first year of operation in Kansas and Nebraska. Its manuals and forms are being modified to meet other state needs.

SDDS is a field instrument, and it should be used in coordination with other evaluation efforts. Nebraska has combined this system with SCRIP.

(SPEC) SYSTEMATIC PLANNING AND EVALUATION CRITERIA

Contact: James Budde
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Though basically a program planning package, SPEC contains specific criteria for evaluation. It is designed specifically for DD service administrators and service providers. Its focus is comprehensive planning at all levels and across sixteen service areas. With formats and step by step procedures, it focuses on the development of a feasible plan that contains built-in evaluation criteria.

The system's tie to these sixteen specific services makes it less flexible and more problematic than some systems. Because it is not evaluation specific, it may be beyond the scope of this project. Though it is in its second year of life, it is being witheld from widespread distribution while its problems are being considered.

Evaluation Programs

(EPSDT) EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT

W. K. Frankenburg, A. F. North, Jr., A Guide To Screening for the Early and Periodic Screening, Diagnosis and Treatment Program under Medicaid, June, 1974. U.S. Department of Health, Education and Welfare, Social and Rehabilitation Service, Washington, D.C.

This is a manual written to assist public officials, physicians, nurses and others in planning and implementing an Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program under medicaid that will effectively meet certain health care needs of children who are eligible for the program. An outline of the contents is included here for reference purposes:

Preface

Introduction -
The Place of Screening In Health Care; The Special Obligations of A Screening Program

Part One:
Organization and Administration of Screening, Diagnosis and Treatment
1. Goals of an Effective Program
2. Component Activities of a Screening, Diagnosis and Treatment Program
3. Administrative Priorities
4. Obstacles to Meeting the Goals and Priorities of EPSDT
5. Settings for Screening; A Recommended Pattern of Care and Some Alternatives
6. Planning and Coordinating
7. Selection of Health Problems for Which to Screen and Tests with Which to Screen
8. Monitoring the EPSDT Program

Part Two:
Screening Procedures
9. Scheduling, Periodicity and Sequencing Procedures; Costs
10. The Interview and Physical Examination in Health Screening
11. Screening for Immunization Status
12. Screening for Dental Disease and Care
13. Screening for Eye Problems
14. Screening for Hearing
15. Growth Assessment
16. Developmental Screening
17. Screening for Tuberculin Sensitivity
18. Screening for Bacteriuria
19. Screening for Anemia
20. Screening for Sickle Cell Diseases and for Sickle Cell Traits
21. Screening for Increased Lead Absorption

Appendix:

1. Ouestionnaire Forms
2. List of Contributors
3. List of Consultants
4. Steering Committee

(RIP) REGIONAL INTERVENTION PROGRAM

Contact: Regional Intervention Program (RIP)
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The Regional Intervention Program (RIP) began in June, 1969. It was developed to provide training for families with children under five years of age whose behavior is so disturbing because of developmental or other disabilities that there is a serious family disruption and whose behavior makes them a high risk for eventual long-term institutionalization.

The program is unique in that it is directed by, and accountable to, the families served. The program is organized into several task forces or modules directed by an Evaluation Committee, made up of parents and consultants that serve at the parents' request, whose responsibility it is to generate policy and evaluate on an ongoing basis the direct services.

Families are introduced to the Program by mothers who participate in the Intake Module. Depending upon the child's problem, they are introduced to the Generalized Training Module, which deals with behavior problems, and/or the Individual Tutoring Module for problems of developmental delay and/or language disorders. A Classroom and Day Care Module provide children with group developmental training. RIP's Liaison Module works toward finding community placements for a child and providing follow-along service. Each of these modules is directed by and operated by trained parents.

Staff in the program consists of mothers whose children have been served by RIP. They are taught to individualize the programs and work toward precise objectives under continuous and reliable measurement feedbacks. Six master's level staff are available to consult with parents.

Families are admitted to the program at no expense and are expected to provide one parent to participate in the program six to ten hours a week for six months after work with their own child is making significant progress.

Selected References

Selected References

Helen Baker and Richard Surles; Client Tracking and Case Registry Systems: Introduction and Annotated Bibliography, Working Paper 3, DD/TAS, 1974.

Roy Bruninghaus and John Pelosi; The Developmental Disabilities Formula Grant Program and Evaluation Systems, DD/TAS, 1975.

Jim Paul, John Pelosi, Ron Wiegerink and Ron Neufeld; Resources to Facilitate the Development of Systems to Identify the Needs of Developmentally Disabled Children, DD/TAS, 1974.

DEVELOPMENTAL DISABILITIES
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