DOCUMENT RESUME

ED 411 615 EC 305 805

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TITLE User's Manual for State MR/DD Information Systems Related to Day and Employment Programs.

INSTITUTION Children's Hospital, Boston, MA. Training and Research Inst. for People with Disabilities.
SPONS AGENCY Office of Human Development Services (DHHS), Washington, DC.
PUB DATE 1992-06-00
NOTE 76p.
PUB TYPE Guides - Non-Classroom (055) -- Reports - Descriptive (141)
EDRS PRICE MF01/PC04 Plus Postage.
DESCRIPTORS Adults; *Data Collection; *Data Interpretation; *Database Design; Developmental Disabilities; *Disabilities; *Employment Services; *Information Utilization; Mental Retardation; National Surveys; Policy Formation; Program Development; Program Implementation; Social Agencies; Vocational Rehabilitation

ABSTRACT

Targeted to mental retardation/developmental disability (MR/DD) and vocational rehabilitation agencies, developmental disabilities councils, consumer and advocate groups, and protection and advocacy programs, this manual is designed to assist in the development of state-level data systems responsive to current accountability requirements. It also provides the basis for improved day and employment services for people with disabilities. The manual is organized around three critical issues facing MR/DD policy makers and program administrators. The first issue, data collection, focuses on critical data sets, data selection, and collection criteria, and data collection formats. The second issue, data utilization, discusses how data are used for policy development, program development, and program monitoring. The third issue, design and implementation, addresses potential solutions to barriers identified in a national MR/DD agency information system survey. The manual stresses two key themes: (1) an increasing need for accountability and responsiveness to contemporary issues in MR/DD services related to employment options, community integration and participation, choices and decision making, and transitioning to environments that are more interdependent, productive, and integrated; and (2) changing data system requirements brought about by the significant paradigm shift that is occurring in MR/DD services. (Contains 38 references.) (CR)

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Training and Research Institute for People with Disabilities

Boston, Massachusetts

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June, 1992

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ACKNOWLEDGMENTS

This Manual is part of the ongoing National Study that began in 1983 on employment and day programs for adults with developmental disabilities. The authors appreciate the support of the funding agency and colleagues who provided valuable comments of an earlier draft. Our special thanks to Drs. Dave Braddock, Mark Hill, John Jacobsen, Dave Mank, and John Noble, Jr. for their suggestions and support.

A project supported in part by a grant from the Department of Health and Human Services, Office of Human Development Services, Administration on Developmental Disabilities: Deborah McFadden, Commissioner.

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USER'S MANUAL FOR STATE MR/DD INFORMATION SYSTEMS RELATED TO DAY AND EMPLOYMENT PROGRAMS

Overview

The purpose of this User's Manual is to assist in the development of state-level data systems that are responsive to current accountability requirements and that provide the basis for improved day and employment services for people with disabilities. The Manual's readership includes MR/DD and VR agencies, DD Councils, consumer and advocate groups, and Protection and Advocacy programs, as they jointly continue their efforts to develop and use Management Information Systems (MIS).

Two significant factors influenced the Manual's development. First, Congress, through PL 100-146 (The Developmental Disabilities Assistance and Bill of Rights Amendments of 1987), mandated national documentation of services provided to people with developmental disabilities. Among other activities, this mandate resulted in the Administration on Developmental Disabilities awarding grants to document the current status of residential services (Amado, Lakin & Menke, 1990), allocation of public resources (Braddock, Hemp, Fujiura, Bachelder & Mitchell 1989), and day-employment services (McGaughey, Kiernan, Schalock, Lynch, & Morganstern, 1991). Second, as part of the Congressional mandate, we recently completed a national survey of state information systems related to day and employment programs (Kiernan, McGaughey, Schalock, Lynch & McNally, 1991). The survey results indicated a wide variation across state MR/DD agencies with respect to both the type of day and

employment data aggregated at the state level and the purposes for which the information is used. A summary of these findings is presented in Table 1.

The Manual is organized around three critical issues facing MR/DD policy makers and program administrators. The first issue, data collection, focuses on critical data sets, data selection and collection criteria, and data collection formats. The second issue, data utilization, relates to how data are used for policy development, program development, and program monitoring. The third issue, design and implementation, addresses potential solutions to barriers identified in the national MR/DD agency information system survey (Kiernan et al., 1991).

Throughout the Manual two themes occur repeatedly. First, there is an increasing need for accountability and responsiveness to contemporary issues in MR/DD services related to employment options, community integration and participation, choices and decision making, and transitioning to environments that are more interdependent, productive, and integrated. Second, data system requirements are changing because of the significant paradigm shift that is currently buffeting MR/DD services. This shift is best characterized by (Schalock & Kiernan, 1990):

*A quality revolution, with its emphasis on quality of life, quality enhancement mechanisms, and quality assurance.

*Living situations and employment in integrated [natural] environments, with an emphasis on natural, as opposed to professional, supports.

*Personal growth and development, with a focus on decision making, empowerment, and choices.

*Accountability, with its measurability and reportability requirements related to programmatic services, costs, and outcomes.

At the onset, it is important to clarify what the User's Manual is, and what it is

Table 1
Current Status of State MR/DD Information Systems Related to Day and Employment Programs[a]

A. Information System's Structure

Mainframe in Umbrella Agency (44%)	Contract Out (2%)
Mainframe in State Agency (26%)	Personal Computer (28%)

B. Consumer-Referenced Data Available

1. **Persons served:** 49 of the 50 states collect information regarding the number of consumers by day/employment service type. In descending order, age and primary disability are the consumer characteristics most available (42 of 50 states), followed by level of retardation (39 states), gender (39), ethnicity (33), and adaptive behavior level (28).
2. **Services provided:** 90 percent of the state agencies collect data regarding the number of persons placed into supported employment, followed by 84 percent for day activity/day habilitation programs, 76 percent for sheltered employment, and 45% for competitive employment or time-limited training.
3. **Costs:** Expenditure data are aggregated by funding source in 96% of the responding states, and by service category in 95% of the responding states. No annualized cost estimates were requested.
4. **Outcomes:** 22 states reported the ability to quantify the number and services of consumers who moved from one service category to another. Sixteen states collect information on the characteristics of consumers who moved, 23 states have wage and hour data available, with only 11 states collecting data on benefits received; 46 of the 50 states collect unmet needs [waiting list] data; fewer than 13 states (depending on the outcome data set) collect information on consumer, employer, or family satisfaction, integration with nondisabled coworkers, or other quality of work life variables.

C. Uses of Data

States are more likely to use the data sets for policy formulation (90%), legislative activity (84%), program development (84%), and program monitoring (78%) activities. The least reported areas of utilization were program evaluation and research (58%), and benefit cost analysis (54%).

a Adapted from Kieman et al., (1991).

not. The Manual is intended to aid state MR/DD agencies to develop a management information system (MIS) that can be used for policy development, program development, and program monitoring. The critical data sets and procedures suggested in the Manual are supported by findings from the national survey of state information systems. The Manual is not a guide to computer systems, for each state has its own unique needs and information processing systems.

Users of the Manual can expect a number of benefits from reading and using the Manual. First, if the suggestions are implemented, the state's information system will be better. Second, at the individual level, users will have a much stronger understanding of the:

*goals of an information system related to day and employment programs;

*proper focus of an information system;

*design and development standards;

*validation procedures; and

*data analysis levels and capabilities.

Alvin Toffler, in his recent book Powershift (Toffler, 1990), suggests that we are currently seeing a shift from violence and wealth as sources of power toward a knowledge base. Similarly, the current rapid social and political changes necessitate a data collection process that is responsive to the rebirth of social activism and constituent groups. Both of these trends underscore the importance and availability of relevant data for the purposes of policy development, program development, and program monitoring.

PART I: DATA COLLECTION ISSUES

Policy makers and program administrators increasingly are asking questions about the effectiveness and efficiency of those programs that fall within the domain of state MR/DD agencies. Four critical service delivery questions include:

*Who is being served, and at what cost?

*What are the outcomes from the services delivered, and how do these outcomes compare across groups of persons served?

*What are the impacts of these services, and do they result in people with disabilities moving into more productive and integrated environments?

*Are all persons who request services receiving them?

This section of the Manual discusses four critical data collection issues related to answering these questions and outlines specific techniques to address each issue. The four issues include identifying critical data sets, defining each set operationally, following data selection and collection criteria, and using standardized data collection formats.

A. Critical Data Sets

Four critical data sets are suggested to answer the above questions and to provide the basis for policy development, program development, and program monitoring activities. These data sets, which are summarized in Table 2, include numbers of persons served, types of services provided, service costs, and consumer-referenced outcomes.

Table 2

Critical MR/DD Data Sets

Persons Served

- Definitions
- Characteristics

Services Provided

- Service Categories
- Usage Patterns

Costs

- Funding Source
- Annualized Costs/Person

Outcomes

- Movement Patterns
- Current Employment Outcomes (Wages, Hours, Benefits)
- Quality Indicators
- Waiting Lists

B. Operational Definitions For The Critical Data Sets

Measurement of the four critical data sets poses significant challenges to state agencies due to both conceptual and pragmatic issues. Conceptually, the challenge is in reaching consensus that the specific measures outlined in Table 2 actually represent the critical data sets; pragmatically, considerable resources are required to obtain the information as well as to process and analyze it. This section of the Manual addresses the first of these challenges and proposes conceptually sound operational definitions for each of the four critical data sets. The definitions proposed are consistent with current federal terminology (Administration on Developmental Disabilities, 1981; P.L. 95-602) and program practices (Schalock & Kiernan, 1990; Schalock & Thornton, 1988).

1. Persons served. There are two operational definition issues here. One relates to the definition used for eligibility determination, and the second relates to the characteristics of the persons served.

A. Definition. The federal adoption of the functional definition of developmental disabilities in 1978 provided legislative endorsement of a more individualized approach to persons with disabilities by shifting from diagnostic categories to assessment of individual functional skills and needs. However, complex issues related primarily to the standardized measurement of functional skills within the major life activities have resulted in delays by state MR/DD agencies in the adoption and implementation of a functional definition. For example, in the most recent survey of state MR/DD agencies (McGaughey et al., 1991), only 20 agencies reported that they use a functional definition, and for the most part, this information is aggregated only at the local service level. Thus, because most state MR/DD agencies do not utilize the functional definition to determine service eligibility or to document consumer

characteristics, we would propose an operational definition of persons served that could include categories such as mental retardation, sensory/neurological, physical, and psychiatric. These categories are defined more specifically in Table 3. These categories are consistent with those proposed by the Administration on Developmental Disabilities (1981), as well as current research in service delivery practices (Schalock & Keith, 1988; Schalock & Kiernan, 1990). Currently, 88% of all individuals served by state MR/DD agencies have a primary disability of mental retardation; of the remaining 12% , 51% have a sensory disability, followed by psychiatric (38%) and physical (11%) disabilities (McGaughey et al., 1991).

B. Characteristics. The second definitional issue relates to the characteristics of persons served. The six demographic characteristics that we propose include age, gender, ethnicity, primary disability category, level of retardation (if applicable), and adaptive/functional skills (see Table 3).

2. Services provided. Again, there are two issues: one is defining the service categories; the second is documenting the amount or duration of services received.

A. Service categories. The term "service category" is used intentionally to focus one's attention on the larger service environment, rather than on specific training or treatment techniques used within those environments. The day and employment services definitions summarized in Table 4 represent those used in the recent state agency MIS survey (Kiernan et al., 1991). These categories represent services funded currently at federal and/or state levels and can be used to evaluate the integrated and facility based day or employment opportunities for people with disabilities.

B. Documenting services. The documentation of services is important for both accountability and evaluation purposes. The problem is that documentation is both time consuming and expensive. Documentation options vary from intensity to duration

Table 3

Operational Definitions and Consumer Characteristics for Primary Disability Groups

Primary Disability Groups	Consumer Characteristics
1. **Mental Retardation**: refers to significant subaverage general intellectual functioning (IQ <70), resulting in or associated with (assessed) impairments in adaptive behavior, and manifested during the developmental period (prior to age 22)	Age Gender Ethnicity Primary Disability (see adjacent column) Level of Retardation (if applies) Adaptive/Functional Skills
2. **Sensory/Neurological**: includes conditions such as epilepsy, congenital bilateral blindness/deafness, autism and traumatic brain injury.	
3. **Physical:** includes conditions such as cerebral palsy, muscular dystrophy, and multiple sclerosis.	
4. **Psychiatric**: includes conditions such as schizophrenic disorders, paranoids disorders, major affective disorders, and dual diagnosis.	

Table 4

Community Day Program/Employment Service Categories

Time Limited Training For Competitive Employment

Environment where most workers do not have disabilities
Time limited job-related supports are provided to the worker with a disability in order to maintain employment

Supported Employment (With Ongoing Support)

Environment where most workers do not have disabilities
Ongoing job-related supports are provided to the worker with a disability in order to maintain employment

Sheltered Employment/Work Activity

Environment where all workers have disabilities
Continuous job-related supports and supervision provided to all with disabilities

Day Activity/Day Habilitation

Environment where all participants have disabilities
Primary program focus: psycho/social skills, activities of daily living, and recreation, and/or professional therapies (e.g., O.T., P.T., Speech)
Continuous supports and supervision are provided to all participants with disabilities

Integrated Day Programs

Participants are adults or youth transitioning from school (no other age restrictions)
Primary program focus: community integration experiences with individuals who do not have disabilities (leisure activities, learning activities, etc.)
Program established to provide an alternative to segregated day programs

Programs For Elderly Individuals

Environment where all participants are 55 years or older
Primary program focus: leisure recreation, nonvocational
May be integrated with elders who do not have disabilities

measures (Schalock & Thornton, 1988). Most service providers and funding/ monitoring agencies generally use a monthly or yearly duration measure. Therefore, we propose that the documentation be in months of service, which will then permit one to determine costs per participant such as described in the following section.

3. Costs.(a) The two issues here relate to funding source and annualized costs per participant.

A. Funding source. The sources of funding within state MR/DD agencies are varied. All but five states in the recent MIS survey reported the availability of expenditure data related to funding source, and all but seven states reported the availability of expenditure data by service category.

B. Annualized costs per person. Being able to account for the cost of a program is a critical program management function. Some measure of programmatic costs is essential for describing the intensity of services provided, for budgeting program replications, and for evaluating whether the impacts produced by the program are sufficiently large to justify the program.

There are a number of different approaches to cost analysis -- all of which are beyond the scope of this Manual. The interested reader is referred to Killaugh and Leininger (1987) and Moriarity and Allen (1987). However, there are several guidelines regarding the operationalization and analysis of program costs, including (Schalock & Thornton, 1988):

(1) Describe the program by service category (see Table 4) and allocate all funds used by the program.

(2) Define the period over which costs will be measured, remembering that the cost analysis period should correspond to any related impact or benefit/cost analysis time periods (most preferably a budgetary period).

(3) Determine average costs of the program.

The advantages of using average costs (guideline #3) include their comparability with estimates of average program effects, as well as the ability to focus on issues of service intensity. It seems reasonable at this point, based on state MR/DD agencies' ability to aggregate fiscal data, to propose the following operational definition of annualized costs per person (Schalock & Thornton, 1988):

$$\text{Average Cost Per Participant} = \frac{\text{Total cost for time period}}{\text{Number of people enrolled during that period}}$$

4. **Outcomes**. The current era of accountability requires that the outcomes from MR/DD services be evaluated to determine whether:

*public policy goals are being reached;

*employment outcomes are improved in integrated employment settings;

*people with disabilities experience a high quality of work life;

*integrated employment and day services result in increased consumer satisfaction;

*persons are moving to more productive, integrated environments.

The four outcome measures listed in Table 5 can provide the basis for evaluating the outcomes from MR/DD employment-related programs. These include [consumer] movement patterns, current employment outcomes, quality indicators, and waiting list information. Operational definitions of each are also given in Table 5.

In summary, this section of the Manual has suggested operational definitions for the four proposed critical data sets related to the people served by state MR/DD agencies, the services provided, the costs of those services, and service outcomes. Although these critical data sets are desirable, it is generally not feasible to collect (or analyze) all the information that people would like. Indeed, the most frequent

Table 5

Proposed Outcome Measures and Their Operational Definitions

Outcome Measures	Operational Measures
1. Movement Patterns	Number and service category of persons who move Characteristics of persons who move
2. Employment Outcomes	Average wage/month Average hours/month Employment benefits received (insurance, vacation, sick leave)
3. Quality Indicators of Day/Employment Services	Consumer satisfaction Employer satisfaction (staff satisfaction in day services) Family satisfaction Integration with nondisabled coworkers
4. Waiting Lists	Number of students graduating who will need day/employment services Number of persons not receiving but waiting for day/employment services Number of persons receiving day/employment services who need a different service

constraint on data collection or analysis reported by 19 state MR/DD state agencies in the 1991 MIS survey was lack of resources (money or persons). Therefore, the following section of the Manual discusses a number of data selection and collection criteria that will assist users in selecting specific measures within each of the four critical data sets.

C. Data Selection and Collection Criteria

The issues of data selection and collection are quite different. Data selection involves determining what to measure, as reflected in the critical data sets summarized in Table 2 (page 6) and defined operationally in the previous section. Data collection involves assessing alternative data sources to determine the quality, availability and cost of the data. These two concepts are discussed in this section and summarized in Table 6.

1. Data selection criteria. What one measures depends upon the program's goals and objectives and the comparisons that one wants to make. In general, the following five selection criteria are helpful in determining what to measure:

Attributed to program: an obvious link between service and outcomes,

Sensitive to change and intervention: services affect potential outcomes,

Obtainable: those measures that one has time and tools to actually measure,

Objective: measures that can be easily quantified and thereby measured,

Prioritized: measures that reflect the program's goals and

objectives.

2. Data collection criteria. Once the specific desired data elements have been selected from among the four critical data sets, six criteria can be used to assess alternative data sources and alternatives. These six include:

accessibility: available from the primary source (e.g., service provider, funding agency),

completeness: availability of the data element for all service recipients,

accuracy: reflects actual services or outcomes,

timeliness: whether data covers the period(s) of interest and how soon after such period(s) the data can be collected,

flexibility: degree to which the data element/set will be influenced by shifts in budgets, policies, research needs and/or quality of the data source,

cost: time and resources required to collect and analyze the data element/set,

In addition to these data selection and collection criteria, one also needs to consider whether the data will be used for policy development, program development, and/or program monitoring purposes. A discussion of these three purposes constitutes Part II of the Manual. However, one needs to keep the three uses in mind when selecting data sets and committing the resources necessary for data collection. What Part II confirms is that the data sets required for policy/program development and program monitoring are the same four critical data sets summarized in Table 2 (page 6) and discussed in the previous section. Users of the Manual will undoubtedly be collecting one or more elements from each data set, and therefore the next section of the Manual discusses specific data collection formats that can be used for both data collection and analysis purposes.

D. Data Collection Formats

Collecting information on the desired critical data sets requires resources. Therefore, the following three guidelines should be followed:

*Data sets chosen should meet the selection and collection criteria summarized in Table 6, and should be used for the purposes of policy development, program development, and/or program monitoring.

*Data sets collected should be clearly defined and easily measured.

*Individual data sets should be collected at the provider level and aggregated at the state (i.e., centralized or distributed data entry) level.

Another way to state these three guidelines is to "begin with the end in mind." For example, although the majority of states currently aggregate data at the state level, many do so only at the regional or county level. This situation makes it very difficult, if not impossible, for states to use data meaningfully for policy/program development and program monitoring. This section of the Manual outlines a procedure whereby a common data input sheet is used by the provider to be shared with the state MR/DD agency for state-level, cross-tab and statistical analyses. The authors realize that the data input sheet is only a model and may need to be modified to reflect the unique needs of each state MR/DD agency.

1. Data input sheet. A model of the proposed data input sheet that would be submitted to the state MR/DD agency by the service provider is shown in Figure 1. Note the following aspects of this model format. First, it allows for consumer referenced input regarding each of the four critical data sets (persons served, services provided, costs, and outcomes). Second, the spread sheet format of Figure 1 represents a reasonable, inexpensive format for handling the data. Most providers have personal computer systems that handle spread sheet/data-based systems very

Table 6

Data Selection and Collection Criteria [a]

Selection Criteria	Collection Criteria
1. Attributed to program	1. Accessibility
2. Sensitive to change and intervention	2. Completeness
3. Obtainable	3. Accuracy
4. Objectively defined	4. Timeliness
5. Prioritized	5. Flexibility
	6. Cost

a. Adapted from Schalock & Thornton (1988).

Figure 1

Service Provider Data Input Sheet

Provider:_____

	Individual Characteristics								Outcomes			Costs	
ID #	Date of Birth	Gender	Ethnicity	Primary Disab. (1)	MR Disab. Level (2)	Adaptive/ Functional Skill Level	Current service category (3)	Date of Placement (day/mo.)	Avg. Hrs. worked per month	Starting Wage per hour	Level of integration (4)	Annual Cost	Primary Funding Source

(1)
Primary Disability

a. Mental Retardation
b. Sensory/neurological
c. Physical
d. Psychiatric

(2)
Disability Level by IQ

a. IQ 24 (profound)
b. IQ 25-39 (severe)
c. IQ 40-54 (moderate)
d. IQ 55-69 (mild)
e. IQ 70 or above

(3)
Current Service Category

a. Time limited training for competitive employment
b. Supported employment
c. Sheltered employment/Work activity
d. Day activity/day habilitation
e. Integrated day program
f. Programs for elderly individuals

(4)
Level of Integration

a. Works with non-disabled persons
b. Limited interaction with non-disabled persons
c. No interaction

well. Third, a modification of Figure 1 has been used successfully in a number of national employment surveys which have found that most service providers are both able and willing to complete the data sets (Kiernan, McGaughey & Schalock, 1990; Kiernan, McGaughey, Schalock & Rowland, 1988; Schalock, 1988). And finally, the proposed input data sheet is not intended either to dictate data collection/analysis formats or replace comparable input sheets that are being used successfully by state MR/DD agencies. However, it should provide a useful model for states that are either developing or modifying their current data collection efforts.

2. State-level formats. Once the data are available to the state MR/DD agency, then the issue becomes how to format it for meaningful analysis and use. A number of model formats are presented on subsequent pages; these reflect different ways the data can be aggregated to permit policy development, program development, and program monitoring.

A. Service category by funding source. The data collection format presented in Figure 2 provides descriptive information regarding the funding basis for each of the service categories. For example, the 1991 MR/DD survey (McGaughey et al., 1991) found that 80% of all state resources were allocated to support segregated day and employment programs. Similarly, 95% of the remaining resources (comprised primarily of federal monies) supported segregated employment programs.

B. Service category by primary disability group. The format presented in Figure 3 can be used to summarize the percent of individuals within each primary disability group in each service category and the percent of disability groups in either integrated or segregated employment settings. For example, the 1991 survey (McGaughey et al., 1991) found that integrated employment currently is used less frequently by persons with more severe disabilities, and that 75% of all persons in integrated employment has a mild or moderate level of mental retardation. Individuals with a primary

Figure 2
Service Category By Funding Source

	Funding Sources					
Service Category	Title XIX (Social Security Block Grant)	Title XIX (Medicaid; Non-Waiver Funds)	Title XIX (Medicaid Waiver)	Dev. Disability Council	Department of MR/DD	Other (e.g.. Self pay, Voc. Rehab., JTPA, HIP, County, Fed. & State grants)
Time-Limited Training						
Supported Employment (Ongoing Supports)						
Sheltered Employment/ Work Activities						
Day Activity/Day Habilitation						
Integrated Day Programs						
Programs for Elderly Individuals						

Figure 3

Service Category By Primary Disability Group

	Service Category						
Primary Disability Group	Competitive Employment (Placed in fiscal year)	Time-Limited Training	Supported Employment (Ongoing Support)	Sheltered Employment/ Work Activity	Day Activity/Day Habilitation	Integrated Day Programs	Programs for Elderly Individuals
Mild Mental Retardation							
Moderate Mental Retardation							
Severe/ Profound Mental Retardation							
Sensory/ Neurological							
Physical							
Psychiatric							

disability other than mental retardation were somewhat more likely to be in integrated environments (14% of those in integrated settings), compared with segregated settings (11%). Across integrated employment categories, the largest percentage (19%) of people with a disability other than mental retardation was served in time-limited training.

C. Outcomes by service category. The format presented in Figure 4 can be used with individual consumers or aggregated to summarize the current employment outcomes and one quality indicator (level of integration with nondisabled coworkers) of day/employment services. The format does not contain other quality indicators, such as satisfaction measures. However, other quality indicators can be added (as 10 states indicated they plan to do). Figure 4 also allows for cross analyses with data available from the provider-referenced data input sheet (Figure I) to permit more sophisticated data analyses such as outcomes by age, disability level, and facility size.

D. Movement patterns. The format presented in Figure 5 can be used to answer important policy and program monitoring questions related to the movement of persons into integrated employment environments. For example, our earlier surveys (Kiernan et al., 1986; 1988) indicated that there had been movement over the last five years from sheltered employment and work activity into more integrated employment environments. However, the data reflecting this trend were obtained from individual vocational and employment service providers. Thus, the 1991 survey contained questions related to the state MR/DD agency's capability to provide consumer movement data. In general, few state MR/DD agencies have this capacity. Specifically, only 22 states have state-level data related to the number and services of consumers who moved during a specific fiscal period, and only 16 have data on the characteristics of the consumers who moved.

Figure 4

Service Outcomes By Service Category

	Service Category						
Outcomes	Competitive Employment (Placed in fiscal year)	Time-Limited Training	Supported Employment (Ongoing Support)	Sheltered Employment/ Work Activity	Day Activity/Day Habilitation	Integrated Day Programs	Programs for Elderly Individuals
Avg. paid hours of work per month							
Avg. wage per hour							
Avg. wage per month							
Avg. level of integration							
% receiving one or more benefits							

Figure 5

Individuals Who Moved To a Different Community Based Service Category During Fiscal Year

	Service Category						
Service Category	Competitive Employment (Placed in fiscal year)	Time-Limited Training	Supported Employment (Ongoing Support)	Sheltered Employment/ Work Activity	Day Activity/Day Habilitation	Integrated Day Programs	Programs for Elderly Individuals
Time-Limited Training							
Supported Employment							
Sheltered Emp./ Work Activity							
Day Activity/Day Habilitation							
Integrated Day Programs							
Programs for Elderly Inds.							

E. Additional state-level formats. The basic matrix format presented in Figures 2-5 can also be used for the other critical data sets shown on the provider-referenced data input sheet (Figure 1). Specifically, costs can be aggregated according to consumer characteristics, service categories, primary disability groups, and movement patterns. Similarly, waiting list data can be aggregated by the first three variables just mentioned. The number of options is limited only by those three guidelines mentioned at the beginning of this section: (1) data sets chosen should meet the collection and selection criteria summarized in Table 6 and be used for the purposes of policy development, program development, and/or program monitoring; (2) the data sets collected should be clearly defined and easily collected; and (3) individual data sets should be collected at the provider level and aggregated at the state level.

In summary, Part I of the Manual has suggested four critical data sets (persons served, services provided, costs, and outcomes) and their operational definitions that can provide the basis for policy development, program development, and program monitoring. Data selection and collection criteria were discussed, along with examples of a provider-referenced data input sheet and state-level data aggregation formats. However, continuing with the notion that one should "begin with the end in mind", the Manual's user will need to relate data collection (Part I) to data utilization (Part II). It is to the three data utilization issues of policy development, program development, and program monitoring that we now turn.

PART II: DATA UTILIZATION ISSUES

Policy makers, program managers, and service providers need to have a clear understanding of how data can be used for the purposes of policy development, program development, and program monitoring. Definitions of each of these uses include:

Policy Development: Using data to change current policies, rules, and/or regulations or to propose new policy initiatives.

Program Development: Using data either to change existing program services or to add new service components.

Program Monitoring: Using data to determine whether programs are meeting their goals and objectives and whether they are in compliance with current rules and regulations.

This section of the Manual outlines the necessary data sets for each of these issues and the specific activities that can be undertaken to maximize the use of the critical data sets discussed in Part I. A summary of this process is shown in Table 7.

A. Policy Development

Recent federal and state policy initiatives have focused on the development of supported employment and supported living in order to enhance the a person's independence/interdependence, productivity, and community integration of people with disabilities. These policy initiatives also reflect the current paradigm shift towards quality of life, natural environments, and personal empowerment. Evaluating current

Table 7

Summary of Data Utilization: Issues, Necessary Data Sets and Specific Activities

Data Utilization Issues	Necessary Data Sets	Specific Activities
Policy Development	Funding Patterns	Outcome Analysis
	Consumer Characteristics	Impact Analysis
	Costs	
	Outcomes	
Program Development	Persons Served	Program Replication
	Services Provided	Program Conversion
	Costs	
	Outcomes	
	Waiting Lists	
Program Monitoring	Persons Served	Monitor Data Selection
	Services Provided	Monitor Data Collection
	Costs	Monitor Data Analysis and
	Outcomes	Interpretation

service practices and policies and developing new ones require data sets which summarize current funding patterns, costs and service outcomes, and activities related to outcome and impact analysis. Each is described more fully below.

1. Data sets. Policy development frequently is based on data showing both the feasibility and attractiveness of a particular course of action. For example, one of the reasons supported employment emerged so quickly as a national and local initiative was its documentation of positive outcomes for persons with severe disabilities (Wehman, 1988). However, policy initiatives also need to be evaluated in light of their described or anticipated outcomes or impacts. The following data sets are suggested for policy development use:

*funding patterns

*consumer characteristics

*costs

*outcomes

2. Activities. The two major data utilization activities related to policy development include outcome analysis and impact analysis. The difference between these two types of analysis are diagrammed in Figure 6 (Schalock & Thornton, 1988).

A. Outcome analysis. This activity can be undertaken to answer questions regarding the outcomes from habilitation services and whether these outcomes are consistent with current or needed policies. As summarized previously in Table 5, the suggested outcomes include:

*movement patterns

*employment outcomes

*quality indicators of day/employment services

*waiting lists

B. Impact analysis. Impact analysis focuses on a program's effects or impacts

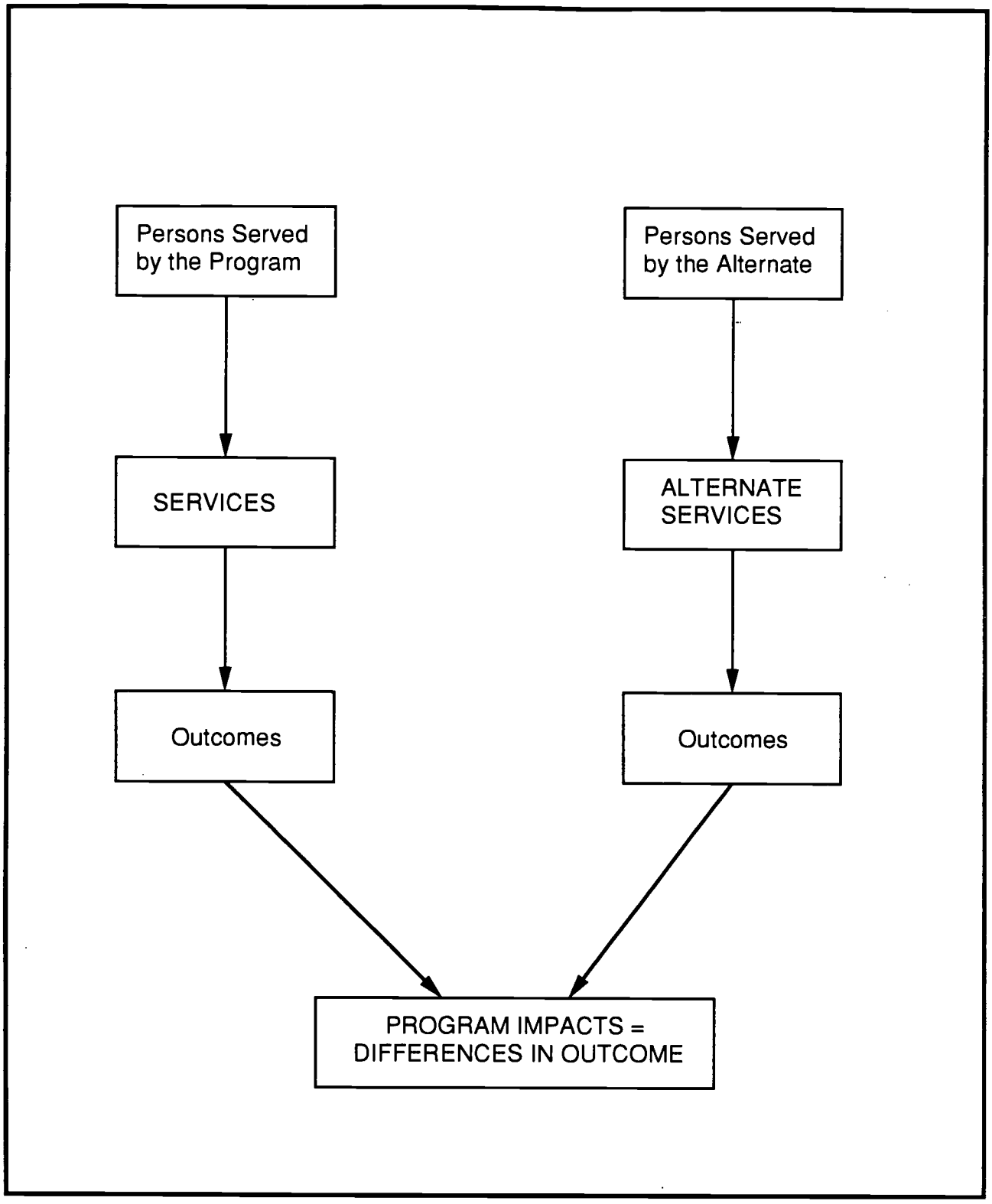

Figure 6.
Distinction Between Outcomes and Impacts

on the targeted population. Although an essential part of policy development, impact analysis can be quite difficult to accomplish because, as shown in Figure 6, it involves making comparisons between what happens in a state program and what happens in the comparison state program (e.g., waiver vs. nonwaiver state). Impact analysis involves data collection, following people over time, and determining what actually happens to the participants, including what would have happened had they not received services. Impact analysis addresses a number of policy-relevant questions such as: did the program have the intended effects on outcomes, how big are the effects, and can these effects be attributed with reasonable certainty to the services provided? Thus, impact analysis not only addresses important policy-related issues, but also provides the basis for benefit-cost analysis. The interested reader can find examples of an impact analysis in Thornton and Fuller (1989) and benefit cost analyses in Berkowitz (1988), Conley and Noble (1990), Noble and Conley (1987), Schalock and Thornton (1988), and Thornton and Fuller (1989).

B. Program Development

Habilitation programs are developed for a number of reasons related to policies, unmet needs, political pressure, state and federal policies, and anticipated outcomes. The necessary data sets and activities involved in this type of data utilization are quite different from those related to policy development. Here, the focus is more on describing and evaluating current programs, with the intent being to develop new programs by replicating successful programs or modifying existing programs through program conversion activities.

1. Data sets. All four critical data sets, (persons served, services provided, costs and outcomes) including unmet need data (waiting lists), are necessary for program development efforts. These data sets provide the basis for two activities;

program replication and program conversion.

2. Activities. Developing day and employment programs during the 1990's will probably not involve the creation of "new" programs in the traditional sense. Rather, many of these "new" programs will result from replicating currently successful employment programs or from converting resources within current programs to provide more integrated employment and supports. These activities are discussed in subsequent sections.

A. Replication. Replicating a successful program or demonstration project is difficult, unless one knows all the details of the program to be replicated. Thus, program replication activities need to be based on a thorough process analysis that describes the model program's internal and external environments (Schalock & Thornton, 1988). The internal environment includes the persons served, selection procedures, services provided, costs, and outcomes. The external environment includes the organizational structure, organizational philosophy, governance structure, resources, funding sources and their certainty, the community, formal/informal linkages to other service providers, and the program's constituents.

Knowledge of each of these internal and external factors is essential for successful replication efforts. For example, the external environment of a rural program is very different from that of an urban program; similarly, the internal environment of a university-based demonstration project is quite different from a community-based program's supported employment component. The knowledge gained from a good process analysis will significantly improve the successful implementation of a program because of the understanding that one has gained about how services are provided within the context of the program's organizational structure and environment.

B. Conversion. We have seen recently a strong movement towards systems

change, or program conversion, in which sheltered workshop and day activity programs devote more of their resources toward integrated employment environments. For example, national surveys (Kiernan & Ciborowski, 1985; Kiernan et al., 1988) of facilities providing vocational services to adults with developmental disabilities placed 17 to 19% of their clientele into nonsheltered settings during the two survey periods of 1984 to 1986. Although there are a number of conversion models, the conversion process typically involves four activities: gaining participant support, determining operational procedures, identifying funding sources, and developing staff competencies (Bellamy, Rhodes, Mank & Albin, 1988; Kregel, Shafer, Wehman & West, 1988 ; Parent & Hill, (1990). The goal of program conversion is not only to convert resources to integrated employment, but also for the program to incorporate the philosophy and structure of successful integrated employment models. This goal is reflected in a number of "best practices", as summarized in Table 8.

In summary, the large number of persons currently waiting for either new or different services is forcing the current state MR/DD systems not only to replicate model programs and convert current programs, but also to pursue alternative service delivery models such as assessing and using natural supports. Although large-scale reliance on natural supports is very new, key components in the development of these supports include an ecological inventory of natural supports, a discrepancy analysis between the person's needed and available natural supports, assessing needed supports (at the individual, co-worker/family/mentor, technological, or service system level), and evaluating the outcomes of support against (Schalock & Kiernan, 1991):

Natural support standards that include: (1) occur in regular, integrated environments; (2) performed primarily by people normally working, living, or recreating within that environment; (3) individualized and person-referenced; (4) coordinated through a person such as a support

Table 8

Best Practices of Agencies With Successful Supported Employment Programs[a]

1. Strong leadership, organizational development and philosophical commitment to support employment.
2. High levels of client family involvement.
3. Provision of a variety of jobs that reflect the range of opportunities available in the community.
4. Use of individual placement, which permits better social integration and job matches.
5. Commitment by disabled employees to the supported employment concept and the specific job held.
6. Assessment techniques that include job analysis and job matching
7. Use of supports such as assistance from co-workers, provision of transport and reasonable job accommodation.
8. Effective on-site job training of employment specialists.
9. Business advisory councils or boards including local business persons who assist with marketing.
10. Non-intrusive job coaching and job support that is phased out as soon as is practical.
11. Good connections with university experts and other consultants.
12. Collaborative efforts among professionals, employers, school personnel, state agency staff, persons with disabilities and their families.

a. Adapted from National Association of Rehabilitation Facilities (1989) .

manager; and (5) outcomes evaluated against quality indicators and person referenced outcomes.

Effectiveness criteria that include: (l) less or different external staff involvement; (2) attainment of greater levels of integration and stronger employment outcomes; (3) increased satisfaction of consumer; and (4) demonstrated acceptance and satisfaction of support provider.

C. Program Monitoring

Users of this Manual are undoubtedly familiar with a number of different approaches to program monitoring including accreditation, compliance reviews, certification, and quality assurance evaluations. These are not the types of monitoring activities proposed here; rather, the focus of program monitoring should be on the data selection, collection, and analysis criteria discussed throughout the Manual. By way of review:

1. Data selection. Four critical data sets have been proposed, including persons served, services provided, costs, and outcomes. Specific data elements within each set should be selected and monitored based on the selection criteria of: attributable to the program, sensitivity to change and intervention, obtainable, and objectively defined.

2. Data collection. Monitoring here should focus on the completeness, accuracy and timeliness of the data.

3. Data analysis. Monitoring data analysis should focus not only on the accuracy and appropriateness of the analyses, but also whether the analyses focus on four critical questions asked by policy makers and program administrators:

*Who is being served and at what cost?

*What are the outcomes from the services delivered, and how do these

outcomes compare across groups of people served?

*What are the impacts of these services and do they result in people with disabilities moving into more productive and integrated environments?

*Are all people requesting services being served?

There are a number of optional mechanisms for monitoring the above questions. Typical activities include systems review at the provider level (Schalock & Kiernan, 1990) or validation samples of data input sheets, computer [data] entries, and analysis and interpretation activities (Schalock & Thornton, 1988).

In summary, this second part of the Manual has discussed three data utilization issues including policy development, program development, and program monitoring. Part II of the Manual built upon the concepts and data collection issues discussed in Part I. Part III focuses on a number of information system design and implementation issues that need to be discussed in order to facilitate and maximize use of the Manual.

PART III: INFORMATION SYSTEM DESIGN AND IMPLEMENTATION ISSUES

The purpose of the final section of this Manual is to address the issue of information systems and to outline an approach readers might take to increase the availability and utility of their state's day and employment service information system. The discussion is built around the need for a systematic approach to information design and development, and the importance of information systems in providing managers with useful and valid data for policy development, program development, and program monitoring. The section is divided into two sub-sections, including (1) information system constraints, and (2) information system design.

A. Information System Constraints

In the 1991 state survey (Kiernan et al., 1991) that prompted the development of this Manual, 50% of the state MR/DD agencies responding reported perceived constraints on their information systems. These constraints included resources, lack of coordination across agencies or levels within the system, needed expansion/updating of the current system, confidentiality, quality of the data, and lack of a mandate regarding data use. Additionally, the overwhelming quantity of desired data was an additional constraint as reflected in comments such as, "we can't collect all the information that people would like", and "we have more data than information."

These findings are consistent with what one finds in the information system literature regarding information systems that frequently are not understandable by

users, sometimes relevant to the decisions at hand, and frequently concentrating more on machine than people considerations (Brackett, 1987). Additionally, the experience of management information system users (e.g., Jacobson, 1991; Jacobson & Scheerenberger, 1985; Rouse, 1986; Vasta, 1985; Wasserman, 1980) suggests additional constraints including:

*ineffective communication between the user community and the developer;

*lack of knowledgeable end users;

*over optimism about development time, development cost, and/or operational costs of the system;

*lack of intermediate steps during which management and customers can review progress and determine the system's status;

*lack of user access, technical assistance, and output provision to end users;

*hardware selection and purchases based on budgetary criteria rather than data base volume, transaction volumes, or statistical manipulation;

*inability to perform inter-data base synthesis;

*inadequate training on form completion and data entry. Insufficient technical support.

*no systematic mechanism for translating policy questions into questions that can be dealt with by data bases;

Overcoming these information system constraints is not easy. However, a number of suggestions for doing so are listed in Table 9. The 10 constraints listed in the table, along with the suggested solutions, underscore the importance of system design factors such as clear goals, understandable processes, and desired products.

Table 9
Suggestions for Overcoming Common Information System Constraints

Constraint/Problem	Suggested Solution(s)
1. Ineffective communication between user and developer	Joint development/implementation/review groups
2. Lack of knowledgeable end users	Inservice training
3. Over optimism about development time, development cost, and/or operational costs	Use historical costs Cost studies based on actuarial data Inter-state purchasing
4. Lack of intermediate review steps	Build reliability and validation steps into ongoing system
5. Lack of user access, technical assistance, and output provision to end user	Shared systems Online systems
6. Fiscal-basis for hardware selection	Multiple year acquisition/funding packages
7. Inability to perform. Inter-data base synthesis	Common ID numbers Knowledge manipulation language and time-relational databases
8. Inadequate training on form completion and data entry	Inservice training
9. Insufficient technical support	Interagency support teams University/College technical support teams/consultants
10. No systematic mechanism for translating policy questions to data-based form	See Figure 7 ('Information System Design')

These factors are elaborated upon in the following sub-section on information system design.

B. Information System Design

Information and information systems are advancing very quickly and, in many cases, faster than the user's ability to integrate the technology with the desired product. But knowledge in and of itself is insufficient; it must be organized in a way that permits answers to important questions and provides useful information to decision makers. In that sense, a state's information system should have clearly defined inputs, throughputs and outputs. Such an information system design model is presented in Figure 7. The model's five components provide the basis for discussing the significant factors that users of this Manual should consider as they attempt to improve their state's information systems related to day and employment programs.

1. Information system goals. The previous section of the Manual discussed how data can be used for policy development, program development, and program monitoring. These uses should be the goals of an information system and thus drive the system's development, implementation, training, and use.

Once the goals for the system are identified clearly, then subsequent steps can be taken. However, the importance of this first step cannot be emphasized too strongly, for unless one begins with the end clearly in mind, it is easy to end up in the wrong place or with data that do not provide managers with useful information.

2. Information system input. Once the system's goals are defined clearly, then the necessary input can be provided. However, before selecting the necessary data sets, consideration should be given to the information needs at different levels within the service delivery system: specifically, the service provider, the state, and the federal government. From this perspective, system designers need to ask seriously

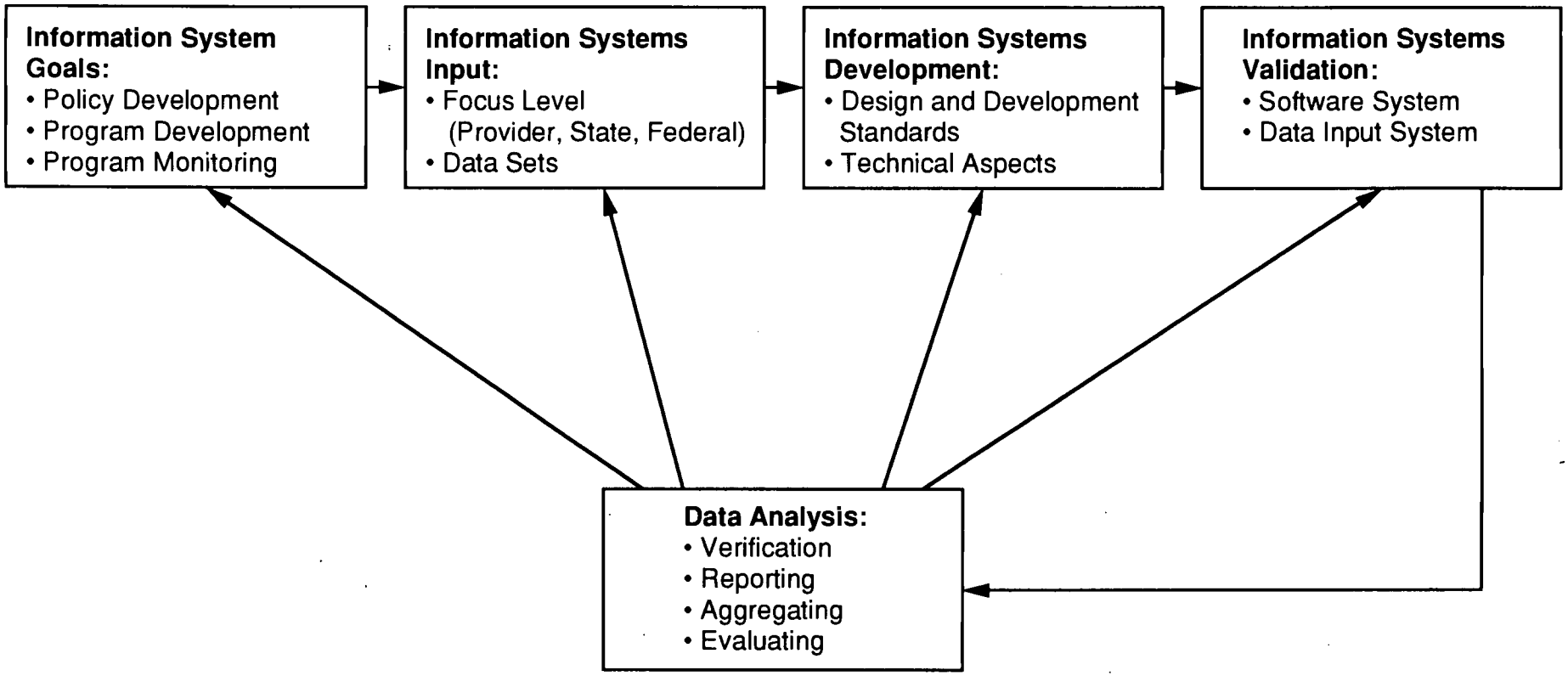

Figure 7.
Information System Design

what are the data needs at each of these three levels. A suggested answer is summarized below (Schalock & Hill, 1986):

Service Provider (agency, county, region): Needs client referenced data including persons served, services provided, costs, and outcomes.

State: Needs the ability to aggregate these critical data sets across service providers and service options and to evaluate the impact of the services provided.

Federal: Needs aggregated data on service outcomes by consumer characteristics and results from (or potential for) impact analyses.

This recommendation regarding shared roles in management information is based on the assumption that providers are responsible for client-referenced information; states are responsible for systems-level information and state-specific policies; and the federal government is responsible for state-level aggregation, state-level comparisons, and national policy development and evaluation.

A dictum in information science is that, "the best information comes from the lowest level in the system." It was this concept that provided the basis for the provider-referenced data collection formats discussed in Part I (Figures 1-5). Thus, state-level information system staff should work closely with the local service provider to ensure that data collection formats and processes are clearly understood and used reliably. If this is done, it will result in greater confidence for inputting the following information data sets:

Policy Development	Program Development	Program Monitoring
Funding Patterns	Persons Served	Persons Served
Consumer Characteristics	Services Provided	Services Provided
Costs	Costs	Costs
Outcomes	Outcomes	Outcomes
	Waiting Lists	

3. **Information system development.** There are numerous definitions and models of information systems that are beyond the scope of this User's Manual. For the present purposes, there are four important facts that users need to keep in mind (and ask about) regarding their state's information system. These include (Wasserman, 1980):

*Information systems are used by persons who are unfamiliar with the technical aspects of computer hardware and software so that the underlying operating system, language processor(s), and hardware should be made as invisible and unobtrusive as possible.

*The way in which information systems are used and integrated into an organization's environment is at least as important as the way that they are constructed.

*Information systems involve access to and modification of large volumes of data, and thus must be organized with the "end in mind."

*The way in which humans interact with the system is of great importance and affects the selection and placement of terminals, hard versus soft copies, and turn around time.

These four facts, when interpreted broadly, underscore the need for clear design and development standards for a state's information system. Five such standards are summarized in Table 10.

The actual development of the information system is very technical and requires knowledge of computer language, data bases, and database environments. Users of this Manual will probably not be "computer specialists"; however, one should understand the questions to ask, the data that are available, and the verification of standards related to reliability, simplicity, user friendliness, economy and evolvability. Entering into this dialog, plus involvement in the validation process described below, will help significantly in overcoming some of the knowledge and training-based constraints summarized in Table 9.

4. Information system validation. Manual users need to consider two levels of validation: the software system and the data input system.

A. Software system. In reference to the first type of validation, probably 50% of the development effort on a software system takes place after the software program has been written. Thus, the system must undergo a number of "tests" before it is fully operational. Three of these tests include (Brackett, 1987; Wasserman, 1980): (1) unit testing, in which individual program modules are tested for correctness and whether they meet their specification; (2) integration testing, in which two or more modules are joined together and tested together; and (3) acceptance testing, in which the user determines whether the system conforms to its specifications and goals.

B. Data input system. Reference was made previously to a set of data selection and collection criteria that can be used to validate the data sets selected. These criteria and their definitions are presented in Table 11. In reference to these criteria, Manual users will want to ask such questions as, "Do the data reflect important

Table 10

Design and Development Standard for a State's Information System[a]

Characteristics	Definition
Reliability	The system should be available and working properly.
Simplicity	The nature of the user interaction should be simple and easy to use: users should not have to conform to rigid syntax
User Friendliness	The system should provide meaningful error messages, should not terminate unexpectedly, and should enable the user to work with familiar terms and concepts: interactive information systems should provide on-line assistance and other similar features.
Economy	The system should be effective or cost justifiable in terms of both development and operational costs.
Evolvability	The system should be easily adaptable to conform to changing user requirements or to new execution environments (i.e. new hardware or operating systems)

a. Adapted from Wasserman (1980).

Table 11

Data Selection and Collection Criteria And Their Definition

Data Selection Criteria

Attributed to program: an obvious link between services and outcomes.

Sensitive to change and intervention: services affect potential outcomes.

Obtainable: those measures that one has time and tools to actually measure.

Objective: measures that can be easily quantified and thereby measured.

Prioritized: measures that reflect the program's goals and objectives.

Data Collection Criteria

Accessibility: available from the primary source (e.g., service provider, funding agency).

Completeness: availability of data element for all service recipients.

Accuracy: reflective of actual service or outcome.

Timeliness: whether data covers the period(s) of interest and how soon after such period(s) the data can be collected.

Flexibility: degree to which the data element/set will be influenced by shifts in budgets, policies, research needs and/or quality of data source.

Cost: time and resources required to collect and analyze the data element/set.

attributes of the program or services provided?"; "Are the data objective?"; and "Are the data timely?"

Additionally, user's need to validate the accuracy of the data submitted. The usual procedure for accomplishing this is to do a 10% (or more, if necessary) validation sampling in which the accuracy of the data submitted is checked against the primary data source. Corrections or adjustments are then made in the respective data sets.

5. Data analysis. Manual users are encouraged to think broadly about data analysis, rather than simply about numbers, tables, and graphs. In this broader view, data analysis involves different levels including verifying, reporting, aggregating, and analyzing. Additionally, the broader view stresses the relationship among these levels, information system goals, and shared management information.

A. Verifying. This level of analysis may be the most important because of its focus on error rate, missing data, the reliability and validity of the information system's data, and the actual use of the data. If poor quality or low user rates are found, then problems in the system's development or validation need to be addressed (see Figure 7 for proposed feedback loops).

B. Reporting. Reporting is a straightforward function that involves summarizing for the agency (and across agencies) data on the four critical data sets (persons served, services provided, costs, and outcomes). The typical statistics used for this function include mean, median, and standard deviation.

C. Aggregating. A higher level of data analysis includes using a cross-tabs (matrix) approach to summarizing the critical data sets by some common factor such as personal characteristic (age, I.Q., gender), funding source (Title XIX vs. State General Fund), geographical location (urban vs. rural), or program type (supported vs. sheltered employment). The data collection formats presented in Part I provide the

data entry formats for these cross-tab analyses.

D. Evaluating. This level of data analysis involves determining the significance or benefits from habilitation programs. The specific types of analyses conducted include outcome, impact, and benefit-cost (Schalock & Thornton, 1988). As discussed in Part II, this level of analysis is central to program and policy development and requires considerable resources related to comparison groups and complex statistical techniques. Frequently, this level of analysis is conducted by evaluators (for example, Federal contractors or university affiliated researchers) that are external to the state's information system.

In summary, Manual users are encouraged to view the interactive relationship among these four levels of data analysis and the information system's goals and shared management perspective discussed previously. A model that shows this interrelationship is shown in Figure 8.

Manual users should now be able to evaluate relevant aspects of their state's information system related to day and employment programs. Thus, the Manual concludes with the "Information System Assessment" which can be found in Table 12.

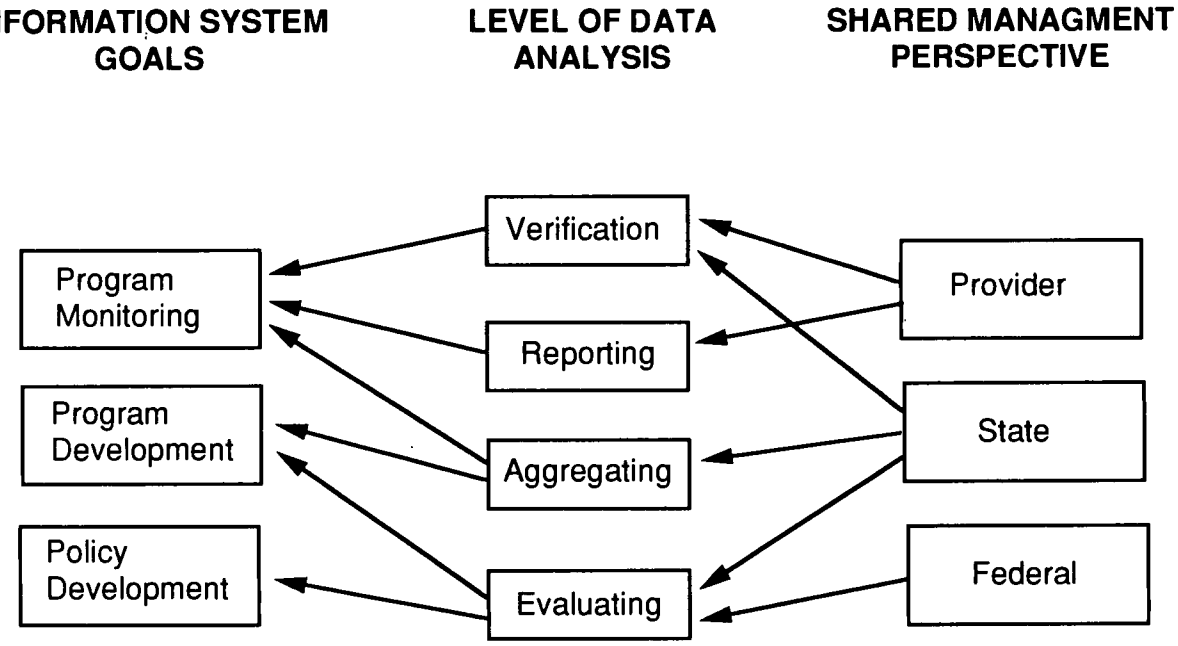

Figure 8.
Relationship Among Levels of Data Analysis, Information System Goals, and Share Management Perspective

Table 12

Information System Assessment

Directions: Answer each of the following questions regarding your state's information system for day and employment programs. Questions asked are based on Part III of the User's Manual.

Question	Evaluation (check) Yes	No	Not Sure
1. Are there clear information system goals related to:			
a. Policy Development			
b. Program Development			
c. Program Monitoring			
2. Is there a clear focus related to:			
a. Shared Management Perspective (Provider, State, Federal)			
b. Data Sets (Persons Served, Services Provided, Costs, Outcomes)			
3. Are there design and development standards related to:			
a. Reliability			
b. Simplicity			
c. User Friendliness			
d. Economy			
e. Evolvability			
4. Are there validation procedures involving:			
a. Data Selection			
b. Data Collection			
5. Does the system have data analysis capabilities related to:			
a. Verifying			
b. Reporting			
c. Aggregating			
d. Evaluating			

Footnote 1

Although the term "cost" will be used throughout the Manual, it is important to point out that "costs" are not the same as "expenditures" or "rates", although these terms are often used as synonyms. Under prospective payment, standardized service, supervision, support, capital, maintenance and supply costs are combined through a rationale to compute rates, and then providers are reimbursed for anticipated expenditures through rates. Ideally, expenditures will mirror reimbursement by rates, but total expenditures will typically hover around the total of individual rates in cost centers with appropriate management control. It is important that a state's MIS is able to project future costs as a foundation for rate calculation (Jacobsen, personal correspondence).

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