

**DEVELOPMENT OF UNIFORM STANDARDS FOR
INTERAGENCY DATA SHARING, CASE MANAGEMENT
INFORMATION SYSTEMS, AND DATA CONFIDENTIALITY:
THE CALIFORNIA INTERAGENCY DATA COLLABORATION**

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The purpose of this paper is to describe the accomplishments and products of the California Interagency Data Collaboration (CIDC), together with some of the challenges we encountered, to help inform similar data standards development efforts in other states or agencies.

The CIDC was proposed by a group of California state and local agency representatives and other children's services participants convened by the Stuart Foundations in early 1993. Far West Laboratory for Educational Research and Development (now WestEd) was designated as the Phase I contractor and funding was obtained from a consortium of 23 California philanthropic foundations in partnership with the California Department of Health Services, the California Department of Education, and the California Governor's Office.

The mission of the CIDC was to improve the efficiency and quality of integrated children's and family services in California by creating an integrated information infrastructure to support cross-agency collaboration at both local and state levels. Its objectives were (1) to reduce the data collection burden on case managers at California Healthy Start Program sites and other interagency services collaboratives, and (2) to facilitate local use of data that are collected to meet non-local mandates. These objectives were addressed through the consensus development of standards and procedures for interagency data sharing and data transmission, functional specification for case management information systems, and confidentiality standards for the management and exchange of client data across agencies.

This project built on the previous work of the national ANSI SPEEDE/ExPRESS groups, the California Student Information System, the Family Health Outcomes Project, and the Youth Law Center. The CIDC consensus building process involved broad participation across state and local public agencies, Healthy Start sites, and software vendors.

PHASE I

Far West Laboratory (now WestEd) was funded to conduct Phase I from April, 1993 through March, 1994. During Phase I common definitions and coding structures were produced for three levels of core data elements: (1) core linkage data, (2) minimal and essential case management data, and (3) other core case management data. A subset of these data standards recently has been adopted as formal policy by the California Department of Health Services across all health services programs. In addition, 43 standards for case management information systems also were developed across the following seven functional categories: *system functionality, system design, user interface, system security, management reports, interconnectivity, and vendor services, agreements, and training*. Finally, 23 standards for protecting the confidentiality of client data were developed across the four categories of *basic principles, permissible disclosures, procedures to protect confidentiality, and automated systems*.

PHASE II

After a one-year hiatus, additional work was funded from March, 1995 through September, 1995 to a collaboration of research and information systems contractors including Walter R. McDonald and Associates, Far West Laboratory/ WestEd, UCSF Family Health Outcomes Project, National Center for Services Integration, and Philiber Research Associates. This phase involved extending the work of Phase I to include further development of the Level 3 data standards and standards for measurement of service delivery and program outcomes, development of site and vendor support materials and a training conference, and field studies of existing collaboratives.

MOST SIGNIFICANT CHALLENGES

As part of our formative evaluation of the CIDC we attempted to identify and elaborate the challenges faced by the collaboration in accomplishing the goals of the project. The five most significant challenges we found are described below. It is noteworthy that all of these challenges were based in either human or funding issues, none were technology-based.

1. ***Cross-agency cultural and language differences.*** Substantial time and effort was often required of a data standards task group to reach a common definition of one single term used differently in different human service subcultures. For example, tracking *referrals* for services was an important component of the MIS functional specifications and the term *referral* required a careful and precise definition. Participants from health services agencies tended to view a *referral* as recommendation for services from one provider to another often more specialized provider. Educators viewed *referral* as a request by a teacher for services for a student by some other professional within the school district. Child protective services staff defined *referral* as an initial reporting of potential child abuse to be investigated. Case managers from integrated services collaborations interpreted *referral* as a recommendation for services to an agency outside the collaboration. Three of these meanings involve some type of specialized or outside services but still have subtle differences important to standards definitions and resulting category coding systems. The child abuse related meaning is fundamentally incompatible with the other three meanings. Initial task group discussion focused on trying to convince the outnumbered child protective services representatives to agree to change their use of the term, or at least add a modifier such as “child abuse referral.” After several hours, it became clear that they were not going to agree to this. *What was at stake was not just an arbitrary term to allow efficient use of common data, but instead a link to their professional culture and a piece of their professional identity.* In the end, the other group representatives compromised and agreed to the more specific phrase “service referral.” Everyone was reasonably satisfied with this decision, but we had run out of time that afternoon without agreeing on any other data element definitions that afternoon. There were many other similar cross-agency cultural and language issues to be resolved, some not as vivid as this example, but all important to resolve and in total very time intensive and exhausting.
2. ***Concurrent standardization initiatives.*** Concurrent with the CIDC, major data standardization initiatives were underway in each of the three primary participating state agencies (Education, Health Services, Social Services). To some extent the CIDC was able to build on this work and at the same time inform it, however, in other cases our interagency efforts were dwarfed by the within-agency initiatives. This was especially true when concurrent initiatives were much better funded than the CIDC; when concurrent initiatives within different agencies or even within the same agency were themselves incompatible; and when initiatives were experiencing substantial problems of their own, generating insecurity and perceived need for protection of turf.

3. ***Management of donated labor.*** The CIDC was able to accomplish what it did to a large extent as a result of the donated staff time provided by participating state and local agencies. Many knowledgeable staff put in long and productive hours in addition to their other within-agency responsibilities. The challenge was managing a large pool of donated labor. When a promised review summary does not appear on time, or task group members do not show up for a scheduled meeting, there is little recourse other than skillful and gentle persuasion - often but not always effective. Another issue relates to authority and influence versus availability. For the work of the collaboration to have maximum impact, agency administrators at the highest level needed to be actively involved and informed. But agency staff who were available to attend the numerous meetings required often did not have that level of within-agency influence themselves, and sometimes did not have sufficient access to those who did to affect maximum agency impact.
4. ***Diversity of funder expectations.*** The foundations that funded the CIDC rightly approached the effort from the perspective of the needs of the local collaborations. Few of the associated foundation program staff had background or in-depth understanding of the data systems aspects of the our work. Funder education about realistic expectations and the time and effort required to perform this type of activity was an ongoing and time consuming component of the project. This challenge was magnified by the consortium nature of the funding: twenty individual California foundations, some large and some small, each contributed to the pool of money from which the CIDC was funded. Within this group level of interest in the CIDC varied substantially, and among those most interested relative priorities across potential products and accomplishments differed. These differences complicated the work of the project, and were especially salient during funding negotiations.
5. ***Unstable and intermittent funding base.*** The CIDC was funded in small phases and sub-phases, leading to gaps in progress and loss of momentum between the end of one period and the start of the next. This loss of momentum attenuated the efficiency of the collaboration and the ultimate impact of the project's work. At each funding decision point, the issues of relative priorities slowed and eventual would stall the project's work. The dissolution of the State-Foundation Consortium partnership during Phase 2 of the CIDC deflated the foundations' motivation and ability to continue with planned funding of later phases. In hindsight it would have been wise to diversify the funding base through applications for federal funding dollars or other sources early in the project.

SUMMARY OF SELECTED REPORTS

Phase I Final Report: Standards for Data Exchange and Case Management Information Systems in Support of Comprehensive School-Linked Services, March, 1994

This report provides standards and procedures intended to serve as tools to local comprehensive integrated services sites and software vendors that are developing and implementing case management information systems for the management and exchange of client data. The report is also intended to influence new development and future revisions of data systems, databases, and reporting requirements of related state agencies and programs. The executive summary of this report is reprinted below.

Section I: Introduction discusses the purpose and intent of the standards, the types of programs and situations to which they apply, six applicable data exchange models, and three likely data exchange situations. This section also includes definitions of the three categories of standards: *primary*, *secondary*, and *conditional*.

Section II: Core Data Elements Directory and Definitions, includes the directory of elements selected for inclusion in the three levels of core data: *Level 1 (core linkage data)*, *Level 2 (minimal*

and essential core case management data), and *Level 3 (other core case management data)*. Definitions and coding structures are provided for Levels 1 and 2 elements, together with initial mapping to selected data systems. (Definitions and coding structures for the Level 3 data elements are provided in the Phase II report described below).

Section III: Case Management Information System Functional Specifications Standards, provides 43 design and functionality standards for case management information systems. These standards are intended both for the site staff who will be evaluating or locally designing a CMIS, and for vendors and other CMIS developers who will be modifying or designing systems.

Section IV: Confidentiality Standards for Data Sharing and Case Management Information Systems provides 23 standards related to confidentiality and issues in sharing data across programs. In addition, Appendices B and C include charts of federal and California statutes and regulations pertaining to the sharing of client data.

Phase II Report: *Level 3 Data Exchange Standards for Other Core Case Management Data*, December, 1995

This report contains data exchange standards for Level III data elements: *other core case management data*. Included are 32 education-related data elements, 36 for health, 35 for social services, and 19 for tracking service referrals and encounters. Appendices include a table of service categories and definitions as selected from the InfoLine Taxonomy of Human Services, a discussion of confidentiality issues related to these data elements, and relevant coding tables from the California Student Information Services data dictionary.

Phase II Resource Books: (1) *A Resource Book for Local Initiatives*, December, 1995; and (2) *A Resource Book for Vendors and Other Systems Developers*, December, 1995

A Resource Book for Local Initiatives is to introduce comprehensive integrated services collaboratives to key concepts, issues, and stages in the process of developing an information system to meet their needs, and to provide guidance regarding options and features to look for as they develop or purchase such systems. Many of the concepts and issues apply to coordinated or integrated information systems efforts regardless of whether those systems are manual paper and pencil files or automated systems. It is therefore a resource book for any integrated services site that seeks both to better coordinate and better document their efforts to provide more effective services to children and families.

A Resource Book for Vendors and Other System Developers is designed to provide vendors and other system developers with an overview of the service delivery context, the information and communication needs, the system components and functions required to meet these needs, and some issues to be prepared for during the course of planning, developing, and implementing an information system in a comprehensive, integrated services environment. A number of concepts and issues addressed in this document are common to any system development effort, regardless of context. There are others, however, that are unique or particularly challenging in the multiagency context that characterizes comprehensive services initiatives. This resource book draws from the experience of those communities that have implemented or have begun development of systems in this context.

REPORT AVAILABILITY

The four reports listed above can be obtained at no charge by writing the Foundation Consortium for School-linked Services, 1321 Garden Highway, Sacramento, CA 95833.

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PHASE I FINAL REPORT EXECUTIVE SUMMARY

STANDARDS FOR DATA EXCHANGE AND CASE MANAGEMENT INFORMATION SYSTEMS IN SUPPORT OF COMPREHENSIVE SCHOOL-LINKED SERVICES

This report is intended as a guide for local comprehensive integrated school-linked services (CISLS) sites and software vendors in developing and implementing case management information systems for the exchange and management of client data. The report is also intended to influence new development and future revisions of data systems, databases, and reporting requirements of related state agencies and programs.

The report summarizes the first phase of work of the California Interagency Data Collaboration (CIDC). The ultimate purpose of the CIDC is to improve the efficiency and quality of integrated children's and family services provided in California. To support this goal, the direct objectives of the collaboration are:

- *to reduce the data collection burden on case managers at local Healthy Start sites and other similar interagency collaborations; and*
- *to facilitate the local use of data which must be collected to meet non-local mandates.*

These objectives have been addressed through the consensus development of three types of standards:

1. *data translation standards for sharing core data elements among local agencies, and between local and state agencies;*
2. *functional specification standards for local case management information systems; and*
3. *confidentiality standards related to sharing client data between agencies.*

These are the standards presented in this report, as described below.

CORE DATA ELEMENTS

Section II includes a directory of the three levels of core data elements selected for development of data translation standards. Detailed definitions and coding structures are provided for Levels 1 and 2 elements, together with initial mapping to the national and California student transcript data standards (*ANSI SPEEDE/ExPRESS Transaction Set 130* and the *California Student Information Services (CSIS) Student Data Handbook*, draft version). Definitions are not yet available for Level 3 elements. Additional work on selection of data elements for Level 3, together with development of definitions and structures for the Level 3 data elements, should be part of any future work of the collaboration.

These standards are intended for use as a common data translation language across programs and agencies. Use of these standards for data representation within local or state databases is optional and not required for participation in data exchange. However, to effectively participate an agency's data must be collected in a manner which is translatable to and from these standards with minimal loss of information.

All data names, definitions, and coding structures are designed to be maximally compatible with ANSI TS-130 and CSIS. Where our local interagency data sharing needs differ or go beyond those addressed in

these systems, we intend to apply for changes and work with these groups to ultimately reach the goal of full compatibility across systems.

Level 1: Core Linkage Data

This minimal set of data elements was selected to provide the greatest likelihood of successful matches of individuals across databases. It contains the following elements:

- Client Name
- Date of Birth
- Gender
- County of Birth
- State of Birth
- Country of Birth
- Reference Number
- Reference Number Type
- Mother's Name
- Mother's Maiden Name

Level 2: Minimal and Essential Case Management Data

These elements were selected as the smallest subset of data which should readily be available to a case manager for a new client who has already completed an intake for another program. The following elements are included for (1) *the client*, (2) *the primary contact*, (3) *one or more other parents or guardians*, and (4) *one or more other family members*:

- Name
- Date of Birth
- Gender
- Reference Number
- Reference Number Type
- Marital Status
- Lives in Household
- Street Address, City, State, Zip Code, and Telephone Number
- English Proficiency
- Preferred Language

Also included for *the client* only are:

- Interpreter Flag
- Race/Ethnicity

And for each *family member*:

- Relationship to Client

Level 3: Other Core Case Management Data for Sharing

These are data considered optional for sharing, and consist of the CISLS evaluation data together with other important data elements which potentially might be shared across some programs. Initial priority

elements have been selected so far in the following categories (please see Section II of the report for the complete listing):

- Education
- Health
- Household Information
- Risk Indicators
- Service Referrals and Encounters
- Pregnancy Outcomes

CMIS FUNCTIONAL SPECIFICATIONS

Section III contains 43 standards for case management information system (CMIS) functional specifications. These standards are intended to apply to several situations, including modifying an existing system, evaluating and purchasing a new system, or working with a vendor or in-house data systems staff to design and develop a CMIS unique to the user.

The 43 standards are organized into seven functional categories:

1. *System functionality* describes the functions required of a CMIS to satisfy the information management needs of a comprehensive integrated school-linked service program.
2. *System design* describes the capabilities to be met by the configuration of hardware and software employed, independent of the particular computer or operating system.
3. *User interface* describes system features which facilitate and enhance the users' interaction with the computer system, such as data entry, menu choices and system help.
4. *System security* provides standards for protecting records from inadvertent or intentional disclosure, unauthorized access, and loss.
5. *Management reports* identifies important system generated reports for case management and resource planning.
6. *Interconnectivity* describes capabilities for importing and exporting data from external systems, automating eligibility determination, and assisting case managers in annotating case records.
7. *Vendor services, agreements and training* presents standards for ensuring a happy and ongoing relationship between agency and vendor.

Each of the 43 standards presented in Section III has been classified into one of three categories: *primary*, *secondary* or *conditional*. Primary standards are those that should be met by all systems, unless a sound professional reason is available to show why it is not necessary or technically feasible to do so in a particular case. Secondary standards are desired as goals, but likely to be beyond reasonable expectations in some situations. Conditional standards are those which vary with the application, and may be either primary or secondary depending on the situation.

Explanatory comments, examples and cross-references are provided to assist the user, regardless of computer experience, in understanding and applying the standards.

CONFIDENTIALITY

While data sharing between agencies usually increases the efficiency of serving clients and can lead to better, more comprehensive case management, it also poses potential threats to client privacy. Service providers must keep in mind that their clients are being asked to provide information that is often sensitive, personal and private. The final section of this report presents standards for protecting the confidentiality of client information in the course of interagency data sharing. It aims to strike a balance between the needs of clients for privacy and the needs of agencies for client information.

This section discusses the importance of protecting the privacy of children and families, and presents 23 standards for protecting the confidentiality of client data. The standards are organized into the four categories of: (1) *basic principles*, (2) *permissible disclosures*, (3) *procedures to protect confidentiality*, and (4) *automated systems*. Each standard should be considered "primary"; it is essential that every participating agency and program adhere to each standard in order to fully safeguard client confidentiality. These standards include four major principles which serve to ensure that confidential client information is disclosed only when necessary, thereby limiting the potential harm that can result from sharing sensitive client data:

1. Agencies should presume that client information and records are confidential and should not disclose client data unless a specific exception to the presumption of confidentiality applies or the disclosure is authorized by the client, a court or another appropriate mechanism.
2. An interagency collaborative effort should satisfy the strictest legal and professional standards for confidentiality owed by any participating agency.
3. Agencies should collect and record only that information that is genuinely needed to fulfill the goal of serving the client. This principle suggests that agencies can minimize the potential of harming clients through improperly disclosing personal data by maintaining or sharing only the minimal necessary information.
4. At the initial meeting with each client, or soon after, agency personnel should conduct a thorough and meaningful discussion with the client about the agency's practices with regard to confidential information. Clients who understand how information about them will be maintained and used are more likely to seek services and allow their information to be shared with other agencies.

Also provided (in Appendices B and C) are charts of federal and California confidentiality statutes and regulations. These charts contain detailed information on all federal and California statutes and regulations pertaining to the handling of confidential information about children and families. The charts are intended to assist school-linked services collaborations, as well as other interagency collaborations, in developing memoranda of understanding and interagency agreements regarding sharing client data.