

Identifying Sharable Data in the Utah Department of Health

Child Health Advanced Records Management (CHARM) Utah Department of Health

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Barry E. Nangle Ph. D. and Sharon Talboys

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Executive Summary

Project Description

The Child Health Advanced Records Management (CHARM) project has proceeded on several fronts in the Utah Department of Health. At the same time that the architecture and the middle-ware were being developed, others have been engaged in working with program managers to identify the data that can and should be shared across programs. This report summarizes the latter effort.

Approach

While identifying the data to be shared in an integration project is an aspect of gathering the requirements for the project, identifying shareable data in the context of CHARM involved activities that are not strictly requirements gathering. The benefits of integrating child health information systems are not always readily apparent to all stakeholders, so an aspect of gathering requirements in this case was creating cross-organizational governance structures that could nurture an expanding scope of shareable data over time. In addition, we used traditional requirements gathering methods of collecting artifacts, such as forms, data dictionaries and documentation. These formed the basis for interviews with health program managers focused on identifying data they collected that might be of interest to other programs, and data from other programs that could be used in their own program.

Conclusion

The pre-CHARM context of data sharing in the Utah Department of Health provides sufficient experience with successful use of shared data to give most child health program managers a fairly positive orientation to the CHARM project. The immunization registry is, perhaps, the best example managers see of successful deployment of an application based on integrated information. Interviews with management of six programs that collect child health data showed that managers could identify a substantial number of specific data elements that could be practically shared across programs to enhance services to children.

Recommendations

The CHARM project should proceed with design of CHARM services, based on these findings, to utilize shared information in operational information systems. For example, the Early intervention program should draw information on risk for hearing loss and immunization status as CHARM services that use the real-time data in the hearing screening and immunization registry databases. A number of similar applications for CHARM are described in this report.

Introduction

In the context of a public health department, shareable data are data that are releasable by one public health program and useful to another program. Achieving a consensus within the Utah Department of Health on shareable data under the Child Health Advanced Records Management system (CHARM) has been an evolutionary process. Although models of shareable data for several programs have been agreed upon, the evolution is hardly complete. This report focuses on the process through which health program managers have identified the data they will use and share across programs in an integrated approach to child health information in Utah. That process is ongoing.

The outcome of data sharing will ultimately be the changed business processes of those who use child health information systems to deliver services. Since that goal is still in the future, this is a report about the journey to that destination. It begins with a discussion of the context of sharing public health data in Utah, and then describes some of the activities and formal processes used to identify sharable data. The report concludes with a description of the current consensus on data sharing within the department of health.

The Context of Sharing Data under CHARM

The Benefits of CHARM

A number of benefits of sharing data across public health programs serving children in Utah have been identified, and the intent to capture these benefits has guided the process of identifying sharable data.

Benefits for Families

An interesting result of focus groups that were conducted to assess the need for CHARM was that parents of children receiving services could express the need for sharing operational data much more readily than program managers. The desire of the parents who participated in the focus groups to reduce requests for redundant information from health programs seemed much more urgent and heartfelt than any data sharing needs expressed by health program managers. Parents saw redundant data collection as a problem that affected them personally, and clearly had the expectation that wise use of current information technology to share data among programs ought to be able to reduce their burden of providing the same data to several health programs.

Benefits for Health Programs

Program managers identified two categories of benefits of sharing data with other programs. First, sharing data with certain other programs enables tracking program coverage. For example, the Early Hearing Detection and Intervention (EHDI) program is

statutorily responsible to conduct newborn hearing screenings for every child born in Utah. Integration of EHDI data with birth certificate data reveals infants in the birth registry who are not screened. Similarly, Vital Records should have a birth certificate for each Utah birth, but evidence from linkage of the birth registry with newborn screening programs showed that unregistered births sometimes occur in Utah hospitals. So, programs providing population-based services are interested in sharing data for the purpose of tracking cases that might fall through the cracks.

Secondly, health program managers expressed a lot of interest in sharing access to data items on their clients that are collected by other programs. Some of this interest is operational, as in the case of Early Intervention providers' interest in immunization status for the purpose of ensuring adequate immunization of Early Intervention clients. Another anticipated operational use of shared data is early notification of infant death, so that programs do not unwittingly contact families of deceased clients. Heelstick Screening data identify the physician conducting the follow-up screening, and this is useful operational information for a number of health programs. Perhaps the most often mentioned piece of information program managers would like from other programs is the mere fact that one's client is receiving the services of another program.

In the CHARM needs assessment focus groups health program managers reviewed the data items potentially available from other programs and found many items interesting more from a statistical or analytical point of view than from an operational point of view. That is, programs such as the Birth Defect Network and the Neonatal Follow-up Program found virtually all of the medical items on the birth certificate interesting and potentially useful. While these data will expand the available medical history of clients in those programs, it is not clear how such detail will be useful in the context of the CHARM architecture, at least not without a great deal more thought given to the types of CHARM information services programs wish to integrate into program operations.

As mentioned, program managers are not as passionate as parents about the potential for CHARM to reduce redundant data collection. Even when data appear on the face to be redundant across programs, managers are wary that data gathered outside of their own intake or interview processes are truly equivalent. Still, the process of gathering data sharing requirements revealed some long term potential for CHARM to reduce redundant data collection, especially among the programs that serve large numbers of newborns: birth registration, heelstick and hearing screening and WIC.

Benefits to Public Health

Although the CHARM architecture does not describe a data warehouse, the linkages across data sets created through integration have great potential for enhancing our analytical resources. CHARM will facilitate creation of a rich data set for present and future efforts in child health surveillance. By linking screening data, birth certificates and child health services data a large number of health outcome indicators and risk factors will be brought together for the entire population of children born in Utah. Along

with new opportunities for surveillance, such a data set is a potentially significant resource for basic research on the genetics of newborn disorders.

Background: Existing Data Sharing Arrangements in the Utah Department of Health

Part of the context of CHARM is the prior experience of those in the Utah Department of Health with data integration and data sharing across public health programs. Health program managers have experienced some of the benefits of data sharing in the past, but are also aware of some of the difficulties associated with integration of data resources. This experience shaped perceptions in the identification of sharable data and should be described.

Data Integration under the Utah Statewide Immunization Information System (USIIS)

The USIIS program (Utah's Immunization Registry) is increasingly seen as the model for CHARM in the Utah Department of health. USIIS provides up-to-date immunization status for Utah children by combining identifying and clinical data from a variety of sources. USIIS is populated by birth data (including Hepatitis B immunization) after hospitals submit electronic birth certificates to the Department of Health. The base data are displayed to immunization providers in the WebKids application, which is used to add immunizations, as well as new patients that have moved into the state.

In addition to immunization data entered through WebKids, data arrives in USIIS from a variety of sources. The WIC Bridge enables a bi-directional flow of data between the immunization-recording module of the WIC information system and USIIS. WIC clients and their immunization information can populate the USIIS system through the WIC Bridge and immunizations that WIC clients receive from any immunization provider are returned from USIIS to the WIC system over the Bridge. The WIC Bridge is a complex piece of software developed in-house in the Utah Department of Health specifically to achieve WIC/USIIS integration. Indeed, the difficulty of developing and maintaining bilateral data exchange mechanisms for achieving integration suggests the need for more elegant tools embodied in the CHARM architecture.

In addition to WIC, USIIS gets patient and immunization data from several Utah health plans. Some of these sources are billing data, but clinical immunization data are also exchanged through an HL-7 gateway. Billing data are also submitted to USIIS by immunization providers through the Utah Health Information Network (UHIN), a billing clearinghouse, as well as through batch transfers using commercial office practice management systems.

So far, integration in USIIS has been focussed on gathering information from other data systems for the purpose of assembling a complete registry of immunizations of Utah children. The large number of users of USIIS (719) in the health care provider community, however, could form the basis for disseminating information beyond

immunization status, such as newborn screening results, to providers. The immunization registry in Utah, however, is powered by a coalition of health plans, immunization providers and public health professionals who are, understandably, focussed on growing the registry to the point of universal registration of immunizations and use by public and private providers to coordinate immunizations. The timing of expanding the USIIS user interface to include other clinical information depends on the USIIS program's success in reaching this primary goal.

Health Program Administrative Use of Vital Records

Population of the immunization registry with birth data is the most thorough use of vital records for health program purposes, but vital records are used for a variety of similar purposes in Utah.

Immunization High-Risk Registry. In the 1980s Utah developed a regression model of inadequate immunization using risk factors present on the birth certificate. Immunization survey data from Utah two-year-olds were used to develop a model of immunization status composed of demographic variables gathered on birth certificates. The model is used monthly to extract a subset of infants at high-risk for inadequate immunization for follow-up by local health departments.

Child Fatality Database. Death certificates for deceased children are linked to birth certificates and case files of the Office of the Medical Examiner. These cases are reviewed continually by an interdisciplinary team of public health, law enforcement and human service professionals. The data are stabilized into annual child fatality review data sets for analysis and reporting.

Birth Defects Monitoring. The Utah Birth Defects Network extracts selected birth, death, and fetal death records to combine with program files based on active surveillance conducted at Utah hospitals. Ongoing files are maintained for analysis and reporting.

High-Risk Infant Surveillance. Historically, some Local Health Departments have used their copies of birth certificates to monitor cases of birth defects, low birth weight and other morbidity, for the purpose of scheduling home visits by public health nurses. The electronic birth certificate is registered directly with the State Health Department, eliminating this local resource for infant health surveillance. So, the selection process has become automated, and listings of infants with certain conditions are provided to Local Health Departments for their home visiting programs.

Medicaid Data Warehouse

The Utah Medicaid program is a division of the Utah Department of Health. The program has recently completed the initial phase of a data warehouse containing monthly extracts of Medicaid claims and eligibility data, as well as several human services data sets. Current birth and death records for the whole Utah population are also extracted and placed in the warehouse monthly. The data model for the birth and death data was

developed based on plans of Maternal and Child Health analysts for evaluating health outcomes for Medicaid recipients. At this writing, the vital records, which contain most of the health outcomes of interest, have not been linked to the Medicaid or human services data, but that linkage is a goal for the warehouse.

Legal Framework for Data Sharing

Disclosure of Health Information under the Utah Code

The process of gathering requirements for sharable data included review and discussion with program managers of laws and regulations that govern the disclosure of individual health information by public health programs. Aside from reportable diseases, such as sexually transmitted diseases and hospital discharge data (neither of which is included in plans for CHARM), the disclosure of individual health data by health programs in Utah is governed by one of two chapters of the Utah Code. Disclosure of vital records is governed by Title 26, Chapter 3 of the Utah Code, the “Utah Vital Statistics Act.” Most other public health data are controlled by Title 26, Chapter 3, “Health Statistics.”

Discussions of data confidentiality tend to be rather abstract, so it was important to refer to actual sections of the Utah Code when talking about data sharing with program managers. The code sections are pretty brief, so it is worth reprinting them here. The general provision covering most health data is as follows:

26-3-7. Disclosure of health data -- Limitations.

The department may not disclose any identifiable health data unless:

- (1) one of the following persons has consented to the disclosure:
 - (a) the individual;
 - (b) the next-of-kin if the individual is deceased;
 - (c) the parent or legal guardian if the individual is a minor or mentally incompetent; or
 - (d) a person holding a power of attorney covering such matters on behalf of the individual;
- (2) the disclosure is to a governmental entity in this or another state or the federal government, provided that:
 - (a) the data will be used for a purpose for which they were collected by the department; and
 - (b) the recipient enters into a written agreement satisfactory to the department agreeing to protect such data in accordance with the requirements of this chapter and department rule and not permit further disclosure without prior approval of the department;
 - (3) the disclosure is to an individual or organization, for a specified period, solely for bona fide research and statistical purposes, determined in accordance with department rules, and the department determines that the data are required for the research and statistical purposes proposed and the requesting individual or organization enters into a written agreement satisfactory to the department to protect the data in accordance with this chapter and department rule and not permit further disclosure without prior approval of the department;
 - (4) the disclosure is to a governmental entity for the purpose of conducting an audit, evaluation, or investigation of the department and such governmental entity agrees not to use those data for making any determination affecting the rights, benefits, or entitlements of any individual to whom the health data relates;
 - (5) the disclosure is of specific medical or epidemiological information to authorized personnel within the department, local health departments, official health agencies in other states, the United States Public Health Service, the Centers for Disease Control and Prevention (CDC), or agencies responsible to enforce quarantine, when necessary to continue patient services or to undertake public health efforts to control

communicable, infectious, acute, chronic, or any other disease or health hazard that the department considers to be dangerous or important or that may affect the public health;

(6) the disclosure is of specific medical or epidemiological information to a "health care provider" as defined in Section 78-14-3, health care personnel, or public health personnel who has a legitimate need to have access to the information in order to assist the patient or to protect the health of others closely associated with the patient. This Subsection (6) does not create a duty to warn third parties;

(7) the disclosure is necessary to obtain payment from an insurer or other third-party payor in order for the department to obtain payment or to coordinate benefits for a patient; or

(8) the disclosure is to the subject of the identifiable health data.

Amended by Chapter 86, 2000 General Session

The statute is very current, reviewed by the Department of Health Data Statutes Committee in 1999, with amendments adopted by the 2000 Utah State Legislature. So, this may be regarded as a statement of current Department of Health policy on disclosure, as well as State Law. Note that disclosures of identifiable health data generally require consent, but that some important exceptions have been engineered into the law to permit the sort of data sharing envisioned in the CHARM project. Thus, the following do NOT require consent or authorization by the subject of the record:

- Disclosure to other states and federal agencies, important for such things as regional and national immunization coordination.
- Provision of identifiable data for bona fide research.
- Disclosure for disease control and other public health purposes.
- Disclosure to private health care providers for patient care purposes.

Vital Records are controlled under a law unique to that area, as follows:

26-2-22. Inspection of vital records.

(1) (a) The vital records shall be open to inspection, but only in compliance with the provisions of this chapter, department rules, and Section 78-30-18. It is unlawful for any state or local officer or employee to disclose data contained in vital records contrary to this chapter or department rule.

(b) A custodian of vital records may permit inspection of a vital record or issue a certified copy of a record or a part of it when the custodian is satisfied the applicant has demonstrated a direct, tangible, and legitimate interest.

(2) A direct, tangible, and legitimate interest in a vital record is present only if:

(a) the request is from the subject, a member of the subject's immediate family, the guardian of the subject, or a designated legal representative;

(b) the request involves a personal or property right of the subject of the record;

(c) the request is for official purposes of a state, local, or federal governmental agency;

(d) the request is for a statistical or medical research program and prior consent has been obtained from the state registrar; or

(e) the request is a certified copy of an order of a court of record specifying the record to be examined or copied.

(3) For purposes of Subsection (2):

(a) "immediate family member" means a spouse, child, parent, sibling, grandparent, or grandchild;

(b) a designated legal representative means an attorney, physician, funeral director, genealogist, or other agent of the subject or the subject's immediate family who has been delegated the authority to access vital records;

(c) except as provided in Title 78, Chapter 30, Adoption, a parent, or the immediate family member of a parent, who does not have legal or physical custody of or visitation or parent-time rights for a child because of the termination of parental rights pursuant to Title 78, Chapter 3a, Juvenile Courts, or by virtue of

consenting to or relinquishing a child for adoption pursuant to Title 78, Chapter 30, Adoption, may not be considered as having a direct, tangible, and legitimate interest; and

(d) a commercial firm or agency requesting names, addresses, or similar information may not be considered as having a direct, tangible, and legitimate interest.

(4) Upon payment of a fee established in accordance with Section 63-38-3.2, the following records shall be available to the public:

(a) except as provided in Subsection 26-2-10(4)(b), a birth record, excluding confidential information collected for medical and health use, if 100 years or more have passed since the date of birth;

(b) a death record if 50 years or more have passed since the date of death; and

(c) a vital record not subject to Subsection (4)(a) or (b) if 75 years or more have passed since the date of the event upon which the record is based.

Amended by Chapter 255, 2001 General Session

Disclosure of vital records in Utah has also been recently reviewed and the law amended in 2001. For the purposes of CHARM, the ability of the Department of Health to share vital records information is quite similar to other identifiable health data, including:

- Records are available to any level of government (local, state, and federal) for their official purposes.
- Identifying data may be provided for approved research.
- Consent of the subject of the record is not required for the disclosures specified in the statute.

The Utah Vital Statistics Act is based on the Model Vital Statistics Law developed and maintained jointly by the National Center for Health Statistics and the National Association for Public Health Statistics and Information Systems. The current Model Law can be seen at

<http://www.cdc.gov/nchs/products/pubs/pubd/other/miscpub/miscpub.htm#modelstate>.

Federal Regulations that Impact CHARM

Among the programs targeted for the first phase of integration under CHARM, only the Early Intervention Program is affected by federal restrictions on data sharing. Though gathered and managed by the Department of Health, Early Intervention client information constitute educational records, governed by FERPA, the Family Educational Rights and Privacy Act. Under FERPA, parents of children in Early Intervention must authorize disclosure of health information, even for public health purposes. Here is an excerpt from the FERPA-related federal regulations that give the requirements for data disclosure:

§ 99.30 Under what conditions is prior consent required to disclose information?

(a) The parent or eligible student shall provide a signed and dated written consent before an educational agency or institution discloses personally identifiable information from the student's education records, except as provided in § 99.31.

(b) The written consent must:

(1) Specify the records that may be disclosed;

(2) State the purpose of the disclosure; and

(3) Identify the party or class of parties to whom the disclosure may be made.

(c) When a disclosure is made under paragraph (a) of this section:

(1) If a parent or eligible student so requests, the educational agency or institution shall provide him or her with a copy of the records disclosed; and

(2) If the parent of a student who is not an eligible student so requests, the agency or institution shall provide the student with a copy of the records disclosed.

(Authority: 20 U.S.C 1232g (b)(1) and (b)(2)(A))

The exceptions to this requirement (described in § 99.31) include cases of health or safety emergencies, which do not apply to the CHARM related applications. So, Early Intervention data shared under CHARM requires parental consent for disclosures to public health programs.

Non-legal Confidentiality Concerns of Program Managers

Program managers expressed a number of concerns about data sharing under CHARM that went beyond simply observing the laws governing disclosure of individual health data. To engage managers in the vision of developing new business processes based on integrated information systems it is insufficient to develop a consensus on the legality of sharing program data. Rather, the following, overriding concerns about data sharing must be overcome.

Data stewardship. Managers of health programs are self-conscious stewards of the data they collect from the publics they serve. They do not so much fear the legal implications of an improper disclosure of client information as the challenge to program integrity that might occur from an unwanted use of disclosed information. Managers see their program data as a resource that they should maintain a high level of control over for the long-term benefit of their clients and the program itself. Any loss of such control should come in exchange for benefits that render the entire equation favorable for the program and its clients.

Preventing misleading interpretations of program data. An often expressed concern of program managers is that use of program data outside the program risks placing facts outside of context. Program managers especially fear that summary statements or generalizations made by people without an in-depth understanding of the limitations of their program data might be spurious or misleading.

Trust and organizational transparency. Sharing data sometimes means exposure of a program's data quality, coverage levels, staff productivity and other program attributes that might enable untutored judgements about the management of a program. An organizational environment in which such information is used constructively, where

managers need not fear the negative consequences of transparency, is probably a prerequisite for widespread data sharing.

The Process of Identifying Shareable Data

As mentioned at the outset, identifying the data shareable under CHARM is evolutionary. Some of the contextual information provided so far helps to explain why there might be surges and retreats in developing something like CHARM. Clearly, the various stakeholders do not have the same perceptions of the costs and benefits of the project. So, what might be a simple process of requirements gathering in a program-specific information system development project, has been more of a process of increasingly engaging program managers in focussing on the potential benefits of CHARM.

Key Structures and Activities

The methods used to engage program managers were both traditional requirements gathering techniques and nontraditional constituency - building approaches, designed to obtain some buy-in along with gathering information. These are some of the key organizational structures and activities that were part of the process:

Charm Core Council (CCC). This group has been comprised of (1) the program managers of child health service programs targeted for information system integration under CHARM, (2) several senior Department of Health managers, and (3) the technical CHARM staff and consultants. This group is presently being reconstituted a little to more closely conform to the successful model of the USIIS Oversight Committee, which steers the Immunization Registry. The CCC has been meeting every two months for over a year, however, and has been an important organ for developing a consensus on what data are shareable, and under what conditions, through CHARM. The CCC has reviewed prototypes of CHARM system components, participated in legal briefings on the confidentiality of child health data, and, in general, provided input on the potential uses of integrated data in public health programs.

Needs Assessment. During calendar years 2000 and 2001 a child health data integration needs assessment was conducted in Utah, in connection with Genetic Services planning. This planning effort provided the resources and the opportunity to bring together a large number of stakeholders for focus group discussion of child health data integration issues. The participants included the program managers who now form the CCC as well as parents of children receiving services, private providers and child health advocates. Ideas about the costs and benefits of data integration that arose during those sessions and were documented in the needs assessment report continue to be a foundation for current assessments of what is shareable data.

Face-to-face Interviews. Two analysts conducted 2-3 interviews each with the programs targeted for the first phase of integration under CHARM. The interviews were the basis of the following activities:

1. Communication of CHARM capabilities to programs.
2. Identification of program's business needs.
3. Gathering data dictionaries.
4. Having programs identify data they are willing to share.
5. Having programs identify data they would like from other programs.
6. Development of data sharing agreements.
7. Clarification of data rules, authority, and default options.
8. Development of conceptual data models of all and shareable data.
9. Development of physical data models.
10. Identification of agent requirements for each program.

Program Perspectives on Shareable Data

The USIIS Program

The Utah Immunization Registry, of course, is an integrated data system that rests on its ability to obtain demographic and immunization data from other data systems. The widely perceived success of the program is the reason CHARM has USIIS as a model. Under CHARM, USIIS will primarily be a provider of immunization information to programs providing child health services that wish to know a child's immunization status. USIIS management is comfortable in this role, since providing information for immunization coordination is the mission of the program.

The program is currently less comfortable in the role of disseminating other public health information to private providers that use USIIS for immunization coordination. Management can envision this as a CHARM service to USIIS users at some point in time, and have acknowledged that the availability of other types of information could encourage more private providers to become USIIS users. However, the USIIS program does follow the direction of its Oversight Committee, and that committee has expressed its will that the time is not right for USIIS to focus on issues beyond immunization coordination.

Newborn Heelstick Screening

Currently, newborns in Utah have six required screenings for metabolic and non-metabolic disorders. This program follows-up on positive screens and manages the entire population-based database of screening results. The program has a history of sharing data with other public health programs, including providing contact information for the Pregnancy Risk Assessment and Monitoring Survey (PRAMS). In requirements gathering interviews program management identified the following potential for data sharing under CHARM:

- The Birth Defects monitoring program could identify cases using newborn screening information.
- The Child Development Program currently requests test results manually, and this process could be automated.
- Physicians sometimes request test results.
- There is an overlap of Newborn Screening clients and clients in the Neonatal follow-up program, which gathers its own demographic and health items from families.
- The program would like early notification from vital records data in the event of a deceased infant.
- It is hoped that CHARM will enable timely dissemination of new identifying information in cases of adoption. Similarly, the program needs accurate and timely information when serving children in protective custody.
- The program would like to know all the other public services their clients are receiving.

Newborn Hearing Screening

Screening for sensorineural hearing impairment is required for all Utah newborns. The Early Hearing Detection and Intervention Program (EHDI) manages the hearing screening data that are gathered in Utah Hospitals. Data sharing is crucial to the EHDI program for two reasons. First, the population in the EHDI databases overlaps virtually 100 % with the other universally required newborn public health services, birth registration and newborn heelstick screening. Sharing data among these three programs is important for assurance of universal coverage of the programs.

Second, it is important that EHDI disseminate hearing screening results to programs and providers of services to children that may have hearing impairments. In this way, the program seeks to fulfill its goal of assuring follow-up diagnosis and intervention for children with positive screening results. The program currently shares hearing screening data manually with a number of other programs, including Early Intervention, which serves many children with hearing loss. The program is also very interested in making hearing screening results available to private providers, along with “forecasts” of diagnostic tests that are due.

So, for Newborn Hearing Screening, shareable data include information from the other newborn registries that EHDI needn’t collect directly, and output of screening results to child health service providers.

Birth Defects Network

This program conducts surveillance of major birth defects in Utah and maintains a database of about 1,000 cases per year, or about 2 % of Utah births. The program’s expectation of CHARM is similar to EHDI, in that the primary interest is in obtaining richer newborn data from existing public health data sources and assuring follow-up intervention for the cases ascertained by the Birth Defects Network (BDN).

Data sharing with Vital Records. BDN is currently one of the few data systems that feed back data to Vital Records. The BDN obtains detailed case data from hospital sources which are used to correct the statistical data collected on birth certificates, which is incomplete with respect to congenital malformation data. This is a manual process that could be more automated under CHARM. At the same time, birth certificate data, especially the various text fields describing risk factors and newborn conditions, could be better screened for birth defects surveillance, and this could be a CHARM service.

Data sharing with providers. The program would like to know what services children in their case files are receiving, and conduct follow-up activities based on that information. Identification of the current pediatric provider would be useful information. Birth defects prevention is important to the BDN mission, especially folic acid supplementation for potential mothers. The program has educational, counseling and supplement provision programs in this regard that could benefit from information from other programs about at-risk women.

BDN management has relatively complex concerns about data confidentiality under CHARM. While cognizant of the advantages of data sharing, birth defects surveillance data have a tradition of very high levels of security and confidentiality. Management's concerns reflect precisely the concerns of parents, heard during the CHARM needs assessment process, for special treatment of information that might make families vulnerable to detrimental decisions by insurance companies. It is not clear at this point that birth defects case information is itself shareable under CHARM.

Early Intervention

Background. The Early Intervention (EI) operational data system is being developed concurrently with the CHARM architecture, so some detail on EI operation is instructive. The program provides early intervention services statewide for young children with development delays and/or disabilities under the age of three years through the provisions of the Individuals with Disabilities Education Act (1997 Amendments). Children with a measurable delay in one or more of the following developmental areas: cognitive, communication, social or emotional, adaptive, or physical development (includes health, motor, hearing, vision) qualify for services. Services include multidisciplinary evaluation and assessment; service coordination among providers, program and agencies; provision of specialty and therapy services such as special instruction; nursing; physical, occupational, and/or speech therapy; family support; service coordination and other related services and strategies to build on family strengths and child potential. Services are available statewide through local service delivery personnel and are provided in the child's natural environments including the home, and community settings in which children without disabilities participate. Some services are provided without cost to families, other services require a co-payment, which is based on a sliding fee scale. Referral of a child to the program can be made by anyone concerned about the child's development.

Data sharing needs. The program is interested in direct referral from another CHARM program that comes complete with all the relevant CHP data. EI would like hearing screening information on its clients, as well as immunization status. Program management is interested in services clients are receiving from Children with Special Health Care Needs programs. As noted in the Legal Framework section of this report, sharing of EI data is governed by FERPA. So, parental consent is specifically required for any data shared with other programs under CHARM.

Vital Records

A number of child health programs are interested in CHARM services involving birth and infant death records. The newborn screening programs anticipate measuring program coverage against birth registrations and others will enhance surveillance efforts under CHARM. All of the CHARM participants wish updates in the case of infant death and adoption. The information that a vital event has occurred on a certain date, then, is of primary interest to other programs. While use of vital records demographic and maternal and child health data may carry the potential for reducing redundant data collection in the long run, the phase I CHARM programs have not described immediate applications for that service. There is much greater overlap of vital records data items with programs such as WIC, which are not in a position to participate in CHARM initially.

The Vital Records Office will use CHARM services, first, in the same way as the newborn screening programs, to identify infants screened but not in the birth registry. Updates of current information on individuals in the birth registry are of little value to vital records, since the operational use of birth data are to provide certified copies of the facts of birth and to produce annual statistics. Corrections to statistical information based on health program data are helpful, and Vital Records anticipates some automation in the receipt of those through CHARM.