



## ENHANCING MHSIP TO MEET THE NEEDS OF CHILDREN

Final Report

Task Force on Enhancing MHSIP to Meet the Needs of Children

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## EXECUTIVE SUMMARY

Since its inception in the mid 1970s, the Mental Health Statistics Improvement Program (MHSIP) has made significant progress in enhancing mental health statistics, in fostering the development and implementation of a uniform core of mental health data items and in supporting the use of statistical information to improve clinical and management decisions. The progress made, however, did not adequately address the unique information needs of systems that serve children and adolescents.

Problems with regards to MHSIP-compatible children's data encompassed the areas of systems content, coverage and integration.

- o The MHSIP content and data standards consisted of items primarily suitable to adults rather than to children, e.g., the details of presenting problems at time of admission, assessment and definition of severity, residential arrangement, etc.
- o The definition of the system providing mental health care to children had to be re-examined, because most such services to youth were provided outside the specialty mental health system.
- o Data integration across data sets and across components of the system of care presented difficulties

unique to children services that had to be resolved.

At the request of the MHSIP Ad Hoc Advisory Group, a task force was convened and charged with addressing the problems identified and enhancing MHSIP to meet the needs of children. The Task Force consisted of the 12 individuals, representing a wide range of stakeholders, who prepared this report.

The charge to the group was to: 1) propose enhancements of the MHSIP content to support mental health services to children, 2) review the issues of coverage, interface with adult systems and information about generic services to children with mental disorders, and 3) prepare a report incorporating enhance content and recommendations concerning coverage and high priority issues, such as definitions of the target groups. The tasks were accomplished over 17 months through review and discussions, individually and in meetings.

### **Statement of Principles Concerning Data Collection and Children Mental Health Services**

Early in its deliberations, the Task Force reviewed relevant developments pertaining to mental health services to children and adolescents; changes in service philosophy, programs and information systems. As a result, the first set of recommendations of the group are that: 1) services and data to support children's mental health care be forward thinking and flexible enough to accommodate the changes that continue to occur at an accelerated pace, and 2) that the system have a set of principles that are articulated throughout the data collection process. Key principles, detailed in Chapter II of the report are:

1. The data system coverage should be inclusive
2. Data should be shared across agencies
3. The data should have a clear and agreed-upon utility
4. Participants, especially the families of children who have mental disorders, should be invested in the data collection process
5. Every effort should be made to avoid demeaning terms and minimize the negative effect of collecting the data
6. The data should be easily accessible to potential users who have an authorized need and right to know
7. The data system should promote effective and efficient service delivery
8. The data system should support communication, advocacy and marketing
9. Data elements, their definitions and data networking protocols should be standardized and compatible

#### **Recommended Content Enhancements**

The Task Force examined each of the data sets and recommended several types of enhancements. The enhancements entailed additions to current minimum sets, new items for the minimum sets, additions to current recommended sets and new recommended items.

Organization data set: 1) addition of non-specialty mental health to the item on type of organization, 2) separation of figures on children from those on adults for 11 of the current minimum set items, e.g., admission, program capacity, volume of service, etc., and 3) new items for the minimum set on mental health staff hours and client hours in non-specialty organizations, such as schools.

Client/patient data set: 1) addition of program elements, e.g., supportive services and prevention,

wherever applicable, 2) addition of presenting problems to include developmental disability, child-family conflict, role difficulties in school, etc., 3) addition of sub-items, such as child protection agencies, to referral sources and referral upon discontinuation, 4) several sub-items of residential arrangements, e.g., detention center, residential treatment center, boarding school, etc., 5) addition of "age-out" as a sub-item of discontinuation status, 6) addition of 4 new items to the minimum set - household composition, custody/guardianship, languages (other than English) of the child and his/her care-giver(s) and details about current school level, 7) enhancements of 2 recommended items - education at time of admission and employment, and 8) four new recommended items - family participation in service planning, family participation in treatment, participation of other agencies in service planning, and participation of other agencies in provision of services.

Human resources data set: addition of child mental health as a training and professional specialty and as separate professional experience.

Event data set: 1) a change in the way data are captured about all staff members participating in a service event, 2) standardized, but locally defined, type of service event, 3) addition of school and detention center to location of event, and 4) a recommended item on whether an event is included in the treatment plan.

Financial data set: addition of one item, average age of receivable, to the minimum set.

The recommended enhancements and related comments are elaborated on in Chapter III.

### Paradigm Shift

The Task Force examined key concepts articulated in the Data standards for Mental Health Decision Support systems (FN-10) to ascertain whether these concepts should be retained and promoted for information systems tailored to children services. The concepts examined were: 1) the importance of data, data standards, comparisons and data-based decision making, 2) the role of mental health organizations in the identification and definition of the mental health service system, 3) the merit of standardized minimum data sets, and 4) the importance of impact assessment.

An enhanced MHSIP to meet the needs of children was found compatible with many of the MHSIP concepts and the Task Force endorsed the main tenets of FN-10, i.e., the MHSIP ideology, collaborative style and most of its content. Needed changes were identified, however, in recognizing the role and function of families of children who have mental disorders, importance of coverage and inclusion of data on mental health service needs of and services provided to children in the community and in other health and social service systems, a desired shift from organization to person-based statistical system and the need for compliance and impact information that reflects inter-organization coordination and systems integration.

Reconceptualizing MHSIP for children is essentially a paradigm shift from an organizationally based to a multi-agency organized system of care and from an organizationally-based to a person-based data system. The reconceptualization is necessary because responsibility to serve children and adolescents with mental and emotional disorders is shared by several categorical agencies, e.g., mental health, child welfare, education, public health and juvenile justice. At the very least, a sound information system about children and adolescents who have mental disorders should cover: 1) data on both mental health and generic services and needs of children served by the specialty mental health system, and 2) mental health services and needs of children served by other systems.

A two-fold reconstruction of the current design of mental health statistics is suggested by the Task Force: a rethinking of the theoretical basis and its structure. In FN-10, management (and sometimes

regulation and control) is the dominant rationale and framework for the data system, i.e., data systems are put into place to provide managers with the information they need to acquire and allocate resources, maintain oversight, account for resources used and assess impact. It is assumed that, while clinical functions should also be supported by data, there is less need for data standards because direct service providers, clinicians and their supervisors, have most of the information they need to serve and treat each client. In systems that serve children, however, this is rarely the case, as multi-agency and authorities are involved and sound clinical care requires the sharing of pertinent (and authorized) information. Joint clinical responsibility, shared among categorical agencies, for treatment and support of the child and family is suggested as a more appropriate conceptual and theoretical base for data system for children.

FN-10 operationally defines the mental health system as a constellation of all specialty mental health organizations. For children, however, the existence of a multi-agency system of care is a necessary ingredient for appropriate service delivery. The ability to support joint clinical decisions requires an integrated service plan, thereby suggesting the need for common data standards and (at least partially) shared data system.

The Task Force recommends a data system to support a three-tier organizational configuration:

1. A state-level compact of categorically defined agencies providing endorsement and streamlined financing for an effective integration of effort at service delivery,
2. A local level consortium of all the key responsible operating agencies, and
3. An agency, identified by the consortium to either provide specific services, or take the lead in managing the care of an individual child.

The keystone of this structure is the multi-agency consortium at a community, or local level that will facilitate service access and use, minimize duplication of effort and foster collaborative planning and service delivery. Different levels of intensity of intervention may be provided by different sectors of the system of care. For example, prevention and early intervention that involve large number of children may be delivered in primary care and education setting, short term, crisis intervention and wrap-around services may be delivered by child welfare systems and intensive services by the specialty mental health system. Data on mental health organizations and the children they serve should cover the comprehensive, enhanced data standards of MHSIP, while data on non-specialty mental health organizations and children in their care may be somewhat limited in scope and detail.

The common service plan, developed under the authority of the multi-agency consortium, and the activities entailed in implementing it are the principal areas of data recording and integration. The development and maintenance of the common plan on behalf of the consortium manage the contributions of the various public systems in the care of the individual child. It is consistent with the principle of joint clinical responsibility and the statistics collected in that process combine event, financial, staff and client data that would normally reside in diverse agencies. The content of the data system consists of three groups of items:

1. Common data - data created or collected and maintained by authorized staff. Custodial responsibilities for the common database reside at the consortium level and its content includes demographic information (name, gender, race, birth date, etc.) and no sensitive , diagnostic, or clinical data.
2. Shared data - unique data that are made available to authorized staff across agencies for viewing. Custodianship is within the originating agency. The content includes service planning, service events, etc.
3. Unique data - data created for functions within a particular agency. The custodian is within that agency. The content includes highly sensitive data that could be released only with informed consent.

The suggested paradigm is described in details in Chapter IV.

### **Recommended Next Steps**

In order to carry out the recommended paradigm shift, it is suggested that two strategies be considered. The first involves joint, federal level departments and agencies. The second involves a Center for Mental Health Services (CMHS) initiative, augmented by participation of representatives of other, relevant federal and state agencies. These strategies are described in Chapter V of the report.

The first strategy is the establishment of a Federal Interagency Committee on Data Collection for Children's Mental Health, jointly convened by the U.S. Secretary of Health and Human Services, the U.S. Secretary of Education and the US, Attorney General. This group will:

- o Interface across federal entities in areas related to data standards for children and youth with emotional, mental, behavioral and neurobiological disorders and their families
- o Examine policies, regulation and laws related to data collection across and within agencies and systems
- o Commission reports and meetings regarding data collection across agencies and systems
- o Recommend policy, regulations and/or legislative actions to improve the collection of data across agencies

The second strategy calls for the establishment of a Federal/State, Multi-Agency Committee on Data Standards for Children's Mental Health, convened by the MHSIP with CMHS as the lead agency. This multi-disciplinary group will:

- o Develop standards for a shared data collection system
- o Collaborate with the suggested Federal' Interagency Committee on Data Collection for Children's Mental Health
- o Involve staff from other agencies to develop data elements and standards
- o Involve representatives from consumer and professional organizations
- o Develop a set of data collection procedures for the multiple agencies that serve the target population

### **Critical Issues**

The charge to the Task Force on Enhancing MHSIP to Meet the Needs of Children directed the group to examine several difficult issues, discuss them and suggest future actions for their resolution. These included the definition of the population, functional assessment, aging out (i.e., the transition out of children systems) and any other pressing issue.

Defining the population. Defining the population of concern and who should be the clients of the service system entails four separate questions: 1) What is the total population of concern? 2) What is the priority population? 3) How is the target population defined across child serving agencies?, and 4) Is the client the family or the child?

The Task Force submits that the population of interest should be defined very broadly as all children from birth to adulthood with emotional, behavioral, mental, or neurobiological disorders, regardless of the categorical agency in which they are served. Two types of priority populations are suggested. The first consists of what is often referred to as children with serious emotional disturbance (SED). No operational definitions are offered, largely because of the lack of universally accepted instruments to measure the functioning and symptoms of children across age and cultural groups and in different residential and community contexts. States should develop their own operational definitions, using, for example, the definition of emotional or behavioral disorders developed by the National Mental Health and Special Education Coalition, or the definition used in making disability determination for Social Security and Medicaid benefits for children under the age of 18. The second priority group consists of children and youth who have mental health problems and who are served by two or more categorical child-serving agencies.

Families play at least three major roles in mental health care of children. Family members may provide a caring environment in which service is delivered to children. In this context, they may be involved in family support services or be receiving other services designed to strengthen the family. The second role that family members may play is functioning with professionals as partners in the provision of mental health services for their child. A third possible role involves the family as a recipient of care, e.g., of family therapy. The statistics system needs to be flexible enough to capture appropriate data regardless of which of these roles families are performing. Sufficient detailed information about the family must be obtained to permit accurate description, justify appropriate billing, assess outcomes of interventions and meet information needs of policy makers and administrators.

Functional assessment. Another critical issue is the lack of instruments to capture level of functioning information for children with emotional disorders. Childhood disorders are classified using symptomology, behavioral and functional information. Little progress has been made, however, in developing valid and reliable measures of functional assessment and, therefore, no single instrument can be recommended at this time.

Aging-out; the transition out of children systems. Services for children have upper age limits which define the termination point of the services. There is great variability in these age limits depending upon the category of service and the state in which the services are rendered. In maintaining information systems for child/adolescent services it is essential that the child/adolescent be followed through the aging-out period to assure continuity of care, whenever it is needed. It is recommended that: 1) each state define its own criteria for aging out, and 2) an aging out sub-item be added to the item on discontinuation status, to aid in the assessment of linkage to the adult system.

Need for on-going structure and processes to assist with technical issues. Problems with inadequate technical knowledge are exacerbated by a rapidly changing technology. Technical knowledge is needed for selection and purchase of both hardware and software, knowledge that could have major impact on the cost and time associated with developing and implementing new and/or enhanced automated data systems. It is recommended that MHSIP institute an ongoing structure and process to promote knowledge on hardware, software and communication technology (for both adult and children data systems), produce and maintain a set of guidelines and/or standards for technical issues and assist with decisions and choices of design, hardware and software. It is also recommended that each state design and implement utilities for a flexible, secure and user-friendly data system.

Guidelines and principles for data sharing for collaborators in children's services. Information sharing across organizations is considered an essential element of coordinated service delivery to children and their families. Data sharing, however, is hampered by the divergent missions, expectations, practices, use of data, policies, procedures and regulations of agencies involved. Turf issues complicate the sharing of data about clients served by multiple agencies and by divergent interests that are often

regulated by various confidentiality mandates. Nevertheless, information sharing could be structured and facilitated by: 1) articulation of the need and rationale for professionals and organizations to share information, 2) specifications of data and information to be shared, including exceptions, conditions for disclosure, expected release forms and right to consent, 3) development of a system for information sharing at the state and local level, 4) process and structured forms for informed consent, and 5) data storage and security.

## I. INTRODUCTION

### Background

Since its inception in 1976, the Mental Health Statistics Improvement Program (MHSIP) has made significant progress in enhancing mental health statistics and information systems, in fostering the development and implementation of a uniform core of mental health data and in supporting the use of statistical information in the management and study of mental health programs. The progress made, however, did not adequately address the unique information needs of systems charged with providing, assuring, or oversight of mental health services to children and youth. This report is a proposal for both short and long range enhancements of MHSIP to meet the information needs of systems serving children and youth.

The MHSIP philosophy and data standards have been formally endorsed and adopted by multi-state organizations and are in process of implementation in most states and territories. The progress of the MHSIP can be attributed to the stewardship provided by the MHSIP Ad Hoc Advisory Group, the long-term participation and financial support of the Division of Applied and Services Research (DASR), National Institute of Mental Health (NIMH)<sup>(1)</sup>, and the voluntary participation of state mental health authorities and several task forces convened by the Advisory Group. The task forces have produced the conceptual framework, the data standards and global designs for MHSIP-consistent information systems. These incremental developments contributed to the preparation of Data Standards for Mental Health Decision Support Systems (FN-10). Unfortunately, this work and the resulting publication did not adequately address data needs in relation to children mental health services.

Beginning in 1989, a DASR initiative resulted in the awarding of NIMH grants to most states to implement uniform, integrated mental health data collection systems. The intent of this grant program was to implement data collection activities ensuring the availability of statistical information on the care and treatment of persons with mental illness. With respect to children, however, this goal could not be fully achieved within the current frame of MHSIP.

Input from providers of mental health services to youth and from the 141451? community have identified several issues and concerns about children's data and statistics. Problems with regards to MHSIP-compatible children's data involved the areas of systems content, coverage and integration.

- o Despite the intent of the architects of MHSIP to include all target populations, the content and data standards consist of items primarily suitable to adults, rather than to children. Examples of such items in the client/patient data set are the details of presenting problems at time of admission, assessment of severity of condition - or functional level - at admission, residential arrangements, etc.

- o The coverage of programs providing (adults) mental health statistics was envisioned in FN-10 as all mental health organizations. This is clearly inadequate for children, because many organized public mental health programs and services to children are not within the domain of state mental health authorities. Some are parts of educational, juvenile justice and child welfare systems, others are parts of state authorities charged with all services to children.

o As with adult MHSIP, integration across data sets is essential for management and research purposes. The ability to integrate children's data with the rest of MHSIP is also necessary to track clients, assure continuity of care and monitor the "aging out" youth, i.e., those reaching the age of adulthood.

The MHSIP Ad Hoc Advisory Group has recommended that these problems be addressed by a task force consisting of representatives of state mental health agencies, public and private providers of services to children, families of and advocates on behalf of children with mental disorders and other experts involved with data systems that reflect services to children. In response, Jack Burke, M.D., Director of DASR, approved in March, 1991, the convening of and financial support for the Task Force on Enhancing MHSIP to Meet the needs of Children. The Task Force consisted of the 12 members who prepared this report and whose names and affiliations are listed up front.

The overall objective of the Task Force was to review the design and data standards of MHSIP and, where the system did not meet the information needs related to mental health services to children, recommend specific adaptations, which would: 1) augment the design and content of MHSIP to reflect children mental health service systems, and 2) facilitate the meeting of information needs of children mental health programs managers for statistical data. The work to be accomplished consisted of the following three parts.

1. Review the charge, develop a workplan and focus on needed content. Propose changes in content required to enhance MHSIP to include data relevant to children's mental health services.
2. Review the issues of coverage, interface with adult systems and information about generic services to children with mental disorders.
3. Prepare a report, incorporating: a) the design of the content of MHSIP data that are relevant to children and adolescents, i.e., items, subitems, rationale and expected utility, and b) issue-oriented discussion and recommendations concerning next steps in relation to coverage, interface with the rest of MHSIP and development of a definition of children with severe mental disorders.

The Task Force was to meet four times over a period of 15 months. The work of the Task Force was to be accomplished both collectively during the meetings, and individually, by each member, between meetings. The initial meeting of the Task Force was in May of 1991. The rest of the meetings were in October 1991, February 1992, and June 1992.

## **Method and Approach**

As charged by the MHSIP Ad Hoc Advisory Group, the Task Force approached its assignment in several phases. First the group reviewed its charge, work plan, expected schedule, tasks, assignment and general orientation. In this phase, the group reviewed the information currently obtainable from MHSIP-consistent Systems, as described in FN-10, through formal presentations of: 1) the conceptual framework of MHSIP, its history and design, and 2) the MHSIP-consistent system in process of development and implementation in one state. A philosophy of mental health services to children and related values and principles were articulated as the basis for the intended enhancement of MHSIP.

Next, the group reviewed and discussed existing and known difficulties of meeting information needs about children with emotional, behavioral, mental, or neurobiological disorders and their service requirements. The extensive discussions of both the conceptual framework and content of MHSIP standards is summarized below in the section on integration with FN-10.

In the next phase, and as requested by the Advisory Group, the Task Force reviewed the data standards in detail and, through individual homework assignments and group discussions, drafted proposed

changes in the content to enhance MHSIP to meet the needs of children and adolescents. The proposed changes and corresponding rationale, prepared in a format that was consistent with FN-10, are described below in the chapter on content modification.

Early in its deliberation, the group agreed that a key element in the conceptual framework of MHSIP and its coverage needed a major enhancement in order to meet the information needs of systems serving children and adolescents. While most of the information needs about children's mental health services were consistent with MHSIP, the notion of service provision by one mental health organization did not seem to reflect current practices. This is because only a small proportion of children with emotional, behavioral, mental, or neurobiological disorders are served by the mental health specialty system and because multiple categorical agencies are involved in serving such children. At a minimum, these agencies include mental health, education, child welfare, juvenile justice and public health. In many states, however, children with mental disorders are also served by the separate agencies of developmental disabilities (DD), substance abuse (SA) and vocational rehabilitation. Sound mental health services to children and adolescents cross both organizations and service systems and the essential data should be encompassed in a system that is more complex than the one described in FN-10. Addressing this paradigm shift occupied a major part of the deliberations of the Task Force. The group tackled the proposed paradigm shift via group discussions, attempts to depict the desired coverage graphically, and homework assignments. The resulting model is described in the chapter on reconceptualizing MHSIP for children as a data system for a multi-agency, organized system of care.

The last phase of the Task Force was devoted to a review of unfinished issues (e.g., definition of high priority target groups, integration with adult data systems, etc.) and suggested needed actions. The review of sections and preparation of this report were the last tasks performed by the Task Force.

## II . STATEMENT OF PRINCIPLES CONCERNING DATA COLLECTION AND CHILDREN'S MENTAL HEALTH SERVICES

Since 1984, the Children and Adolescent Service System Program (CASSP), within the National Institute of Mental Health, has encouraged states to build and/or expand children's mental health services or systems of care. A system of care is defined as:

".. a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and challenging needs of severely emotionally disturbed children and adolescents" (Stroul and Friedman, 1986).

Furthermore, in 1986, CASSP program officials, CASSP grantees, and advocates for improvements in mental health services for children agreed upon a set of principles or values on which systems of care should be based. These principles state that:

1. Services should address the child's physical, emotional, social, and educational needs.
2. Services should be individualized in accordance with the unique needs and potential of each child and guided by an individualized service plan.
3. Services should be delivered in the least restrictive, most normative environment that is clinically appropriate.

4. Families and surrogate families should be full participants in all aspects of the planning and delivery of services for their children.
5. Services should be integrated, with linkages between child-caring agencies and programs and mechanisms for planning, developing, and coordinating services.
6. Case management or similar mechanisms should be provided to ensure that multiple services are delivered in a coordinated and therapeutic manner and that children move through the system of services in accord with their changing needs.
7. Early identification and intervention for children with emotional problems should be promoted by the system of care in order to increase the likelihood of positive outcomes.
8. The children should be ensured smooth transitions to the adult service system as they reach maturity.
9. The rights of the children should be protected, and effective advocacy efforts for children and youth should be promoted.
10. Children with serious emotional disturbances should receive services without regard to race, religion, national origin, sex, physical disability, or other characteristics, and services should be sensitive and responsive to cultural differences and special needs (Stroul and Friedman, 1986).

These statements were a dramatic departure from the traditional beliefs and practices that dominated the children's mental health field. However, the state-of-the-art for delivering mental health services to children has been experiencing even more rapid advances since these principles were adopted a short five years ago.

Some of the more salient advances since 1986 include:

- o Sensitivity in language used in describing the population of children;
- o Emphasis on home-based as well as community-based service settings;
- o Increased value of family participation and collaboration in the delivery of services;
- o Increased involvement of multiple systems in the design and delivery of treatment; and
- o Publication of the National Plan for Research on Child and Adolescent Mental Disorders.

In summary, effective, state-of-the-art systems of care for children and adolescents are beginning to have these characteristics: They are flexible, family-centered, and provide home and community-based programs. They also are sensitive to cultural and ethnic differences among the population of children and adolescents, and encourage collaboration between and among agencies and with families.

It is similarly essential that any system for gathering and analyzing data pertaining to children's mental health services reflect a set of principles and values that are congruent with scientifically and socially validated best practices. It is, therefore, recommended that mental health data collection strategies and systems pertaining to children and adolescents have two characteristics. First, that the system be forward thinking and flexible enough to accommodate the changes that continue to occur at an accelerated pace. Second, that the system have a set of principles that are articulated throughout the data collection process. Some key principles to keep in mind when designing an effective data system include:

1. The data system coverage should be inclusive. It should include the entire population of children and adolescents having emotional, behavioral, mental or neurobiological disorders. It should also include agencies that deliver non-mental health services to these children, as well as non-mental health specialty agencies which deliver mental health services to this population.
2. Data should be shared across agencies. Collaborative and cooperative data system development will facilitate joint service planning, coordination, monitoring and evaluation processes. It is important to remember, however, that children and adolescents have rights. The service system has a responsibility to provide the child and family with the opportunity to participate in these processes. Likewise, the data system design should provide the technical means for the treatment team (including the client and family) to adopt standards and principles for constructive data sharing, while maintaining utmost confidentiality among the team members. Feelings of trust and professionalism should be developed, encouraged, and maintained among the participants.
3. The data should have a clear and agreed-upon utility. Data should provide support for decision-making at all levels of users, including the front-line direct service worker. This is important for clinical decisions as well as those involving fiscal matters, staffing, program development and management priorities. Data should be selectively reported according to their purpose; i.e., not all data need to be reported to all levels of the system on all clients regarding all services all of the time. The data to be collected should be clearly connected with purposes that are important to the participants in the child mental health service system, and should provide information about the levels of competency of those that work with the clients. It is important that all users of data be provided with sufficient training tailored to emphasize the use of data that will support them in their roles as informed team members. This training should be available to (and from) professionals, volunteers, administrators, clients, families, advocates and other relevant service system participants, so that a workforce is developed that is sensitive to the needs of families and children.
4. Participants should be invested in the data collection process. Children and adolescents are members of families that have a wide variety of strengths and needs. These families are often perceived as "dysfunctional" when, in fact, they are merely experiencing normal reactions to a serious lack of appropriate, affordable and accessible services and supports. This presents uniquely diverse and challenging environments for establishing data-based decision making. One way to facilitate this investment in the data collection process is to seek and enlist the aid and involvement of family members from the start, while respecting their unique strengths, preferences, and needs. Parents must be welcomed as equal partners on the service planning team, participating in establishing the need for data, the data content, and data collection methods to be used.
5. Every effort should be made to minimize the negative effect of collecting the data. Data forms, screens, and reports should be designed to use appropriately sensitive language in referring to the children and families about whom data will be collected. Language used to label data elements and code values for data elements in data collection instruments should set a tone of "people first," referring, for example, to "children and adolescents with emotional, behavioral, mental, or neurobiological disorders" rather than "disturbed children" or "the disturbed", which are devaluing and demeaning. Similarly, terms like "dysfunctional" and "schizophrenogenic" in referring to families are blaming and unnecessary and are likely to reduce cooperation.
6. The data should be easily accessible to potential users who have an authorized need and right to know. System developers have a responsibility to reward those who maintain/provide data by making the outputs useful and available. This increases the likelihood that a high quality of data will be maintained. Children and adolescents and their families should be encouraged and assisted to learn about service choices and options available to them. In order to improve coordination and continuity of care, other treatment team members also need the capability to access appropriate assessment, service

and resource capacity data.

7. The data system should promote effective and efficient service delivery. A properly functioning data network can and should support the principle that services ought to be affordable, accessible, available and appropriate. To accomplish this, all relevant community service agencies should be encouraged to participate in the data network. This will facilitate integrated, flexible service planning and implementation that can be tailored to suit each family's unique characteristics. It will also facilitate blended funding strategies and shared knowledge about available capacity in existing service programs.

8. The data system should support communication, advocacy and marketing. Services should be community based, and the data system should facilitate strong interagency outreach components so that the education, mental health, child welfare, vocational rehabilitation, judicial, and health systems are aware of the programs, plans, and outcomes for each child they serve. Data should facilitate prevention and early intervention strategies as well as treatment of those whose problems are already clearly identified. It should not pose a barrier for the strengthening of natural support networks to aid in the treatment process. Children should live and interact in environments which are normalizing and least restrictive, which challenges designers to maximize the unobtrusiveness of the data systems they develop.

9. Data elements, their definitions, and data networking protocols should be standardized and compatible. This is a general rule that underlies all of the others listed above. If coverage is to be inclusive and data are to be shared across agencies, this cannot be accomplished without standard definitions of content. Standardization is essential for the data to have a clear and agreed-upon utility. Investment in the data collection process will be reduced if participants use different data languages. Without compatible networking protocol it would be impossible to make the data easily accessible to authorized users. If done correctly, the very process of developing standard and compatible data systems can serve as a vehicle for organizing the entire community service system toward effective and efficient service delivery. Finally, no data system can support communication, advocacy and marketing unless the components have common meaning and connotation.

### III . RECOMMENDED CONTENT ENHANCEMENTS TO CURRENT PARADIGM

Enhancements to the MHSIP content are necessary for improved services to children and adolescents and for accountability. Additional relevant items and sub-items could capture, for example, important clinical information, such as presenting problems that are characteristic of children. organizational and service information specific to children will enable systems managers to capture information for internal management, e.g., for cost accounting and rate setting, and for reporting, e.g., participation in the National Reporting Program and preparation of Block Grant and PL99-660 reports. The recommended enhancements are presented below. They are organized, by data set, in terms of: 1) enhancements to current items in the minimum set, 2) new items for the minimum set, 3) enhancements to recommended items, and 4) new recommended items.

## Organization Data set

The organization data set is an important component of MHSIP. The set serves the following two, major functions:

1. It captures and contains data on a structural unit of the specialty, mental health services system; nature of the organizational entity, its auspices, service components, staffing, budget, clientele and services provided.
2. It serves as a vehicle for capturing, processing, storing and (sometimes) transmitting detailed data on clients, staff and service events.

As a result, the organization data set is essential for both internal management and for external accountability, e.g., as a means for providing information to consumers, state legislators and federal agencies. For example, data provided by mental health organizations are necessary for reports related to both the State Comprehensive Mental Health Services Plan Act (PL99-660) and the federal Block Grant.

Within the service system, however, there are fundamental differences between mental health care for adults and for children; the kind of differences that should be built into the relevant data systems and reflected in information for management and accountability. Deliberations of the Task Force have produced both suggested enhancements to the current design of the organization data set, and suggested fundamental changes. The enhancements are listed below, the fundamental changes are described in the chapter on paradigm shift.

## IV. THE NEED FOR AND SUGGESTED PARADIGM SHIFT

### Integration of Enhancements into FN-10 Conceptual Framework

The purpose of the following brief analysis was to foster the integration of a desired, enhanced MHSIP that meets the information needs of serving children and the conceptual framework delineated in FN-10. The analysis covered four issues: 1) reiteration of key MHSIP concepts, 2) identification of the degree of fit between FN10 concepts and needed data about children, 3) identification of main/major difficulties and opportunities, and 4) a suggested resolution.

### Key FN-10 Concepts:

Importance of data, data standards, comparisons and data-based decision making. MHSIP is a multi-faceted program. It promotes an ideology about the use of data for improved decisions and for making a contribution to clients' services and outcome. It is also a program that consists of data standards and related collaborative projects. The content of FN-10 includes a recognition of the political environment within which services are provided, the complexity of service systems, potential difficult dynamics in complex systems and frequent difficulties in capturing and obtaining desired data. Nevertheless, key MHSIP concepts promote the notion that standardized data could and should be used to improve decision making. A most important utility of data is in performing comparisons; same organization over time, across organizations, across client groups, etc. Such comparisons require comparable data and, therefore, data standards.

Mental health organizations. Another key concept in FN-10 is the view of mental health organizations as major components of the service system and as the vehicles for capturing relevant data. Organizations are defined in terms of their charter, structure, mission, clientele and activities; all of which involve mental health needs and services. In addition to the functional definition, mental health organizations are described as consisting of smaller building blocks of program elements (inpatient, outpatient, partial day, case management, emergency and residential programs). In all cases, program elements are - and should be - also cost centers. Mental health organizations can be categorized through a taxonomy of both program elements and the services provided within them.

Decision support. The use of data to support decisions is presented in FN-10 as an extension of the functions of management. Managers are charged with providing the best care by maximizing the impact of limited resources. They acquire and distribute resources, shape activities and processes, monitor and account for the use of resources and assess the impact of activities. These major functions can be performed using information on who (client) receives what (service) from whom (staff), at what costs and with what effects. Integration of data across data bases and performance comparisons are essential features of sound use of data for these management functions.

Minimum data sets. A key concept embedded in MHSIP from its inception in the mid 1970s has been the notion that data comparability is contingent on the adoption of conventions about terminology, so there is understanding and clarity about the meaning of pertinent data. It is assumed that despite differences and unique attributes of systems, organizations, individual clients and staff, there is a core of minimum, common data that are applicable to all. It is further assumed that, akin to other fields, the choice of items for that common core and their definitions can and should be standardized, in order to enable meaningful use of data.

Assessment of impact. It is stressed in FN-10 that managers have a responsibility to assess the impact of the service system and of service activities. The scope of informational needs of management is quite broad. Managers need to know whether they have the right system, whether service organizations are doing what they are supposed to do and whether they are doing it well. Managers need data and information on the adequacy of the service system, the equity of resource distributions, appropriateness of policies and procedures, efficiency of operations and effectiveness of the services. A decision support system, such as one modeled after MHSIP, aids managers by producing, for example, performance indicators that reflect compliance, productivity, cost containment and effectiveness.

#### Degree of fit between FN-10 and an enhanced MHSIP to meet the needs of children

Most of the conceptual framework presented in FN-10 is congruent with a data system designed to meet the information needs related to children's mental health. This is true for the MHSIP ideology, collaborative style and most of the content. The design of MHSIP, as presented in FN-10, however, is not totally consistent with children's service systems in three areas.

The design of MHSIP is organizationally based, i.e., the relevant system is defined as a constellation of largely independent, mental health organizations. Mental health organizations make up the system and are the vehicle for capturing data about the system, its staff and its clients. As a result, mental health organizations define the universe for the data about the system. For example, only clients of mental health organizations are part of the client database and persons needing, or receiving mental health services within other systems are not. The MHSIP Ad Hoc Advisory Group has already articulated and presented a direction for further development, in which the program will move from an organizational to a person-based design. Such a change, however, has not yet materialized.

As described in FN-10, mental health organizations are assumed to be self contained, i.e., data internal

to the organization are used for both clinical decision concerning individual clients and for program and agency management. External data, if any, are used for comparisons only. In other words, data at the service level concern an individual mental health organization; neither multiple, agencies, nor systems other than mental health. This model of data systems is insufficient for children services, because mental health services are provided by different categorical agencies and because children with mental disorders are served by multiple agencies and across service systems. This complex system of care requires data for planning, coordination and integration of services, across organizations and across categorical agencies.

A related area of incongruence between the design of MHSIP and needed data about children is in the area of service evaluation; resources and outcome, quality and effectiveness. A MHSIP-type assessment of compliance and impact is based on individual program element or organization. As such there is neither a data set, nor an assessment domain that reflects inter-organizational, or cross service system dynamics.

### Key opportunities

First, in focusing on adults, FN-10 contains no recognition of the role and function of families of children who have mental disorders. Working with such families will require a reexamination of: 1) the role and definition of clients, collaterals and staff, and 2) data about the family that are needed to support clinical and administrative decisions.

Second, children served by the specialty mental health system are probably a small part of all those who could either benefit from treatment, or already receive mental health services, but outside the specialty mental health system. Data are desired, therefore, about mental health service needs of and services provided to children in the community and in other health and social service systems.

Third, while a service organization might have all or most of the pertinent information about an individual adult client, this is rarely, if ever, the case with children. A child who has a mental disorder needs multiple services, and a coherent plan of coordinated and comprehensive services. At the very least, children with mental, or emotional disorders need both mental health and educational services. Most likely, the needed services would be provided by multiple organizations and, therefore, cross service systems. Thus, service level data can hardly be provided by self-contained, single organizations.

Finally, compliance and impact information must reflect inter-organization coordination and systems integration. Information, and performance indicators about the appropriateness, adequacy, efficiency and effectiveness of service organizations should be supplemented with indicators about service coordination and linkage to mental health, as well as to generic services.

In this report the Task Force has: 1) endorsed the main tenets of FN-10, 2) identified conceptual problems, per the above, and 3) made recommendations how conceptual enhancements could be made.

## **Reconceptualizing MHSIP for Children:**

### **The Multi-Agency organized System of Care**

#### Statement of general consent

As reflected in FN-10, MHSIP has developed a theoretical basis for national standards for data collection and management. This theoretical framework was geared historically to the development of

community mental health policy, as reconsidered in the Mental Health Systems Act of 1980, because work on MHSIP was initiated in the period of review and reconsideration that led to that Act. Although services for children and adolescents with severe mental and emotional disorders were included in the community mental health model, its primary focus was on adult services and systems being developed in the community as an alternative to traditional institutional care. The theoretical argument advanced by MHSIP reflects that focus.

The Task Force finds that, while adjustments can be made to improve MHSIP's capture of relevant data on children and adolescents, a fundamental shift of paradigm -- a reconceptualization -- is required if relevant data systems are to be developed to support services to children, adolescents and their families, through clinical management, systems management and policy development. The primary reason for this is the reality that responsibility to serve children and adolescents with serious mental and emotional disturbances is shared by other categorical agencies and entitlements, namely, child welfare, education, public health and juvenile justice. Often, other agencies, e.g., developmental disabilities, substance abuse and vocational rehabilitation are also involved.

The basic premise for reconceptualizing a sound data system to support services to children is the need to expand both the data content and the coverage of service providers within and outside the specialty mental health system. A sound information system about children and adolescents who have mental disorders should cover:

1. Data on both mental health and non-mental health services and needs of children with mental disorders who are served by the specialty mental health system, and
2. Mental health services and needs of children served by other systems

Several assumptions will guide the re-conceptualization below. First, discussion of the children's mental health system must include recognition of the range of disorders, contextualized within a developmental framework. Second, there must be a recognition of the range of systems involved with children. In the adult service system, the mental health organization assumes leadership responsibility. However, if the same data collection model were applied to the children's area, only a small percent of children with mental health needs would be included in the data set. This is because most children who have mental disorders are not served by the specialty mental health system. Therefore, development of the data sets for children should take into account that multiple major service systems, not one, currently provide services to children and their families. Finally, the data sets must recognize the inclusion of families who are involved with the child's developmental process and must be considered full participants in the treatment of their disabled child.

Both the theoretical and organizational principles, within which a WISH? for children can be responsibly established, require a reconstruction - a fundamental rethinking - of the current system as conceived by traditional mental health. This reconstruction entails two key elements: first, a theory of a statistical system focusing particularly on the concept of "ideology", and, second, the organizational context of a statistical system focusing on the concept of a mental health system broadened into the context of a "system of care" for children and adolescents with emotional and mental disorders. These two elements define the basic dimensions of the paradigm shift from the current adult-oriented MHSIP?, if it is to be adapted to the needs of the troubled child or adolescent. These elements carry with them important implications for a child/adolescent MHSIP: organizational changes to support effective integration of effort in service delivery, the distinction of different levels of care leading to more intense intervention as needed, the importance of the "common plan" and the dismantling of barriers among the categorical agencies that serve children.

#### Dimensions of the reconceptualization

Theory of a statistical system. The theoretical framework for MHSIP is provided by Regier's discussion of the translation of information into policy. Regier (1986, as cited in FN-10) suggested that policy is affected by four factors: political idealism, or "ideologies", political pragmatism, implementation expertise and the research data base. The first of these factors assumes the most salience in Regier's conceptualization of the process of translating information into policy. Alternative choices are presented (FN-10, footnote 1, page 107) to describe the types of frameworks that are appropriate in the construction of organizational data sets: management (largely through regulation and control), or clinical responsibility. Because clinical responsibility is constrained by the exigencies of cost containment and by other controversies within managed care, FN-10 selects management as the dominant framework for the data system. This selection is based upon the pragmatic relationship between superordinate auxiliary levels and the mental health provider organizations in the adult mental health system.

Because decategorized, or integrated service delivery across different systems is clinically required for effective treatment for children, the selection of management for the conceptual framework raises some questions. Separate regulations of responsible categorical agencies and conflicts of control and turf currently paralyze and fragment efforts to constructively coordinate services for these troubled children. The resulting maze of regulations obviates the possibility of centralized management, or control. The rationale of integrated service delivery for children and adolescents seems to necessitate another conceptual starting point. Joint clinical responsibility shared among categorical agencies for treatment and support of the child and family may be a more appropriate conceptual base for a data system for children.

Organizational contest for a statistical system. FN-10 operationally defines the mental health system as a constellation of all specialty mental health organizations for the pragmatic reason that individual organizations, however various they may be, provide definable boundaries that are necessary in implementing information gathering procedures. For children, however, the existence of a multi-agency system of care is a necessary ingredient for appropriate service delivery. For children with mental or emotional disorders, responsibility is shared by multiple key service systems: mental health, education, child welfare, juvenile justice, substance abuse, and health. In the adult system, where mental health services have a more singular locus of control, the data are essentially contained within one (mental health) system. However, mental health data collection for children consistently cross service sectors. The joint decisions made by the responsible agencies in serving the child and family, i.e., the joint "clinical" decisions, also require a "decision support system" as articulated by MHSIP. The ability to support these clinical decisions at the front lines of the children's system, while maintaining cost-efficient and cost-effective service delivery across agencies, requires an integrated service plan and, therefore, common data standards. The fundamental principle guiding service provision as well as data management for children must, therefore, shift to reflect a shared responsibility across all service sectors.

For purposes of clarifying the concept of multiple system integration, the following framework is presented. According to this framework, the mental health system should be replaced by the concept of a generic system of care, created by an inter-agency, or multi-agency consortium at a community, or local level with organized services through which it can exercise its joint responsibility. The purposes of the consortium encompass the following:

1. Facilitation of service access and use across agencies
2. Reduction of duplication
3. Planning and inter-agency collaboration organizational configuration

To achieve the needed systems integration, an organizational structure should be developed to include three levels:

1. A state-level compact of categorically defined agencies providing endorsement and streamlined financing for an effective integration of effort at service delivery,
2. A local level consortium of all the key responsible operating agencies, and
3. An agency, identified by the consortium to either provide specific services, or take the lead in managing the care of an individual child.

This three-tier, local system of care is a service-providing entity which reflects the strength of the local consortium's commitment to work together effectively for the benefit of the individual child and family. It is organized with a single point of accountability, a clear governance authority and a capacity, directly or through delegation, to provide individualized services to children and their families. It is also organized to integrate clinical decision making with financial and program operations, monitoring and directing the process of service delivery to insure effectiveness and efficiency. The intended coverage of the data system to support services to children is depicted below.

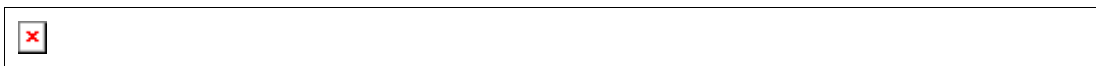
#### Necessary Coverage for a Children's Data System

		Service Domain					
		Organization		Consortium		Auxiliary	
		MH	Non-MH	MH	Non-MH	MH	Non-MH
Clients	MH	a	b	b	b	a	b
	Non-MH	a				a	
Service Needs							
Service Data							

a = Items included in MHSIP standards and consisting of full data sets

b = Items not always included in MHSIP standards and consisting of full client and event, but only partial organization, human resources and financial sets

This design for the coverage of information systems for children makes distinctions among the information needs at the organization, consortium and auxiliary levels. It promotes the need for both mental health and non-mental health data on clients of the specialty mental health systems and, largely due to feasibility issues, suggests that the amount of information from agencies other than mental health be reduced. The consortium version of the basic question mentioned in FN-10, i.e., "Who receives what, from whom, at what cost and what effect?" is presented in Figure 1. The structure of the proposed paradigm is presented in Figure 2.

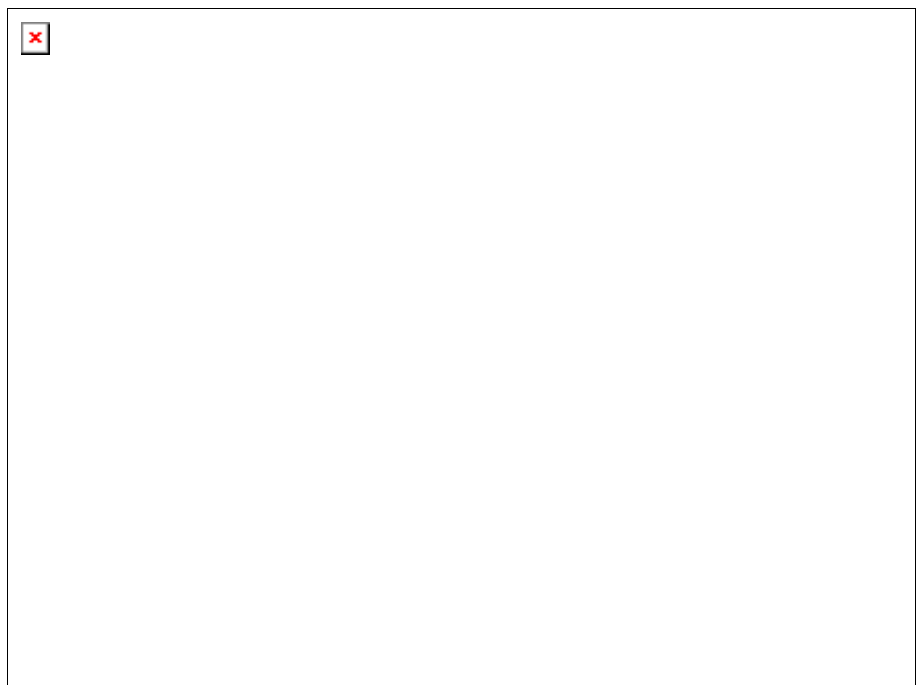


CONSORTIUM VERSION OF "WHO RECEIVES FROM WHOM,  
AT WHAT COST TO WHAT EFFECT

PARADIGM SHIFT  
FROM FIVE DISCRETE  
SERVICE ENTITIES TO  
SHARED ACTIVITIES  
AND PRODUCTS

Managing levels of intervention

Another important aspect of child/adolescent mental health is the critical importance of the formative and developmental process of growth. The systematic outreach to detect and intervene, to assess any irregularity or problem in the child's development is critical, and is one of the most glaring



failings in the present system. A child/adolescent data system that reflects a multi-agency organized system of care will entail a structured sequence of services that can be comprehensive and layered according to the degree of involvement and the intensity of the system's services.

Interventions might occur at three levels. The first level of services would entail prevention/early intervention services and services that could be made available to all children. Usually, these services, if available, are delivered in primary care and/or education settings. The second level would include short-term, crisis intervention services and wrap-around services that often are delivered through child welfare systems. The third level would be for those children most in need of intensive services. The multi-agency consortium and its system of care would be organized to provide this intensive care as much as possible in the context of the child's family and community. Interventions at this level would be through the development and maintenance of a common plan, devised by the consortium's system of care to focus the integration of effort and formalize the joint clinical responsibility for the child and his or her family.

As the level of intensity of services shifts, the most appropriate settings in which to deliver those services may also shift from one service system to another. Consequently, a restructured organization of services to children and their families needs to be erected to include the types of services and types of staff efforts that are needed and the necessary data to support service decisions.

#### Characteristics of data collection standards for the multi-agency system of care

A sound, MHSIP-consistent data system for children would maintain most of the principles articulated in FN-10, such as reliance on a data pyramid reflecting different levels of data detail at different levels of the service system. The enhanced features of this system will include a common service plan and the capacity to adapt the minimum data set to meet the reporting needs of the different categorical public systems. Additionally, the data system should have: 1) a flexible service taxonomy that can be agreed-upon and used by multiple agencies; 2) the functionality to document service events across agencies; and 3) a well-designed computer network to facilitate access and communication among agencies. With a good taxonomy of service codes it will be easier to accommodate the multiple levels of service and the sequence in which they are delivered. Furthermore, if a table-driven relational database management system is used, it can be changed as the data policy environment changes across agencies.

At the service provision level of the system of care, the common plan, developed under the authority of the multi-agency consortium, and the activities entailed in implementing and monitoring it are the principal areas of data development. The development and maintenance of the common plan on behalf of the consortium will manage the contributions of the various public systems in the care of the individual child. It will be consistent with the principle of joint clinical responsibility and the data collected in that process will combine event, financial, staff and client data that would normally reside in a wide range of diverse agencies. The content of a minimum, cross-agency data set must be designed so that it satisfies the needs of each categorical system. Data gathering methods will more likely require some mapping of items from one system onto others.

At auxiliary levels - the state compact of categorical agencies, and the relevant federal agencies - the cross agency minimum data sets should deliver filtered, or less detailed data to meet the needs of policy and resource allocation decision making in each categorical environment. The most dramatic failings of current social policy with respect to children and adolescents with serious mental and emotional disorders stems from the rigid categorical mentalities of the public systems. It is extremely important that the development of a child/adolescent MHSIP eliminate as much as possible unique categorical requirements of agency-specific data sets and promote cross-walking to the dialects of the different service traditions. In this way, the current artificial fragmentation of policy for these troubled children

can be eliminated.

## Principles for Developing a Multi-Agency Data system for Children's Services

The purpose of this section is to discuss the issues raised when multiple organizations serve the same individual. Although the policy issues related to the sharing of data are prominent in any such discussion, they are covered in a later section, while this section deals exclusively with data modeling concepts. The basic premise of this section is that development of a multi-agency data system is best accomplished in two separate phases: 1) development of a system that is technically flexible enough to accommodate any data sharing policy, and 2) development of policies and procedures. This approach allows for changes in policies and procedures while maintaining a functional data system.

### Importance of under management support

Developing a multi-agency data system starts with obtaining a high level of communication with, and commitment from upper management in the individual agencies. Without such involvement, the development and implementation effort is likely to fail. The potential pitfalls in the policy and political environments and the inertia of status quo make this support essential to a successful outcome.

### Major objectives

The development of a multi-agency data system has three major, data-related objectives: 1) to facilitate services integration and documentation, 2) to obtain unduplicated counts of service recipients across agencies, and 3) to realize efficiencies in the storage and retrieval of data by all the participating agencies.

### Data types

The design of the content of the data system should identify the universe of data and the categorization of the items into three groups: common, shared, or unique to the individual agencies participating in the consortium. These data types are defined as follows:

**Common data.** Data created or collected and maintained (including the functions: add, change, delete, view and browse) by authorized staff from two or more members of the consortium. Custodial responsibilities for the common database would logically reside at the consortium level, i.e., a designated data unit that maintains the security and integrity of the common data. Generally, the demographic records, including such items as name, gender, race, birth date, address, telephone number and identification numbers are likely candidates for designation as common data. These contain no sensitive diagnostic or clinical data.

**Shared data.** Unique data that are made available to authorized staff across agencies for viewing and browsing, but which can be added, changed and deleted only by the agency which created or collected the data. Custodianship is within the originating agency. Data related to service planning, service events, admission/discharges to/from consortium agencies can be found among the data that are shared.

**Unique data.** Data created by, or collected specifically for the purposes of conducting business within a particular agency. The custodian is within that originating agency. Highly sensitive recipient data usually is unique to the specific agency and must be specifically and formally approved by the client under informed consent procedures before release.

### Strategic analysis and design

The first step is to have the participants conduct a strategic analysis of the data requirements of the consortium. This should result in specification of logical groupings of data sets that explicate: 1) the data sets (what will be the intended topics of data, e.g., clients, staff, providers, family members, services, service events, contracts, etc.), 2) the relationships among the groupings (how the groupings will be related, e.g., whether a provider should have only one, or many contracts, whether it would be possible to browse service events by clients, etc.), and 3) the data elements within each data group. At this stage it is not necessary to fully develop the data dictionary for the data elements.

This model should be compared to those of the existing data systems in each individual agency to facilitate a preliminary decision about which data could, or should be common, shared, or unique. At this stage of development, the strategic analysis can go on despite any agreement or lack thereof on this issue. When the project reaches the design stage, however, this decision must be made so that the storage capacity and performance of the hardware platform can be estimated. At this stage, too, a more fully developed data dictionary should be compiled, specifying the field length, data definitions, data type, code tables and other particulars.

### Common registration

One of the major decisions will revolve around the sequencing of registering the person on the common system. Does each staff member enter data into the common record(s) first and download it to his/her agency's specific system, or into the agency system and upload it to the common system? Logically, control for duplication of records necessitates having some form of inquiry into the common system to permit the end user to see if the service recipient is already known to the system. This requires on-line access for those staff involved in registration. Another less preferred alternative is to use a batch process which saves all the registration and then updates the common system at another time. This will result in error reports, e.g., when the system finds a duplicate recipient, which someone at each agency must analyze and resolve.

### Updating common data

Another issue that will arise is the possibility that accurate common data, e.g., home address, will be changed by someone who has information on a recipient. The question arises as to who has ultimate responsibility for that particular data item. For some data, a solution is to use a source verification approach. This permits someone to update data if his/her source is more "official" than someone else's. For example, as a source for date of birth, a certified copy of a birth certificate is "higher" than a driver's license, which is "higher" than self report. This approach, of course, requires a data element for "source type" and a hierarchical list of sources.

### Security profiles

In order to facilitate flexible use of the common/shared parts of the system, the design should include functions for creating and maintaining security profiles. These profiles allow the system administrator to create a package of screens and functions, to name it, and to assign it to any end user. The profile defines which screens the user can access, as well as limits the functions the user can perform. As a further protection, the system should automatically time out anyone who cannot get his/her user's code/password right after, e.g., three attempts. Designated custodians should be required to develop specific procedures for the assignment and removal of security profiles.

### Some final remarks on sharing data

There are many technological tools at our disposal for accomplishing the electronic sharing of data. Data system support and maintenance, as well, are important long term issues that should not be

ignored. The major barriers are policy issues, e.g., confidentiality and the inertia of the status quo (turf guarding is but one example) . A truly effective service system for children and perhaps for adults, as well, requires that all the members of the team (including the consumers) are working toward the same goals. A service system that keeps everyone on the team in daily ignorance about significant clinical issues is destined for failure. The children and their families deserve more than that.

## V. RECOMMENDED NEXT STEPS

Implementing the recommended paradigm shift will be a major task. The challenge lies in the fact that children and youth with emotional, mental, behavioral, and neurobiological disorders may be receiving services from multiple systems. These systems include education, child welfare, mental health, juvenile justice, public health, developmental disabilities, substance abuse agencies and/or vocational rehabilitation. Few, if any, of the agencies in these other systems may know that the child or youth receives services from other agencies. In order to address this problem, immediate strategies need to be developed so that the data collected as part of the new paradigm will portray a more accurate picture of children's service patterns across and within systems.

Therefore, and in order to carry out the recommended paradigm shift, it is suggested that two strategies be considered. The first involves joint, federal level departments and agencies. The second involves a CMHS initiative, augmented by participation of representatives of other, relevant federal agencies. The two strategies are described below.

### Jointly-Convened Federal Committee

This recommendation involves the establishment of a Federal Interagency Committee on Data Collection for Children's Mental Health, jointly convened by the U.S. Secretary of Health and Human Services, the U.S. Secretary of Education, and the U.S. Attorney General. This group of high-ranking staff from the departments and agencies that define data collection policy pertaining to services to the target population of children would:

1. Serve as a Federal Interagency Committee concerned with data collection for children and youth with emotional, mental, behavioral, and neurobiological disorders and their families;
2. Examine policies, regulations, and laws which impede the collection of data across and within agencies and systems;
3. Commission reports and meetings regarding data collection across and within agencies and systems; and
4. Recommend policy, regulatory, and/or legislative actions to improve the collection of data across and within agencies and systems.

The agencies on this Committee should include, but not be limited to:

HEALTH /HUMAN SERVICES	EDUCATION	JUSTICE
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<ul style="list-style-type: none"> <li>o Child, Youth, and Family Bureau</li> <li>o National center for Child Abuse and Neglect</li> <li>o National Institute on Child Health/Human Development</li> <li>o Centers for Disease Control</li> <li>o Runaway Youth Program</li> <li>o CMHS</li> <li>o Maternal and Child Health</li> <li>o Medicaid/Social Security</li> <li>o NIMH</li> <li>o NIDA</li> <li>o NIAAA</li> <li>o National Center for Health Statistics</li> </ul>	<ul style="list-style-type: none"> <li>o Office of Special Education Programs</li> <li>o National Institute on Disability and Rehabilitation Research</li> <li>o Rehabilitation Services administration</li> <li>o Elementary and Secondary Education</li> <li>o National Center for Educational Statistics</li> <li>o Office of Indian Education</li> <li>o Head Start</li> </ul>	<ul style="list-style-type: none"> <li>o Office of Justice Program</li> </ul>
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#### MHSIP/CMHS-Convened Federal/State Committee

This recommendation involves the establishment of a Federal/State Multi-agency Committee on Data Standards for Children's Mental Health, convened by the MHSIP with CMHS as the lead agency. This multi-disciplinary group of key staff from the departments and agencies that are responsible for collecting data pertaining to services to the target population of children would:

1. Develop standards for a shared data collection system across and within systems that serve children and youth who have emotional, behavioral, mental, and neurobiological disorders and their families;
2. Collaborate with the suggested Federal Interagency Committee on Data Collection for Children's Mental Health;
3. Involve staff from other categorical agencies to develop data elements;
4. Involve representatives from consumer and professional organizations; and

5. Provide a set of systematic, comprehensive, and useful data collection procedures for the multiple agencies that serve children and youth in the target population.

Because CMHS (formerly part of NIMH) has extensive experience in data collection procedures regarding adults who use the mental health system, it is important that CMHS take the lead in this endeavor. Based on the new paradigm, there is an urgent need to involve other categorical, child-serving systems immediately in the data collection process. This will ensure that data collection elements and procedures are similar, resulting in accurate information on which to base decisions regarding children and youth who have emotional, behavioral, mental, and neurobiological disorders.

#### Composition of the committee

As youth with emotional or behavioral problems and their families are often served by multiple child serving agencies, these agencies should be involved in the development and implementation of MHSIP for children. Participants for the further development of the MHSIP elements for youth should include representatives from special education, juvenile justice, child welfare, mental health as well as consumer/advocacy organizations. Specially, representatives from government agencies as well as national associations representing professionals and families should be included. An example of the agencies and associations that should be included in the further development of MHSIP for children are:

#### **Education:**

- o United States Office of Special Education
- o National Association of Special Education Directors

#### **Juvenile Justice:**

- o United States Department of Justice, Office of Justice Program
- o National Council of Juvenile and Family Court Justices
- o National Association of Juvenile Correctional Agencies

#### **Child Welfare:**

- o Children's Bureau in the Administration for Children, Youth and Families
- o National Association of Public Child Welfare Administrators

#### **Mental Health:**

- o Center for Mental Health Services
- o National Institute of Mental Health
- o State Mental Health Representatives for Children and Youth

#### **Advocacy/Consumer Organizations:**

- o Federation of Families for Children's Mental Health
- o National Alliance of the Mentally Ill
- o Association for Retarded Citizens
- o National Mental Health Association

**Developmental Disabilities:**

- o American Association on Mental Retardation
- o American Academy on Mental Retardation
- o Association for Children with Retarded Mental Development

**Substance Abuse:**

- o National Association of State Alcohol and Drug Abuse Directors

The first strategy has the advantage of endorsement by and support of the highest levels. The second will address needed standards and, yet, might also be easily accomplished. In order to operate effectively and efficiently, it is strongly recommended that CMHS fund a full-time staff person to administer and conduct the day-to-day business of the committee(s). Participating agencies might contribute to offset the expenses incurred in reports, papers, and/or other activities related to the operation of the committee(s).

## VI. CRITICAL ISSUES

### Defining the Population

The charge to the Task Force on Enhancing MHSIP to Meet the Needs of Children directed the Task Force to adapt MHSIP to children and their special needs. To do this it was necessary to define the population, i.e., to answer the question, "Who is the client?" Answering this question requires examination of several sub-questions including: 1) What is the total population? 2) What is the priority population?, 3) How is the target population defined across child serving agencies?, and 4) Is the client the family or the child? Each of these questions will be examined individually.

#### Defining the population

The population of interest is defined very broadly as all children from birth to adulthood (as defined in each state) with emotional, behavioral, mental, or neurobiological disorders. These children comprise the target population regardless of the categorical agency in which they are being served.

#### Defining the priority population

Following extensive discussions, the Task Force reached agreement that, at this time, it was not advisable to provide an operational definition of the priority group, often identified as children with serious emotional disturbance (SED). This results in part from the lack of a universally accepted instrument(s) to measure the functioning and symptoms of children across age and cultural groups and in different residential and community contexts. The Task Force proposes that, for the present time, states develop their own operational definitions, using principles identified by The Child and

Adolescent Services System Programs (CASSP). In particular, states may want to consider adopting or adapting the definition of Emotional or Behavioral Disorders developed by the National Mental Health and Special Education Coalition (Forness and Knitzer, 1990), which provides a more inclusive definition than many focused on SED and which is compatible with CASSP principles. A second possible model is the definition used in making disability determinations for SSI and Medicaid benefits for children under the age of 18. Each of these model definitions is described below.

The definition developed by the National Mental Health and Special Education Coalition is designed to replace the definition of SED in the Education of the Handicapped Act. It states that Emotional or Behavioral Disorder refers to a condition in which behavioral or emotional responses of an individual in school are so different from his/her generally accepted, age-appropriate, ethnic or cultural norms as to result in significant impairment in self-care, social relationships, educational progress, classroom behavior, or work adjustment.

- o This category may include children or youth with schizophrenia, depression, anxiety disorders, attention deficit disorders, or with sustained disturbances of conduct or adjustment.
- o Emotional or Behavioral Disorder can co-exist with other handicapping conditions, as defined elsewhere in this law (i.e., Education of the Handicapped Act).
- o Emotional or Behavioral Disorder is more than a transient, expected response to stressors in the child's or youth's environment and persists despite individualized interventions, such as feedback to the individual, consultation with parents or families, and/or modifications of the educational environment.
- o The eligibility decision must be based on multiple sources of data about the individual's behavioral or emotional functioning. Emotional or Behavioral Disorder must be exhibited in at least two different settings, at least one of which is an educational setting.

States may also wish to consider incorporating information from the Social Security Administration's proposed revision of rules for determining whether children have mental impairments that make them eligible for SSI and SSDI benefits. The new regulations propose both diagnostic and functioning criteria for eligibility, including a multidimensional approach to assessing the severity of functional impairment. Two advantages of these criteria are that they are not limited to school age children, and the approach used is similar to the one for determining disability in adults. The dimensions to be assessed include: social function, cognitive\communicative function, personal\behavioral function, and motor function (Social Security Administration, 1989).

Briefly, a child is found to be disabled if he/she:

1. Has a medically determinable impairment and
2. Meets the duration requirement, i.e., the impairment has lasted or is expected to last a continuous period of not less than 12 months or to result in death, and
3. Meets a Listing, i.e., the child has a diagnosis of a listed impairment and all the specific medical findings for that Listing (see Part B of Appendix I of the MA Disability Manual) or
4. Equals a Listing through one of several methods, such as having
  - a. A single unlisted impairment with signs, symptoms, and laboratory findings found under a listed impairment.

- b. A single listed impairment with unlisted medical findings of at least equal severity to the listed impairments.
  - c. Functional limitations that are comparable to the limitations of the listed impairment.
  - d. Multiple impairments, none of which meet or equal a Listing, but whose combined functional effects equal the most relevant Listing.
5. If the child does not meet or equal the Listings, but is markedly restricted in his/her ability to perform age-appropriate activities of daily living and to behave in an age-appropriate manner, as determined by functional assessment, the child may be identified as disabled.

#### Defining the target population across child-serving agencies

Children from infancy to adulthood with mental health problems who are being served by two or more categorical child-serving agencies are considered to be a priority population for receipt of services. All child-serving agencies are encouraged to work together to provide services for these children and their families.

#### Defining the family vs. the child as the client

The paradigm shift suggested in this report recommends that data collection focus on the individual child, rather than on the organization. Because most children are reared in a family setting, mental health interventions often target the family or engage the child's caregivers as partners in providing mental health care to children. The Task Force recognizes that families may play at least three major roles in regard to mental health care of children. The first role is that the family may be providing a caring context in which service is delivered to children. Families providing this context may be involved in family support services or be receiving other services designed to strengthen the family unit. The second role that family may play is functioning with professionals as partners in the provision of mental health services for their child. In such cases the family may often be providing mental health services to their child. A third possible role involves the family as a recipient of care, for example family therapy in which treatment is targeted to include several or all family members. The important point from a MHSIP perspective is that the system that is developed needs to be flexible enough to capture appropriate data regardless of which of these roles families are fulfilling. Sufficiently detailed information must be obtained on the family to permit accurate description, justify appropriate billing, assess outcomes associated with the intervention, and to meet other information needs of policy makers and administrators.

#### **Functional Assessment**

Another critical issue that remains is the lack of instruments to capture level of functioning information for children and adolescents with emotional disorders. Childhood disorders have been classified using both clinical (e.g., DSM III-R and ICD 9) and behavioral classification systems (e.g., Child Behavior Checklist, Achenbach, 1991). While these classification systems lend much to the conceptualization of childhood disorders, they have limited utility in the practical application of treatment and intervention strategies. This concern for the application of treatment and/or intervention for youth with behavioral/emotional disorders is also seen in the current definition of youth with serious emotional disorders used by NIMH in its Child and Adolescent Services System Programs (CASSP). This definition includes children and adolescents who have a mental health problem diagnosable by a classification system (e.g., DSM III-R), or as diagnosable by a classification system based upon social functioning criteria. The level of social functioning, the definition continues, is a critical variable for determining the nature and level of care that is appropriate for children and adolescents. It appears,

therefore, that while classification systems, either behavioral or clinical are important, it is also important to measure the level of functioning of the youth in this population as an added dimension in determining the appropriate intervention, treatment and service mix.

Numerous terms have been given to instruments that measure some aspect of the level of functioning for children and adolescents including adaptive functioning, social functioning, and social skills. Less attention however, has been given to the conceptualization of these measures and the relationship among them. In addition, little progress has been made in developing valid and reliable measures of level of functioning appropriate for children. Development of instruments that capture level of functioning information is a critical issue for the children's mental health field. This information will not only aid in determining appropriate treatment and/or interventions but also the efficacy of the treatment and interventions for this population.

### **Aging-Out; The Transition Out of Children System**

Services for children and adolescents typically have upper age limits which define the termination point of the services. There is great variability in these age limits depending upon the category of service and the state in which the services are rendered. Thus, state mandates for special education for the severely emotionally disturbed are through age 20 in 23 states and through age 21 in 22 states, but in one state the mandated age is 17 and in another it is 25. Social Security criteria for children and adolescents apply to age 18. A similar age range exists for the juvenile justice system, child welfare and other child/adolescent mental health services. Age 18 is often cited in state plans as the upper age limit for child services, but each state sets its own age standards and there is some variation. Most states have limits in the 18-21 age range. States also have different age limit for different types of services within mental health. In some states the department of mental health does not cover child services and so no standards are set.

In maintaining information systems for child/adolescent services it is essential that the child/adolescent be followed through the aging-out period. For some youth there will be a termination of services, but for others a transition from child/adolescent services to adult services will be necessary. Important information features are whether transitional processes are in place when needed, whether they were carried out, and what the outcome was. Outcomes include discontinuation status and referral(s) upon discontinuation. It is recommended that: 1) each state define its own criteria for aging out, and 2) an aging out sub-item be added to the item on discontinuation status. the sub-item will capture data on aging out children and aid in the assessment of linkage to the adult system.

### **The Case for More TechTalk**

Buying a new computer system is somewhat similar to buying a car. Unfortunately, the experience can be akin to taking delivery only to discover that the car has no steering wheel, or no tires. More often than not, additional expenditures are required in order to obtain the essential, but missing parts. Technical innocence on the part of the buyer has, therefore, a major impact on the cost and time associated with developing or purchasing new automated data systems.

The problem of technical ignorance is exacerbated by a rapidly changing technology. As cross-agency service planning and delivery improves, the problem is further complicated by an increasing need to quickly, but securely, access and share information. This usually leads to dependency on electronic data Systems, followed by a desire to apply automation to more and more areas. Automation is very worthwhile because it increases prompt processing, billing, efficiency and decision support. Achieving and maintaining automation, however, is no small task and usually requires that someone spend a great deal of time researching and selecting the proper technology. There is increasing evidence to indicate that technical weakness is a common problem in both the child and the adult MHSIP community, for

which one apparent solution is more technical communication (techtalk) in the MHSIP community.

MHSIP must formally institute an ongoing dialogue on hardware, software, and communication technology, with the explicit purpose of producing and maintaining a set of guidelines and/or standards which could inform members of the MHSIP community about technical issues. This could take the form of a task force on technical guidelines, a newsletter (perhaps a regular section of the MHSIP Updates), an ongoing national technical users' group, a standing agenda item at the MHSIP regional users group meetings, a standing agenda item at the National Conferences on Mental Health Statistics, an electronic bulletin board, and/or some other vehicle.

Some states have already established guidelines. Some have gone further, establishing hardware and software standards which ensure compatibility throughout their systems. Nationally, benefits will accrue if systems are compatible, capable of passing data electronically, or rolling data up from provider to local, to state, and to the national level with minimal difficulties. Such capabilities could eliminate the need to manually complete the forms and reports associated with the National Reporting Program, the Inventory of Mental Health Organization, Block Grant reporting, or the NASMHPD State Mental Health Agency Revenues and Expenditures. Over time, these and other federal/national reporting requirements could be met by using automation technology that would virtually eliminate the completion of data collection forms. There would be similar advantages to be gained at the state and local levels, as well.

Much of the technology is available and in use and some states are already moving data electronically between levels of their systems. The potential for conducting and sharing the results of services and other research, for creating contexts within which to compare states' individual data, and for improving our respective technologies could be greatly enhanced, however, if there is an agreement on a technological vision for the future. Benefits will accrue to the entire MHSIP community. Since data sharing is critical in the children's area, The Task Force recommends that the MHSIP Advisory Group establish a structure to encourage technical dialogue.

#### Utilities for a Flexible, Secure, User-Friendly Data System

The MHSIP FN-10 document contains five data sets which generally cover the data found in most information systems. However, in designing a system which has the function of common registration across multiple agencies, it may be necessary to develop an additional data set. The proposed content of such a data set is usually contained in the Database Management System (DBMS) of an application and included as "Utilities" somewhere in the system. However, the importance and difficulty of addressing the issue of data sharing between agencies may call for a more explicit listing of utilities which should be included in such systems in order to make them more flexible and user-friendly.

One example might be for the software application to permit the client's service plan manager to grant permissions to members of the service team to view certain parts of the client's record (contingent, of course, on client approval) from their office workstations. Another is to permit certain treatment professionals to directly enter service notes in a central client file. A third possibility would be to permit service team members to download already-existing client information from one system to another to avoid asking the client the same questions at every service site. Examples of some functions which might be included in this data set are shown below with the data elements that are needed to perform each function:

#### FUNCTION DATA ELEMENTS

##### **A. User ID (Sign-on)**

1. System date
2. System time
3. User code
4. Password
5. Workstation ID

#### **B. Change Password**

1. User name
2. Date password last changed
3. Number of days left for password expiration
4. Current password
5. New password

#### **C. User Maintenance**

1. User code
2. User type
3. First name
4. Middle name
5. Last name
6. SSN
7. User organization ID
8. User category code
9. Screen time out limit (minutes)
10. Entry menu name
11. First time password
12. Number of days left for password expiration

#### **D. User Activation**

1. User code
2. User type
3. First name
4. Middle name
5. Last name
6. SSN
7. User organization ID
8. User category code
9. Screen time out limit (minutes)
10. Number of days left for password expiration
11. Entry menu name
12. Activate (Y/N)
13. Password

**E. User De-activation**

1. User code
2. User type
3. First name
4. Middle name
5. Last name
6. SSN
7. User organization ID
8. User category code
9. Screen time out limit (minutes)
10. No. of days left for password expiration
11. Entry menu name

12. De-Activate (Y/N)

#### **F. User Security**

1. User code Profiles Maintenance
2. User name
3. Function name
4. Function description

#### **G. Work Class**

1. Category code Categories
2. Category description (Profile Macros)
3. Function name
4. Function description

#### **H. Functions**

1. Function ID Maintenance
2. Function description
3. Function type
4. Associate command

#### **I. Screen Help**

1. Screen ID Maintenance
2. Screen name
3. Help text

#### **J. Workstation**

1. Workstation ID Maintenance
2. Description
3. Workstation type
4. Workstation status
5. Date deactivated

6. Date activated

7. Deactivated by

8. Activated by

In addition to this "Utility" data set, there may be additional items relating to coordination of activities, such as identifying who the lead worker (service plan manager) is across the multiple agencies. Although some of the items included in this section may logically belong to one of the existing five data sets, it may be useful to include them under a separate data set.

## Guidelines and Principles for Data Sharing

### for Collaborators in Children's Services

Information sharing across organizations is considered an essential element of coordinated service delivery to children and families. Organizations serving children and families must work together in an attempt to fill service gaps; avoid unnecessary duplication of service as they design system-wide responses to the complex needs of children and families who experience the debilitating influences associated with emotional disturbances. However, often organizations do not share a common mission, interests, or assumptions regarding information interpretation or usage.

The manner in which mental health professionals use information and the conclusion drawn from data can be very different from those of juvenile justice or child welfare professionals. Organizational interests also differ from agency to agency. It is with these divergent interest groups, all working toward a common concept of coordinated service delivery, that one finds the complex problems associated with data or information sharing.

Interpretation of data is subject to the influences of professional training and organizational bias toward a multitude of factors, including how an organization perceives emotional disturbance and related conditions. Data and information must be managed in a careful manner to limit the potential harm to service recipient, and at the same time provide service providers and service architects with information necessary for coordinated service delivery.

Potentially divergent interests are often regulated by various confidentiality mandates. These mandates originate from different places, including federal statutes or rules, state statutes or rules and interpretations of the federal or state constitutions and state law. In addition, in the absence of statutory provision governing an organization, there are formal or informal codes of professional ethics that regulate the professionals ability to share information with others.

Even with the limitations associated with information sharing, it is possible to develop mechanisms of exchanging data that are effective and practical on a wide scale, while protecting rights of privacy. The concepts of confidentiality need not prevent certain information sharing; just limit the use of that information.

#### The need for professionals and organizations to share information

There are many reasons for sharing information. These include, but are not limited to:

- o Ensure a data driven service delivery system
- o Ensure continuity of services

- o Avoid duplication and achieve efficiency
- o Provide family-friendly services
- o Enforce mandates of statutory service provision
- o Assess community/state/national service need
- o Permit service system evaluation
- o Promote continuous quality improvement
- o Allow for evaluation of satisfaction with services
- o Permit an analysis of resource distribution
- o Provide the fundamentals to improve accountability

Organizations have information needs that are not necessarily contrary to the privacy right of individuals. Using the above framework, it is possible to develop multiple strategies for information sharing across organizations. Nevertheless, the factors involved in confidentiality are very complex and collaborators will need to carefully analyze federal laws, state statutes and review specific case law. It is important to remember that any mechanism or system which is designed to gather comprehensive information - information which could not exist without the collaboration of others - is still subject to the same rules governing the separate data. In other words, the collective rules and strategies regulating the combined information must, at the very least, adhere to the same standards governing the organization or profession from which the information was gathered or obtained.

The following questions must be considered prior to the development of guidelines for data sharing:

- o What kind of information is covered by statute?
- o What form of information is covered?
- o What are the exceptions?
- o What are the explicit and implicit conditions which apply to disclosure?
- o What is the effect of a release form?
- o Who holds the right to consent to release?

The guidelines to be produced must incorporate and be consistent with the answers to these questions.

#### Developing the system for information sharing at the state and local levels

Once collaborating organizations agree with the need to share information, decisions must be made regarding the type and scope of the data. Discussions must involve representatives of all stakeholders and all levels of the system of care. Developing a system for data sharing should include input from:

- o Executive level leadership, across organizations

- o Parents/consumers/advocates, across disability groups
- o Direct line service providing personnel, across organizations
- o Attorneys, across divergent groups
- o Legislative aids to law makers
- o Juvenile court judges
- o Research professionals skilled in information system
- o American Civil Liberties Union
- o Ethics advisors

#### Information sharing through informed consent

With very few exceptions, releasing individually identifiable information requires permission from the individual or one who acts in the best interest of the individual. This permission or consent must be voluntary; meaning no coercion or threat of any type, and informed; meaning the individual fully understands what information is going to be shared and for what purpose, the benefit of doing it, risk of doing it, benefits of not doing it, and risks of not doing it.

Developing a data sharing system (DSS) consistent with "informed consent" will permit transmission of information, as well as provision of delimiters on the scope and use of the information. This approach to information transmission is consistent with the current limitations on data sharing and will provide collaborators with a familiar guidepost in governing their behavior.

Each cooperating organization must develop policies, procedures and forms that comply with specific mandates governing each organization as well as the collective group. It is therefore impractical to design one release form which would address all mandates across the country. Nevertheless, one should consider the following:

- o Avoid broad or blanket release
- o Releases should be printed in multiple languages
- o Releases need to clearly identify the collaborating agencies
- o Who is covered by the release
- o The type and scope of the information to be released
- o How the information will be used, by whom, for what purpose and the benefits and risks associated with releasing, as well as the potential benefits and risks associated with not releasing the information
- o Termination date of the release, which includes the mechanism to terminate the release before the date

Aggregate data should be treated as individual information and transmission and discussions regarding

aggregate data governed as if it were individual data, unless the numbers are large enough to prevent identification. Detailed specifications for confidentiality should be articulated in written safeguards.

#### Data storage and security

Records, data storage, and retrieval must be addressed by the collaborating agencies. Just because information is accessible does not mean it can or should be. The following guidelines should be incorporated into the data management system:

- o Limit access to what is in the system
- o Limit sharing to data that are in the system, i.e., do not require additional data collection
- o Limit the data that can be retrieved from the system
- o Limit the sharing of information to what is necessary
- o Prohibit the exchange of sensitive information, such as therapy notes.
- o Define the boundaries of joint teams that serve a child and identify the data that are both essential for improved services and that do not violate any restriction

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