

FINAL REPORT

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**State of Utah Department of Health**

**Needs Assessment:  
Child Health Data  
Integration**

**February 1, 2002**

This report was funded by the Utah Department of Health with grant monies provided by the U. S. Department of Health's MCH Genetics Services Branch under grant CFDA #93.110A.



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# To the Reader:

Utah's Department of Health (UDOH) is continuing its efforts to develop effective ways to provide seamless services delivery across programs. In a joint effort with families from the community, representatives from private health care practice and Public Health programs within the State and Local Health Departments we have just completed the first step of a process that will enable integration and sharing of child health data. UDOH's Division of Community and Family Health Services is directing this cross-program project.

Over the next two years funds from the Maternal and Child Health Bureau (MCHB) Genetic Services Data Integration (GDSI) grant will be utilized to complete the planning and implementation process. This document presents the results of the Needs Assessment phase of the planning effort. It represents a significant step for the Utah Department of Health towards the development of a confidential, yet shareable child-specific public health information accessible by people with a need to know.

The study's findings provide insight regarding the characteristics which stakeholders feel an integrated automated repository of child health information must have, namely:

- ❑ Capture information once and share information widely among those with a need to know (individuals, families, private providers and other public and private organizations) in an easy to use electronic form
- ❑ Provide confidentiality and security safeguards
- ❑ Collect data based on common standards and definitions agreed upon by principal users of the system
- ❑ The system will be voluntary allowing individuals and families to opt out if they so desire

Health care is behind most other industries in adopting information technology. Meeting the information needs of these stakeholders in an integrated, electronic and easy to use format will require continuing investments of time and resources to establish the technical infrastructure and resolve the critical issues concerning the sharing of information. The vision will only be realized if health care providers also invest in the information technology necessary to allow them to participate in this integrated system. At the same time information system integration must remain accountable to real, articulated business needs, not merely be justified because of its potential to solve data sharing problems. One should also be mindful of the fact that information "systems" include not just technology but the people who use them. An equal amount of attention needs to be placed upon both the technical and human changes required to achieve the vision of information sharing.

As you read this report keep in mind that it is not an end in itself but rather a significant step in an ongoing process to better serve Utah families and to better support those involved in delivering services or administering public health programs. I hope you will embrace this project and all it entails as we plan for and build a future full of great potential for healthy Utahns.

Sincerely,

Rod L. Betit  
Executive Director

## **Executive Summary**

### **Background, Scope and Purpose**

Accurate and timely data are vital for the State of Utah to provide appropriate health services to its citizens. While data exist in myriad array within the public and private health sectors, each database serves its own set of users and is not shared across organizations or health programs. Services are often not coordinated and usually do not constitute a coherent network of care for families. As a result many children do not receive much-needed follow-up. It has been estimated that although 95% of Utah's children receive newborn screening services, nearly one-third of those are lost in follow-up.

Agency personnel and health providers are recognizing the need to coordinate services across program and organizational boundaries to best serve common client families. Accessible, integrated information is the cornerstone for enabling this kind of collaboration.

Developing the capacity to share information among families of children, providers, public health agencies and program staff is a key strategy for the Utah Department of Health (UDOH). Integration of public health data sets would support coordination of services, reduce duplication of services, and promote better health for children. It would also reduce the duplicative data entry universal in all data sets (e.g., name, address, date of birth, etc.). The integration of child health information DOES NOT mean that health programs, agencies or providers must give up their autonomy or that specialized health experts will become generalists. Rather it would enable the sharing of information pertaining to common clients to facilitate better service to our citizens.

In line with these objectives an effort within the Division of Community and Family Health Services (CFHS) is being funded by a federal Genetics Services Data Integration (GSDI) grant. The grant's purpose is to enhance the ability of the Department to generate an accurate and complete profile of the health of Utah's children via the integration of publicly held data sets. The ultimate goal of the two year grant is to create a plan for statewide genetic services and data integration that will be complete and ready for implementation. This project represents a unique effort to look across individuals, programs, organizations and providers to find a common ground for integrating and sharing information.

The activities to be pursued with the grant funds have been structured to include two phases. This report represents the outcome of Phase I, a Child Health Data Integration Needs Assessment (Year One). Phase II (Year Two) will involve the preparation of a detailed plan for implementing the data integration requirements determined during the Needs Assessment. Initial emphasis will be placed on planning for the integration of Vital Records, Newborn Hearing Screening, Newborn Heelstick Screening, Early Intervention, Birth Defects Registry and Immunization Registry data.

The primary objective of the Phase I Needs Assessment was to solicit input from stakeholders representative of those needing access to integrated child health data. This input was critical in order to:

- ❑ determine what information needs to be shared with families and across agencies, programs, and providers
- ❑ determine how the sharing of information would benefit each stakeholder group
- ❑ identify the risks/barriers of information sharing
- ❑ determine whether the benefits of integrating data collected by multiple programs and providers outweigh the risks

This document identifies, in detail, the information that comprises a child health profile as well as other information key to the development of such a profile. Other activities within the Needs Assessment included analyzing the current technical characteristics of the systems targeted for integration, proposing technical alternatives for addressing the data integration needs and developing recommendations for laying the groundwork for sharing information across agencies, providers and constituencies.

### **Child Health Data Integration Stakeholders**

The analyses performed during the course of the Needs Assessment project involved stakeholders from public health agencies and programs, public health advocacy groups, and individuals representing Utah families. Their input was essential to define:

- ❑ what data would be appropriate to be included in an integrated child health profile
- ❑ how integrated profile information would enhance public health services
- ❑ the barriers, risks and issues related to sharing information.

Those invited to participate included:

- ❑ representatives of families of Utah's children
- ❑ public health advocacy groups including consumer advocates from ethnic groups, parent groups, children's interest groups and low income groups
- ❑ private providers
- ❑ UDOH Sr. Management
- ❑ representatives of State public health programs including Newborn Hearing Screening, Newborn Heelstick Screening, Newborn Screening, Vital Records, Immunizations Program, Early Intervention, Hearing, Speech and Vision Services, WIC, Medicaid, and Children with Special Health Care Needs (CSHCN) Clinical Programs

- ❑ representatives of other public health programs such as Centro de la Familia de Utah and the Indian Walk-In Center
- ❑ a representative from UDOH's legal department
- ❑ representatives from CSHCN Information Technology (IT)
- ❑ representatives from UDOH Information Technology (IT)

### **Current “Program Oriented” Environment vs. Envisioned Integrated Environment**

A key activity during the Needs Assessment was the assessment of the current environment. This analysis revealed a “system” of independent service delivery processes and “stovepipe” automated information systems supporting single program oriented services. The stovepipe systems reside on incompatible hardware and software platforms, and often collect the same information. This situation does not support cross-program services delivery or information sharing at a time when the demand is overwhelming.

An integrated approach would enable access to information about the client/family across programs and services. This vision requires that health programs and service delivery partners view themselves as part of a seamless, integrated health entity. Features of such a seamless system include:

- ❑ Cross-program information available for more responsive service delivery, greater capacity for making referrals and enabling follow-up
- ❑ Client/family information that is easily shared among those who have a legitimate need to know
- ❑ Databases containing consistent data capable of being linked or combined
- ❑ Compatible technology platforms resulting from agreed-upon software, hardware, networking and Internet standards

In addition to information needs and standards, software, hardware, networking, and Internet requirements for an integrated, seamless system will need to be defined across the department so that over time technology solutions developed by different programs/organizations become increasingly compatible. Current databases that contain the same information but are defined in different ways and updated inconsistently, are replaced by databases containing consistent data capable of being easily combined.

### **Conclusion**

The findings of this assessment indicate that there is both external and internal support for data integration. Although information sharing raises confidentiality and security issues, this project's stakeholders believe that the potential benefits of information sharing outweigh the risks, assuming adequate security safeguards are in place. Already there have been some small successes in the department in

“testing” the concept. To keep the momentum going and to ensure that support remains high there are several key success factors:

- ❑ UDOH Sr. Management Commitment
- ❑ Shared ownership among agencies and constituencies involved
- ❑ Focus on providing the best service versus how internal processes can be accomplished and by whom
- ❑ Modularized Deliverables. It is important to accomplish the integration in steps in order to ensure that initial efforts successfully meet expectations.
- ❑ Maintaining the integrity of the current systems. The integrated solution must not compromise the integrity of data residing in the department’s current systems.
- ❑ Managing Risks. Project stakeholders identified risks associated with efforts aimed at integrating child health data (discussed below in “Needs Assessment Findings”). These will need to be managed on an on-going basis.
- ❑ On-going funding

### **Next Steps**

Since the findings from this assessment confirm that integration of child health data would be beneficial, it must be determined how best the information sharing can be achieved. The first step in this process is to finalize an implementation strategy. This will enable the Department to plan the effort, build a timetable and identify cost and human resource requirements.

There are several options for integrating child health data. Some are based upon combining data into a single, integrated database. This kind of a solution is sophisticated in function and provides substantial immediate and long-term benefits. However, it is costly to implement (requires redeveloping/replacing existing systems), would introduce substantial business change, and would require a heavy time commitment from UDOH staff during the development, testing and user training phases. Other alternatives enable data sharing utilizing technologies that link or connect multiple systems (each system retains its own database). There are several ways to link systems. Some linking solutions are fairly simple in design, pose less risk, and are less complicated and less costly to implement (but also provide less automated functionality). Other linking solutions are relatively complex in design, more costly and time consuming to implement, and introduce more risk into the development and production life cycles. The technical members of the Needs Assessment team have identified several alternatives. The department will need to assess these options and decide upon a strategy that best fits its needs at this time.

## Needs Assessment Project Approach

Assessing information sharing needs across public health programs, external organizations and providers is an ambitious undertaking requiring a clear understanding of purpose, a process to guide the work and a strategy for getting the right people involved. This section discusses the course taken by the Needs Assessment project team to collect the vast amount of information from key stakeholders.

### UDOH Strategic Direction

Providing direction for the Needs Assessment are key Department of Health goals, objectives and business principles related to:

- ❑ coordinating services among programs dealing with the same client base for the benefit of serving families
- ❑ doing business in such a way that all customer needs are considered
- ❑ entering public health data only once and making it readily retrievable by all authorized people
- ❑ ensuring the accuracy, availability and usefulness of health information

These drivers created the need for this project and the context for examining the data integration requirements.

To specifically address these strategic directives, the department has identified five Information Systems (IS) vision initiatives. One of these, the Child Health Advanced Records Management (CHARM) effort, provides the framework for this project. CHARM's long-term goal is to integrate early childhood related databases with immunization data and later expanding to more child health related databases. The short term goal of CHARM is to link hearing screening records, newborn heelstick screening records, and vital records so that a large number of health outcome indicators and risk factors will be brought together for the entire population of children born in Utah. The current GSDI grant addresses the needs assessment and planning phases for CHARM's short-term goal.

### Needs Assessment Core Team

Core members of the GSDI grant's Needs Assessment team included:

DOH GSDI Grant managers:	John Eichwald, CSHCN Clinical Administrator Lynn Martinez, Program Manager, Birth Defects & Teratology
IT Team Members:	Don Gabriele, UDOH IT

Jane Johnson, CSHCN

MTW Corporation Consultants:

John DiDominic - Evaluation

Rao Mulpuri – Technical Environment Assessment

Maribeth Sturgeon – Facilitation, Management  
Consulting & Final Report Preparation

## **Soliciting Input from Project Stakeholders**

### *UDOH Sr. Management*

Providing direction to the Needs Assessment team were members of UDOH's Sr. Management team including:

Scott Williams, M.D, MPH – Deputy Director, UDOH

George Delevan, M.D. – Director, Division of Community and Family Health Services

Rhoda Nicholas, Chief Information Officer, UDOH

They assisted in identifying stakeholders for the Focus Group sessions and invited them to participate. They were especially interested in ensuring that the needs of both the consumers and providers of health services were considered. Their input was also helpful in identifying risks, key project success factors, and potential issues associated with data integration.

### *UDOH Program Stakeholders*

Because of the number of stakeholders involved in the Needs Assessment it was determined that Focus Group Sessions would provide the optimal format for gathering input, maximizing participant interaction and achieving consensus. To this end, four Focus Group sessions were conducted. Participants in the first two Focus Group sessions were from UDOH programs. Their task was to clarify the definition of a “child health profile” and identify its general parameters, benefits, barriers to implementation and to provide other input.

### *Stakeholders Outside UDOH*

During the third session the unique requirements of groups outside of UDOH were examined. Participants included representatives from public health advocacy groups (including parent groups, ethnic groups, children's interest groups, etc.), Utah families, and other external agencies. In addition to identifying the kinds of information that needs to be shared, participants revealed problems they routinely encounter in navigating through a system of uncoordinated public health programs. They also expressed their concern about the kinds of information that should NOT be shared (discussed further in the “Findings” section below).

### *Input from UDOH Attorney (Lyle Odendahl)*

In order to gain an understanding of confidentiality and security requirements as well as potential issues associated with sharing information across agencies and providers, input was solicited from UDOH's legal department. Topics of discussion included the requirement to comply with HIPAA and other regulations, the need to educate the public about this strategy, and issues related to expanded access to an individual's health information (e.g., sharing health information with administrative staff can be a scary issue, especially if people could look up data about their neighbors).

### Aggregating & Refining Stakeholder Input

Participants in the final Focus Group session capitalized on the groundwork of the initial sessions. Representatives from vital records, newborn hearing screening, newborn heelstick screening, early intervention, birth defects registry, and hearing, speech and vision services---who also attended one of the initial session---analyzed cumulative child health data integration requirements from the earlier sessions. Their work consisted of making refinements to the data to be included in the child health profile and defining "systems" related requirements for the integrated system.

## **Benchmarking with Other States**

In addition to gathering input from the external and internal Focus Group participants, the Needs Assessment project team determined that it would be helpful to "benchmark" its child health data integration requirements against those of other states receiving GSDI funding.

Specifically the team was interested in how others had defined a child health profile. To this end the project team contacted GSDI participants from both Colorado and Missouri<sup>1</sup>. Feedback from Colorado's grant recipients revealed that their conception of the types of information comprising the profile was very similar to that proposed by the Utah Focus Group participants and includes the following types of data:

- ❑ biographical
- ❑ financial
- ❑ child medical information
- ❑ demographic information
- ❑ contact information
- ❑ follow-up information
- ❑ current and underlying diagnoses (e.g., underlying diagnosis might be "cleft-lip" and "cleft-palate"; current diagnosis might be "broken arm")

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<sup>1</sup> Information was not available from Missouri due to a recent change in staff of GSDI grant management.

Colorado's GSDI grant contact characterized their Needs Assessment team's conception of a Child Health Profile as a "thumbnail sketch" of a child's overall health. The information is to be updated by whomever sees the child. The Colorado team elected not to define the actual data elements comprising each of the above categories during the Needs Assessment phase of their integration effort.

## **Current Systems & Technical Environment Assessment**

The process of exploring technical options to support the needs identified in the Focus Group sessions required IT consultants and UDOH IT staff to:

- ❑ develop an understanding of the data requirements
- ❑ understand the new system's environmental requirements
- ❑ review the technical characteristics of the systems targeted for inclusion in the data integration implementation

The logical progression of these tasks required that the development of the technical alternatives follow the definition of the functional, data and environmental requirements as well as the analysis of the current systems targeted for integration. For purposes of this project the requirements gathering activities and current systems analysis tasks were performed concurrently. Members of the Focus Group sessions were tasked with identifying child health data and "systems" requirements such as data currency and historical data requirements, system availability needs, system volumes and usage statistics, and privacy and confidentiality requirements.

To initiate the assessment of the current systems UDOH IT staff developed a preliminary inventory of the department's major systems. The inventory included system descriptions, relevant databases/software, data ownership information, and security and confidentiality restrictions. Detailed platform characteristics and usage statistics were then captured for a subset of this inventory (i.e., the systems targeted for the first phase of the child health integration effort). Specific elements identified during this stage of the assessment included:

- ❑ deployment hardware
- ❑ operating system
- ❑ deployment software (programming language)
- ❑ database/and or File Type
- ❑ location of deployed system
- ❑ total number of users
- ❑ number of concurrent users

- ❑ number of database hits per day
- ❑ volume of data stored
- ❑ usual volume of real time data retrieved
- ❑ peak volume periods (if applicable)
- ❑ unique data identifier
- ❑ batch processing

To complete the analysis of the current systems, the project's technical consultants reviewed the Focus Group sessions' findings and the project's business case (i.e., CHARM and GSDI grant objectives, the department's strategic objectives, business principles, IS vision, etc.). Next they devised a list of questions to assist in aligning the technical strategy with the business drivers (see Appendix A). These questions were then reviewed jointly by UDOH and IT consultant project team members.

The final task of the Needs Assessment was proposing alternatives for enabling the technical implementation of the integration effort. These strategies and the rationale for each alternative are described in detail below (see Implementation Alternatives section).

### **On-going Evaluation**

Evaluation was an on-going part of the Needs Assessment to ensure that the project activities were being carried out and expectations met. In addition to feedback from focus group participants, formal reviews were conducted. These consisted of the following:

- ❑ review of Needs Assessment Project Plans, roles and responsibilities
- ❑ post-Focus Group session review of findings
- ❑ review of preliminary technical alternatives
- ❑ Needs Assessment report review

Additional information from these reviews is provided in Appendix E.

### **Needs Assessment Focus Group Participants**

Identified below are those invited to attend the Focus Group Sessions. Those marked with an asterisk were invited but were unable to attend.

**Focus Group I Invitees: December 5, 2000**

Barry Nangle	Vital Records
Jan Bagley	Newborn Heelstick Screening
Julie Olson	Medicaid
Linda Abel	Immunizations Program
Marcia Feldcamp	Birth Defects Network
Marie Nagata	WIC
Nita Owens	Newborn Hearing Screening
Sandra Schulties	USIIS
Scott Warnick	Health Advocate Utah Issues
Susan Ord	Early Intervention
Tamara Lewis*	Intermountain Health Care
John Eichwald	CSHCN Clinical Administrator
Lynn Martinez	Program Manager, Birth Defects & Teratology
Rhoda Nicholas	CIO, UDOH
Jane Johnson	CSHCN IT
John DiDominic	MTW Corporation
Maribeth Sturgeon	MTW Corporation

**Focus Group II Invitees: December 6, 2000**

Don Johnson	WIC
Fay Keune	Newborn Screening
Holly Balken	CSHCN Clinical Programs
Joyce Gaufin	Medicaid
Margaret Lubke	National Center for Hearing Assessment & Mgmt.
Martee Hawkins	Immunizations Program
Sue Olsen	Early Intervention
Tom Mahoney	Hearing Speech and Vision Services
Wu Xu	USIIS
John Eichwald	CSHCN Clinical Administrator
Lynn Martinez	Program Manager, Birth Defects & Teratology
Rhoda Nicholas	CIO, UDOH
Jane Johnson	CSHCN IT
Maribeth Sturgeon	MTW Corporation

**Focus Group III Invitees: February 20, 2001**

Anthony Smith*	Indian Walk-In Center
Judi Hilman	Health Advocate, Utah Issues
Scott Warnick*	Health Advocate, Utah Issues
Steve Briles	Centro de la Familia de Utah
Chris Chytraus*	Utah Children
Terry Haven	Utah Children
Vivian Garcia	Parent
Gina Pola-Money	Family Voices
Joyce Dolcourt	Governor's Council for Persons with Disabilities

Susanna Serna	Parent
Kathie Peterson	Parent
Jan Brock	Parent
John Eichwald	CSHCN Clinical Administrator
Lynn Martinez	Program Manager, Birth Defects & Teratology
Maribeth Sturgeon	MTW Corporation

### **Focus Group IV Invitees: February 21, 2001**

Barry Nangle	Vital Record
Fay Keune	Newborn Screening
Sue Olsen	Early Intervention
Nita Owens	Newborn Hearing Screening
Tom Mahoney	Hearing Speech and Vision Services
Julie Olson*	Medicaid
Linda Abel*	Immunizations Program
John Eichwald	CSHCN Clinical Administrator
Lynn Martinez	Program Manager, Birth Defects & Teratology
Don Gabriele	UDOH IT
Jane Johnson	CSHCN IT
Maribeth Sturgeon	MTW Corporation

## **Needs Assessment Key Findings & Observations**

Key findings and observations from interviews with stakeholders, focus group sessions and analyses of UDOH's current systems and technical environment are provided below. These findings and the requirements identified in the following section serve as the basis for the recommendations provided later in the document.

### **UDOH's Current "Program-Oriented" Information Environment**

In the current environment, clients are accustomed to repeatedly providing the same information to access an array of services. Often it is only the families that are aware of all services currently being received and they must ultimately coordinate those services.

Those providing services must "dig out" information to understand the client-family, their needs, the services they require and those they are already receiving.

The current services delivery system has the following characteristics:

- program rather than family focus
- redundant processes

- ❑ redundant data
- ❑ fragmented information that is difficult to access
- ❑ incompatible hardware and software platforms

This situation has evolved over time as a result of implementations focused on single program rules, eligibility criteria, and procedures. It has been strongly reinforced by categorical funding and federal regulation. The results include a “system” of independent service delivery processes and “stovepipe” automated information systems that work for single program-oriented services. However, today there is an overwhelming demand for cross-program services for which stovepipe systems were not designed.

### **Department Readiness for Integration**

The department is ready for data integration. This was confirmed at all levels in the organization and with external stakeholders. All groups appear to comprehend the need for integration, its potential benefits and are optimistic that the potential benefits outweigh the disadvantages.

### **Privacy, Confidentiality & Access**

The TYPE of information in a child health profile is not as much of a concern as is WHO will have ACCESS. Although privacy, security and confidentiality concerns exist whenever data about individuals and families are proposed to be shared, families of children whose profiles would be accessible do not seem to be as concerned about the type of information to be shared as they are about who will have access to this information. However, they specifically mentioned that non-health related groups or individuals (such as insurance companies and their attorneys) should NOT have access.

### **Contents of a Child Health Profile**

A child health profile should NOT be an electronic health record. Consistent with the Needs Assessment team's findings from benchmarking with other GSDI grant participants, UDOH Focus Group participants' conception of a child health profile defines it as a “thumbnail sketch” of data that provides an overall “picture” of an individual child's health status---and NOT an individual's complete electronic health record.

### **Platforms of Systems to Be Integrated**

Findings from the analysis of the (existing) systems within the scope of this project depict a technically diverse environment where systems reside on multiple mainframe and PC platforms (using various database software, operating systems, and programming languages). This situation is probably a result of the department's move from a primarily mainframe to a Client/Server, PC and LAN environment. In addition to the maintenance and support issues inherent within such a diverse technical environment, information sharing is hindered, and in some cases nearly impossible, i.e., for those systems currently on platforms not considered to be robust

enough to be integrated. For this reason, two of the systems targeted to be brought into the first phase of the child health integration solution, Early Intervention and Newborn Hearing Screening, will need to be re-platformed before they can be linked with the other systems.

An unfortunate consequence of operating systems on multiple platforms is the necessity of maintaining a technical staff to provide the on-going needed support. Staff with exclusive technical skills, such as an Oracle DBA, can be quite expensive (and especially expensive if that DBA is only supporting one or two systems). Although it is beyond the scope of this assessment some recommendations are put forth for studying the issues related to the variety of platforms and technologies (see Recommendations Section, "IT Recommendations – Development of Department-Wide Technology Architecture").

### **Barriers (Risks) to Integrating Child Health Data**

During the Focus Group sessions participants identified the following as barriers/risks associated with the proposed effort to integrate child health data.

- ❑ The re-platforming of some systems to be integrated in the first phase is not yet completed (see "Platforms of Systems to be Integrated" in the paragraphs above)
- ❑ Next round of funding
- ❑ Participation by the right people
- ❑ People unwilling to allow information to be shared
- ❑ Flexibility of systems – data regulations are constantly changing
- ❑ Technical security constraints
- ❑ Threatened integrity of existing databases
- ❑ Data integrity – if data input into the system lacks integrity, data output by the system will also lack integrity
- ❑ Attitude problems – getting people to work in a different way
- ❑ Technology phobias
- ❑ Past failures that have resulted in built-in resistance

It is important to this project that these risks are monitored and actively managed. To effectively control them, a risk management plan should be created that further analyzes each risk and proposes prevention and mitigation strategies.

## Needs Assessment Requirements

A primary focus of the Needs Assessment was the determination of the requirements for the integration of child health data. Included in this process was the definition of functional requirements, information needs, security, privacy and confidentiality requirements, system workload requirements, and conversion requirements. These requirements are presented by category below.

### Requirements: Information (Data) Needs

#### CATEGORY: ELEMENTS OF A CHILD HEALTH PROFILE (CHP)

Participants from the first two focus group sessions (from UDOH programs) defined a child health profile to include a thumbnail sketch of the following types of information (a complete list of the data comprising each of these categories is provided in Appendix B<sup>2</sup>):

#### Child Health Profile Data

<i>Profile Data Categories</i>	<i>Major Types of Information Per Category</i>
Biographical	Demographics
	Familial Relationships (i.e., identification of siblings)
Medical/Clinical	Screenings: Metabolic, Hearing, Lead, etc.
	Diagnoses: Birth Defect, Hearing Loss, Metabolic Disorder, etc.
	Services: Immunizations, Early Intervention, CSHN, Medical Home, etc.
Eligibility/Enrollment	Medicaid, CHIP, WIC, Early Intervention, Specialty Clinics, etc.
Referral	Referral to Missed Screens, Services, etc.

At a minimum, it was determined that child health profile information needs to be available at the time, or close to the time a service is being provided to a child, so that the service is enhanced by the provider's ability to see and evaluate a child's integrated health picture.

Other findings of the these sessions clarified that the CHP should NOT be a complete, electronic clinical record of a child, but rather a subset of information that would present a picture of the status of an individual child's health.

- CATEGORY: INFORMATION **NOT** TO BE INCLUDED IN A CHILD HEALTH PROFILE:

<sup>2</sup> The data identified by representatives from multiple UDOH programs provided a comprehensive list of data that is shared among, or is common to, two or more programs. These data go beyond what is actually needed for the child health profile. The sheer number of these data elements illustrates the extent to which data among programs is common. This list is provided in entirety in Appendix B.

Although it was generally agreed among Focus Group participants that child health profile information should be shared among those with a legitimate need, parents and health advocacy group participants indicated that individuals should have the ability to “opt out” of an integrated system. (However, they would NOT be able to “opt out” of program specific databases such as Vital Records and other mandatory data collection systems.)

Focus Group participants external to DOH (i.e., parents and health advocacy groups) determined that program eligibility and family financial information should NOT be shared. The rationale for this exclusion is that eligibility information “flags” certain people as being involved in certain programs, having certain financial characteristics, etc. This group of stakeholders also believed that diagnosis information should NOT be shared across programs if a parent elects NOT to make this information available to multiple users.

Other information NOT to be included in UDOH’s integrated child health profile is information closely associated with only a single program, e.g., certain kinds of breastfeeding data for WIC, or data NOT considered to meet the “thumbnail sketch” criteria.

#### □ CATEGORY: REPORTING REQUIREMENTS

Focus Group participants determined that a Child Health Profile is more of an operational type of data collection and not intended to generate reports about services. Therefore, no reporting requirements were identified.

#### □ CATEGORY: AVAILABLE SOURCES OF INFORMATION

Sources of information for the Child Health Profile will include the systems targeted to be linked. For phase one these will include Newborn Hearing screening, Heelstick Screening, Early Intervention, Vital Records, Birth Defects Registry and Immunization (USIIS).

#### □ CATEGORY: INFORMATION FORMAT, MEDIA, QUANTITY & TIMELINESS

Information for the Child Health Profile from an individual program’s system will exist in the format/media of the current system. Any system or core profile data (or key identifying information) for the new system can reside on a suitable existing platform.

Estimated quantity of Child Health Profile records is estimated to be approximately 1,000,000. Expected number of database hits per day is estimated at 1,000.

Data currency needs vary by the category of information that will be accessed:

- immunizations, demographic data and events need to be current (as close to real time as possible)

- characteristics about individuals do NOT need to be real time

□ CATEGORY: DATA STANDARDS, DATA ELEMENTS, & CLASSIFICATIONS

The major classifications of data identified to be included in the profile include biographical, medical/clinical, eligibility/enrollment and referral information. Individual data elements included in each of these categories are provided in Appendix B.

During the Focus Group sessions participants identified and agreed upon standard names for common data elements within the categories of information for the Child Health Profile. These are provided in Appendix B.

□ CATEGORY: ESSENTIAL RECORDS AND INFORMATION FOR CURRENT AND FUTURE PROGRAM AND MISSION

Information considered to be essential in a Child Health Profile is identified in the “elements of the Child Health Profile” at the beginning of this section. For future program needs it is highly desirable that the Child Health Profile system provide the flexibility to accommodate additional elements to comply with changing program regulations or the need to capture additional health information.

□ CATEGORY: RECORDS RETENTION, DISPOSITION, AND ARCHIVAL STORAGE AND RETRIEVAL

Individual health records need to be kept on-line for children from ages zero through eighteen. After eighteen, records can be archived. An acceptable turnaround time for archived records is two to three working days (or possibly more for some programs).

**Requirements: Functional Requirements**

□ CATEGORY: WHAT NEW OR ENHANCED PROCESSES OR CAPABILITIES NEED TO BE SUPPORTED?

Focus Group participants identified the following capabilities to be supported in an integrated child health profile system:

- 24 X 7 access to integrated child health information for private providers (information that will be helpful to them in their offices)
- Access to program-specific child health data 12 hours per day
- Private providers need access to immunization data

- ❑ Ability to link hospital records with other places where health services are provided
  - ❑ Access to data (defined in the Child Health Profile) that is needed by two or more programs
  - ❑ Access to information that aids in follow-up of individual children
  - ❑ “User friendly” information sharing capabilities
  - ❑ Compliance with HIPAA standards (these will drive what CAN and CANNOT be shared and specify appropriate “sign-offs”)
  - ❑ Increased access for families
  - ❑ Elimination of redundant data entry
  - ❑ Streamlining paper work at places where health services are delivered
  
- ❑ CATEGORY: EXISTING DEFICIENCIES THAT NEED TO BE OVERCOME
  - ❑ Unnecessary treatment and evaluation of clients
  - ❑ Excessive turnaround time for early intervention efforts
  - ❑ Data redundancy
  - ❑ Data integrity
  - ❑ Capturing the same information from the same individual/family multiple times
  - ❑ Existing costs
  
- ❑ CATEGORY: WHAT GOALS, OBJECTIVES, AND COMMITMENTS (INTERNAL AND EXTERNAL) NEED TO BE MET?
  - Goals and Objectives for integrated child health information:
    - ❑ Increased awareness
    - ❑ Increased referrals
    - ❑ Improved follow-up (especially during the critical period of birth to 3 years)
    - ❑ Making life easier for families
    - ❑ Assisting providers in tracking additional child health information (e.g., health problems, habits, etc.)
    - ❑ Making information readily available for creating educational plans, special diets, etc.
    - ❑ Streamlining paperwork required at places where health services are provided
    - ❑ Improved public health surveillance
    - ❑ Improvement in overall healthcare and coordination brought about by data integration/sharing
    - ❑ This project’s goals should link to Healthy People 2010
  
  - Commitments to be met include:
    - ❑ Honoring and respecting Utah families’ right to privacy
    - ❑ Committed team - time commitment for implementation and on-going support
    - ❑ Commitment to achieving early success
    - ❑ Commitment, “buy-in”, and shared ownership from agencies involved

- ❑ Commitment to educating the public - to help people understand the value of sharing information and to ensure their sense of security about the data
  - ❑ Commitment of Sr. Management
  - ❑ Commitment of potential users to use integrated data
  - ❑ Commitment of potential users to develop technical skills to use the data (commitment to training)
  - ❑ Commitment from the Utah legislature for the long haul (they will need to be educated)
  
- ❑ CATEGORY: IMPROVEMENTS IN EFFICIENCIES AND EFFECTIVENESS
  - ❑ Entry of certain information only once
  - ❑ On-line access to Child Health Profile Information will improve the quality of overall healthcare
  - ❑ On-line access to Child Health Profile information will improve collaboration and coordination of services
  - ❑ Improve program intervention efforts by decreasing loss to follow-up
  - ❑ Integrated data will enhance and facilitate referrals

❑ CATEGORY: REDUCTIONS IN REDUNDANCIES

To reduce redundancy, certain information such as name, address and some demographic information needs to be captured only once and updated in one place. Not only would this reduce redundancy but also would improve data integrity.

**Requirements: System Workload**

❑ CATEGORY: SYSTEM CAPACITY PROJECTIONS: PEAK UTILIZATION

- ❑ Data storage = 1,000,000 records
- ❑ User base = UDOH program staff, clinicians and providers (public and private) and Utah families (anticipated to result in approximately 1,000 database hits per day)

❑ CATEGORY: EXPANDABILITY & EXTENSIBILITY

- ❑ The solution needs to support expandability and extensibility to progressively build application systems.

❑ CATEGORY: PEAK UTILIZATION REQUIREMENTS

- ❑ 8:00 a.m. to 5:00 p.m. Monday through Friday
- ❑ Heavier usage for quarterly reporting and also in June and December for federal reporting
- ❑ Contingency plans: Existing department backup and recovery procedures will be utilized (contained in the department's Disaster Recovery Plan)

## **Requirements: Security, Privacy and Confidentiality Requirements**

- ❑ **CATEGORY: DETERMINATION OF CRITICALITY, SENSITIVITY, CONFIDENTIALITY, AND PRIVACY OF DATA AND INFORMATION IN THE SYSTEM**

Focus Group participants determined that integrated child health data must comply with department, federal and state regulations for data security and confidentiality (e.g., HIPAA, IDEA, Utah Statue 26-3, Statute 26-25, etc.). Other appropriate safeguards need to be in place to protect the privacy of individuals and families.

Findings from the Focus Group stakeholders external to UDOH revealed that their concern for privacy of child health information was focused more on restricting access rather than the type or amount of information collected and stored in the system. This group also reported problems inherent within receiving services that were uncoordinated and providing information to/retrieving information from single program information systems. Particularly frustrating to this group is the need to provide the same information over and over again (as often as monthly for services requiring financial eligibility requirements).

- ❑ **CATEGORY: IDENTIFICATION OF ANY ADDITIONAL SPECIAL SECURITY CONSIDERATIONS RELATED TO THE STORAGE, ACCESS CONTROLS, AND COMMUNICATION OF DATA**

“Opting Out” Option. Focus Group participants determined that it is permissible for participants to “opt out” of the integrated child health profile system but they CANNOT “opt out” of a database of one of the mandatory data collection systems such as Vital Records.

The only adoption information to be included in an integrated system is the family name of the people adopting the child. All other adoption information must be locked.

Users were not concerned about the amount of information to be stored in the system as long as safeguards are in place to protect individual child health information from unauthorized access.

Insurance carriers can get immunization information. Safeguards need to be put in place to prevent them from “pulling” other information from the integrated child health system.

Corporate entities or businesses should not have access to child health data.

Employers should not have access to their employees' health information contained in the integrated system.

**Requirements: Access Needs**

□ CATEGORY: SYSTEM AVAILABILITY

24 x 7 for providers

12 hrs per day for UDOH program staff

□ CATEGORY: CONNECTIVITY NEEDS FOR SOURCES & TARGETS OF INFORMATION

Access from outside and within UDOH via Internet browser.

Access needs for individuals with disabilities: The department will meet ADA standards.

**Requirements: Space and Environmental Considerations**

□ CATEGORY: FACILITIES REQUIREMENTS FOR SPACE, ELECTRICAL POWER, UNINTERRUPTIBLE POWER SUPPLY, BACK-UP POWER, AIR CONDITIONING, HEATING, PHYSICAL PROTECTION AND SECURITY OF EQUIPMENT, ETC.

UDOH existing facilities will be used.

**Requirements: System Life**

□ CATEGORY: EXPECTED LIFE CYCLE OF SYSTEM

Ten years is considered to be the maximum life expectancy for the system.

**Requirements: Conversion**

□ CATEGORY: REQUIREMENTS TO TRANSITION FROM AN EXISTING SYSTEM, CONVERT DATA FROM DIFFERENT FORMATS/MEDIA, RUNNING OLD/NEW SYSTEM IN PARALLEL

Conversion requirements cannot be determined until an implementation strategy has been selected. Certain options may require conversion, others may not. Also, programs involved in this effort may decide NOT to “draw-in” existing records but include only new records.

## **Issues Identified During Needs Assessment & Items for Follow-up**

In the course of examining the requirements for integrating child health data a number of issues were discovered. These are discussed below

### **Legal and Ethical Responsibilities for Shared, Integrated Data**

Will new integrated data systems increase the legal liability of the department?

Sharing of information and wider access to information carries ethical as well as legal responsibilities. The legal responsibilities will be impacted by the enactment of HIPAA legislation as well as other state and departmental security, privacy and confidentiality mandates. Although the existing responsibilities/regulations were identified earlier in this document, upcoming changes need to be monitored as this project progresses from the assessment to planning to implementation phases.

#### **“Opting out” of the system**

Feedback from parents of children targeted to be included in the integrated system expressed the desire that families be allowed to “opt out” of the system. Physical implementation of this requirement will need to be addressed before security and access procedures are developed. UDOH program administrators have suggested that this requirement be implemented by protecting the child/family information from access by programs or agencies beyond the original point of contact where the information was initially collected.

The impact of having some records unavailable may need to be studied further if this poses a problem for any potential users of the integrated system.

### **Timeliness of Child Health Data**

Birth defects records routinely take as long as six to nine months to generate a report. Reports of live births for individual children are available after 30 days. This is a significant range in timeliness of data. Any changes will require changes in existing business processes as well as modifications to existing systems. Variations in data availability timelines should be addressed before the implementation of the integration system, otherwise, some of the expected benefits of an integrated system may not be realized.

### **Identifier for Child Health Profile**

A common, unique identifier needs to be determined for a child health record. Currently several different identifiers are used across the department, e.g., Vital

Records uses the Birth Certificate #, the Medicaid system uses a child identifier generated from the Department of Human Services, and USIIS uses yet another identifier.

A Birth Record would be a highly predictable attribute for identifying a child in Utah but this number loses its potential outside of the birth cohort (children born outside of Utah). Other challenges also make it difficult to establish and agree upon an identifier, including, for example, anti-government personal rights groups opposed to collection of data pertaining to individuals.

The final determination of what can and will be used as an identifier requires collaboration of the programs involved as well as the technical designers of the integrated system.

### **Policies and Procedures for Managing/Maintaining Integrated Data**

Policies and procedures will need to be developed for how data is exchanged, maintained, and updated in an information sharing environment. Who/what group currently has or will have responsibility for these functions?

### **Eligibility and Enrollment Information**

Need to determine how to resolve the issue of including eligibility and enrollment information in the Child Health Profile. Parents involved in the Focus Groups determined that it should not be included. Program staff need to decide if they can support not having access to eligibility information.

### **Elements Comprising Client Name**

Need to determine what comprises "name" in a Child Health Profile (legal name, "also known as," etc.).

## **The Envisioned Integrated Environment**

### **Overview of the Envisioned Integrated Information Environment**

The goal of integrating child health data is to enable data maintained on individual, disparate systems within Utah's Department of Health to be easily available (via technology such as a common browser interface). A "seamless" system would enable access to information about the client and family across a wider spectrum of services. This means that the right information reaches whomever needs it, whenever it is needed.

Realization of a seamless system can only occur if all of the individuals and organizations involved in delivering health services and administering health programs share a holistic perspective of clients and families and the services provided to them. Naturally, individual program mandates and organizational missions must be met. However, this new vision requires that all health programs and service delivery partners must view themselves as part of a single health entity.

A seamless, integrated system should have the following characteristics:

- ❑ Information is defined consistently
- ❑ Client/family information is easily shared on a need-to-know basis (the system knows WHAT can be shared BY WHOM and under WHAT circumstances. Confidentiality is thereby maintained, but in a way that assists rather than inhibits the proper flow of information required to serve the client.)
- ❑ Cross-program information is available for making referrals, decision making, and responsive service delivery
- ❑ Technology platforms are compatible as a result of agreed-upon standards (this is discussed in the footnote and in the “Recommendations” section below)<sup>3</sup>
- ❑ Automated systems are flexible and responsive to change

***The ultimate goal is nothing less than a seamless “system” that:***

- ❑ Improves the health of Utahns
- ❑ Makes it easier for customers, providers and staff seeking information to obtain the necessary information they need, regardless of where it is collected

Specific information needs and system-related requirements for this vision were defined earlier in this document. Now the discussion turns to the technical considerations for implementing these requirements. The purpose of this section is to outline implementation alternatives, identify the unique technical features or characteristics of each, and to identify each alternative’s benefits and disadvantages as a solution for an integrated child health system.

## **Introduction to Implementation Alternatives**

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<sup>3</sup> In addition to information standards, software, hardware, networking, and Internet requirements for an integrated, seamless system will need to be defined so that over time technology solutions developed by different programs/organizations become increasingly compatible. Current databases, that contain the same information but are defined in different ways and updated inconsistently, are replaced by databases containing consistent data capable of being easily combined.

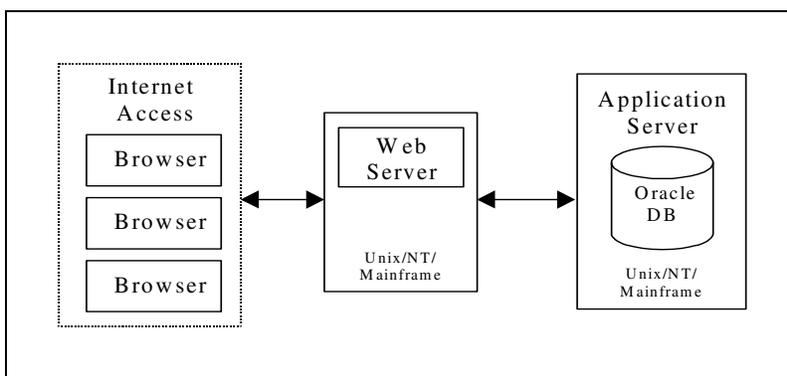
Utah's data sources are implemented on a variety of platforms and may reside in multiple locations. One of the goals of Utah's Child Health Data Integration effort is to coordinate these data sources and to make this data universally available to those with a need to know. The goals of this effort can be met in one of four ways:

1. Reengineering the business processes necessary to collect child health data and architecting a unified solution capable of capturing, maintaining and retrieving this information.
2. Leaving existing business and data collection processes intact and architecting a data warehouse to capture "snapshot in time" views of data that is then made accessible through a common interface.
3. Leaving existing business and data collection processes intact and architecting a core data system that tracks the data associated with the Child Health Profile (CHP). The system would access existing relational database systems for additional data not kept within a CHP.
4. Leaving existing business and data collection processes intact and creating a "virtual profile" application, consisting of only record identifying keys, that accesses data from its existing sources and makes it accessible through a common interface.

Each of these options strikes a different balance between time to implementation, cost, flexibility and robustness. These options can either be considered discrete solutions or used in a phased approach to a final implementation.

### **Option 1: Unified Application Development**

#### **OVERVIEW**



**Figure 1** Possible Unified Application Architecture

The unified application option presents the most robust and comprehensive solution. It calls for transitioning from existing applications for Hearing Screening,

Metabolic Screening, Vital Records, Early Intervention, and USIIS and moving to a unified, online application for the entry, maintenance and display of child health data. This solution works well if the following conditions are met:

1. Sufficient time and resources exist to commit to analysis, development and implementation of a new, comprehensive solution
2. Current system users are willing (and capable) of transitioning to a new application environment
3. The organization's technical infrastructure is able to support the demands of a new online system or there are sufficient resources available to upgrade the infrastructure to make it so
4. Resources are available to maintain the new system after implementation.

Creating a unified application for the maintenance of CHP data would result in a system built from the ground up, for the seamless entry and access of all child profile data. Such a system would ensure the accuracy and timeliness of its data, have a data structure optimized for quick processing and retrieval, provide an integrated and seamless user interface, and incorporate a tightly coupled, multi-level security component.

#### ***DATA LOCATION, ACCESS AND OWNERSHIP***

The analysis phase will determine the specific data elements to be included in the Child Health Profile application. All data, including application, business and security data, will reside within a single database on a common database server. The data within the application's database is owned by the CHP system and can only be modified via its interface.

The "ground up" construction of this unified application allows for the development of a robust security component. This component will specify not only who has access to CHP data but also the type of access, e.g. full permission, view-only, and specific sub-sets.

#### ***SYSTEM ROBUSTNESS AND FLEXIBILITY***

Incorporating rigorous analysis and design processes in the creation of a Unified application should ensure a robust application (capable of supporting business requirements and processes under all but the most extreme circumstances). If the system's design and implementation is modular or class based the system should be readily available for additional enhancement and/or business process changes.

#### ***IMPACT ON EXISTING SYSTEMS AND BUSINESS PROCESSES***

Implementation of a unified application will result in the phasing out of many systems currently in use. Use of the new application may result in business process and organizational changes for the maintenance and use of health profile data. Given these considerations, impact on existing business processes may be quite high. Staff reorganization and retraining costs (and expertise) need to be considered when evaluating the Unified application solution.

***DEVELOPMENT CONSIDERATIONS/LEVERAGE OF EXISTING ARCHITECTURE***

Creating a new application specifically to meet the business requirements of the Child Health Profile system carries a number of benefits: an interface designed specifically to user needs, an architecture tailored for both performance and stability, real-time data access, complete control over data quality, access and security, and ease of future enhancements and modifications (to name a few).

Commiserate with the benefits of the Unified applications are its heavier burden in development cost and time. Significant time must be dedicated to the analysis, design and implementation of a new solution. Data migration from the existing systems to the new system will represent a sizable task to ensure that the data is clean. Development costs will be higher for new systems development than a solution that is “piggy-backed” on to an existing system.

Utah should be able to leverage many of its existing resources and technology in crafting a Unified application solution. Utah’s Oracle database server would work well as a repository for the proposed system’s data. Existing web servers, as long as capacity exists, can be used to provide access to the application. Lastly, in-house programming expertise and development tools can be leveraged in the development of the proposed Unified tool.

## Option 2: Development of a Data Warehouse

### OVERVIEW

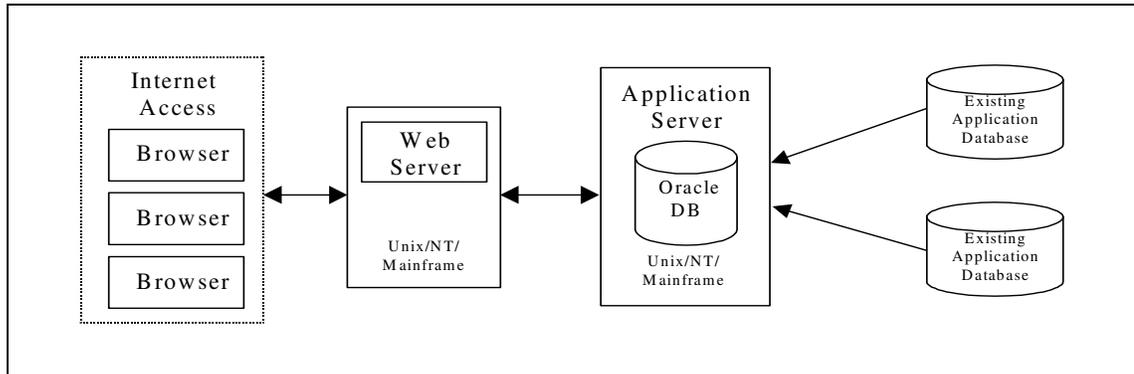


Figure 2 Possible Data Warehouse Configuration

A data warehouse is a snapshot in time of data within an organization. Data from the specified organization's systems is compiled and imported to a data warehouse on a regular basis. The frequency of updates is dependent upon a variety of factors including the need for current data, the time the import processes requires and the downtime and cost warehouse updates entail. Data within the data warehouse is structured to maximize performance and optimized to provide specific types of key information. Data contained within a data warehouse is read-only and can only be changed via updates from the applications that own it.

A data warehousing solution works best when the following conditions are met:

1. A medium amount of development time and resources is available
2. Existing systems adequately gather desired information
3. The data can be organized and compiled in a meaningful way
4. Read-only access to warehoused data is acceptable
5. Accessed data does not need to be real-time

A data warehouse can offer a great deal of flexibility in how its data is used. In addition to specific data retrieval, statistical and analytical reports can be created. Data warehouses can also be "mined" to look for different types of trends and patterns. Because data warehouses are not real-time, development and use issues dealing with data concurrency (e.g. of two sets of data entered at separate times which set is the "most" correct) can be avoided. The implementation of a data warehouse should have little impact on the existing systems that provide it with source data. Because data within a data warehouse is brought in from existing systems, no maintenance interfaces need be developed, resulting in a less expensive solution than that proposed in Option 1.

### DATA LOCATION, ACCESS AND OWNERSHIP

The location, access and ownership of data are decentralized in a data warehouse solution. The data contained within the data warehouse itself is owned by the data warehouse. It can be accessed only through its own (online) interface. The data within the warehouse should not be modified once it has been imported. Data feeding the warehouse comes from any number of different sources. Each of these sources owns its own data and is responsible for its access, maintenance and integrity. Only by making changes to data in one of these sources is it possible to update the data residing within the data warehouse.

#### ***SYSTEM ROBUSTNESS AND FLEXIBILITY***

Data warehouses are excellent tools for data retrieval, organization and analysis. Data contained within a data warehouse is structured to optimize data access, resulting in fast data retrievals and powerful capabilities for creating analytical and statistical reports. Because data within the warehouse can not be updated the system is extremely robust. The warehouse's self-contained data structure makes adding new methods for organizing and defining relationships relatively simple -giving the system a great deal of flexibility. Because the warehousing solution does not allow users to directly access data contained within the systems that feed it none of these systems should suffer any performance degradation during their normal operation.

#### ***IMPACT ON EXISTING SYSTEMS AND BUSINESS PROCESSES***

The implementation of a data warehouse should have minimal impact on the organization's existing systems and business processes. Existing data gathering and maintenance applications remain in place along with their accompanying business processes and organization structures. The process of importing records into the data warehouse may have a performance impact on the source systems. Scheduling the import process at off-peak times should eliminate potential problems.

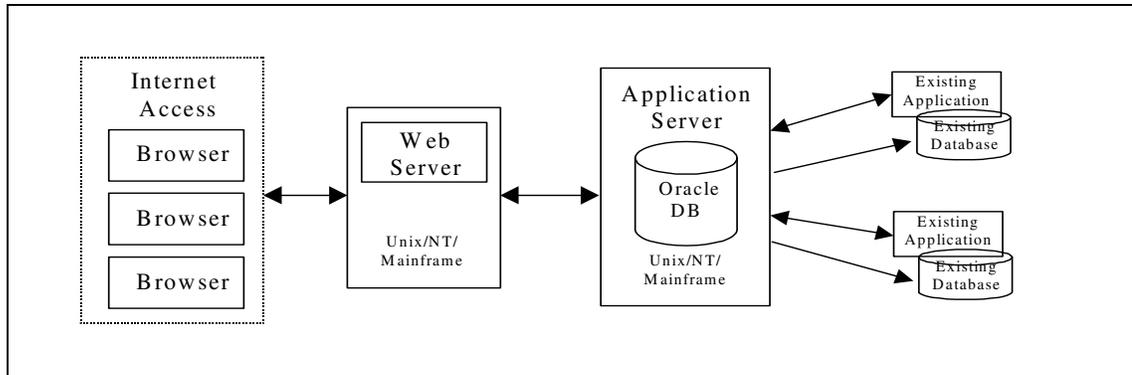
#### ***DEVELOPMENT CONSIDERATIONS/LEVERAGE OF EXISTING ARCHITECTURE***

For a data warehouse to be successful its data must be accurate. Key to the implementation of a data warehouse is determining which data sources take precedence when two or more data sources contain conflicting information for the same individual. A data warehouse streamlines access to data by eliminating spurious information. The process of defining which data to include within a data warehouse includes determining which data should be specifically excluded.

Much like Option 1 (developing a Unified application), Utah should be able to leverage its existing programming expertise and technical environment (Oracle database and web servers) to implement a data warehousing solution. Developers knowledgeable in existing systems should be leveraged in the development of the batch loading programs for populating the data warehouse.

### Option 3: Developing a Core Data Access Application

#### OVERVIEW



**Figure 3** Possible Configuration for a Core Data Access Architecture

The Core Data Access solution can be considered a hybrid of the first two options, a data maintenance and access system internally storing a subset of information that comprises all the data identified with a Child Health Profile. Additional functionality allows users to access data from its native system(s) not included in the health profile data.

This solution is appropriate when the following conditions exist:

1. Real-time data access is essential
2. Data needs to be maintained and accessed from multiple sources -the original data gathering applications and the new Core Data system
3. There are a medium to high level of resources available for analysis, design and implementation
4. There are plans to transition from the existing systems, over time, to the Core Data Access system

The Core Data Access solution works well in an environment where current business and organizational structures are being retained but additional resources need access to health profile data from outside this established infrastructure. Because multiple systems have the ability to modify data within this solution, there are a number of data ownership issues that must be resolved for this solution to be viable. Establishing a set of business rules determining how data in multiple applications is to be synchronized is paramount.

#### **DATA LOCATION, ACCESS AND OWNERSHIP**

Data is owned and accessed by multiple systems. Core data is owned both by the Core Data Access application and the systems supplying the data. Non-core data is owned by its native application. Security for the Core Data Access system controls who, what and how data is accessed through its interface. Each system either feeding or providing linkage to data within the Core Data Access system is responsible for its own access provisions. Modifications to core data can be

made through both the Core Data Access system or through one of the native systems that provides this data to the Core Data Access system.

#### ***SYSTEM ROBUSTNESS AND FLEXIBILITY***

Keeping the Core Data Access application and the existing systems' data synchronized is key to the success of this solution. Sophisticated, rules-based components will need to be developed to ensure that data contention and concurrency issues are adequately addressed.

The tight coupling of the existing systems with the proposed Core Data Access solution makes each of these systems highly dependent on the others. Failure of one of these systems potentially impacts the ability of the system to run as a whole. The Core Data Access system can only be as robust as the weakest system it incorporates.

Flexibility is also affected by the need to keep each of these systems synchronized. Changes to the definition (contents) of a child health profile or the contents of any of the systems containing non-core data may result in the need to modify or re-code the Core Data application's data access and synchronization components, making the system less flexible than other possible solutions.

The capture of Child Health Profile in a centralized, core database should offer robust reporting and analytical capabilities on this information.

#### ***IMPACT ON EXISTING SYSTEMS AND BUSINESS PROCESSES***

Existing systems for entering data in native applications can remain substantially unchanged. Analysis needs to examine how data changes made from the Core Data Access application may affect the native users understanding and ownership of this data.

Because the Core Data Access application can access native systems to retrieve non-core data it may impact the performance of these natives systems. Analysis needs to determine the capacity of the existing systems to handle additional data access (particularly during predicted peak usage periods).

#### ***DEVELOPMENT CONSIDERATIONS/LEVERAGE OF EXISTING ARCHITECTURE***

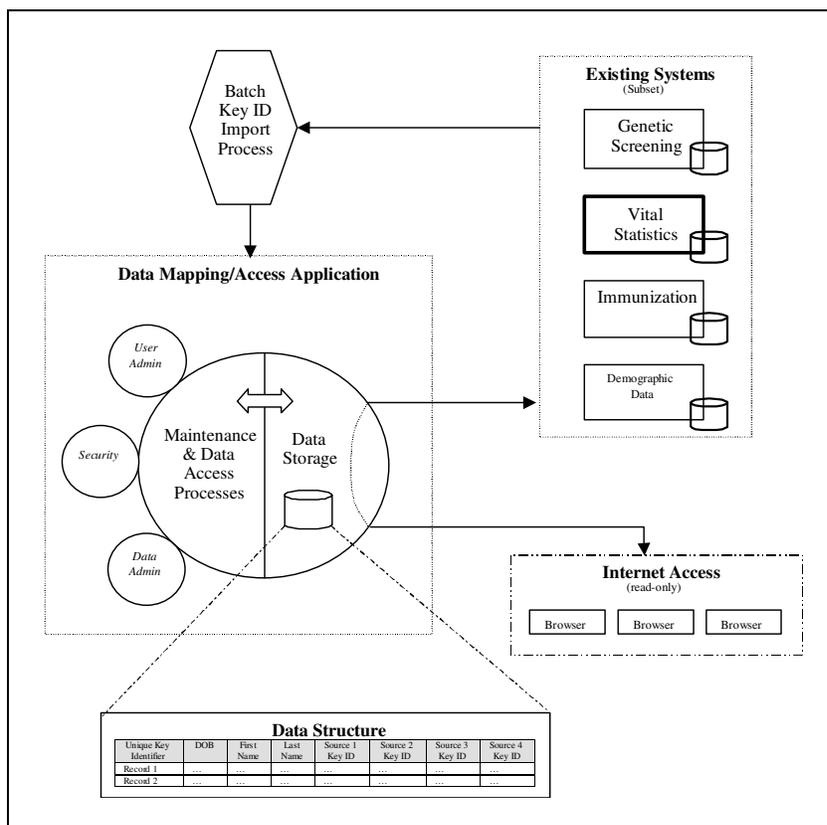
The proposed Core Data Access system should be implementable using Utah's existing technical infrastructure and expertise. Core data can reside on and be maintained by the existing Oracle database server. Provided sufficient capacity exists, an existing web server should be able to provide access to the proposed system's web interface.

Particular attention needs to be paid to the number and robustness of new online data modification interfaces. Each interface will need to contain at least the same number and types of data integrity validations as its native system counterpart. Synchronization logic will need to handle changes made from both the native and Core Data Systems. Data concurrency issues need to be resolved to ensure that

additional demands on existing native systems do not result in unacceptable performance.

## Option 4: Creating a “Virtual Profile” Application

### OVERVIEW



**Figure 4** Proposed Key Mapping Application Deployment

The Virtual Profile application is a small footprint application that at its core contains a small set of tables that act as a map, or index, to data existing in other systems. A record exists in the application for each child entered into UDOH's child health “network”. The record contains the key identifying information (e.g. the child's first and last names and his/her date of birth). The rest of the record describes where additional data resides within the state of Utah's existing data landscape and how to retrieve that data.

A Virtual Profile application is an appealing solution if the following conditions exist:

1. There are relatively limited amounts of time and resources available for development and implementation
2. There needs to be minimal impact on existing systems and processes

3. The system needs to be able to adopt changes to the definition of a health profile over time with minimal, to no, re-coding
4. Access to existing health profile records needs to be real-time with access to new health profile records acceptable in near-real-time

A Virtual Profile solution is dependent of its original data sources for accessing, displaying, and reporting on CHP data. Failure in one of these systems will prevent this style of application from providing complete CHP data. Because the system neither stores nor modifies this source data it should have no impact on any of the existing systems it accesses.

#### ***DATA LOCATION, ACCESS AND OWNERSHIP***

A key map table drives the Virtual Profile system, containing identifier information for retrieving data from Utah's native systems. Supporting tables within the Virtual Profile application determine what data elements within the native systems comprise a health profile record. The key map table and health profile data definition tables are owned by the Virtual Profile system and can only be modified by an administrator of this system. The native data retrieved through the Virtual Profile system is read-only and belongs to its native systems. Data within these systems can only be modified from their native interfaces, not the Virtual Profile application.

An option for ensuring the consistency of data across existing systems would be to modify existing systems to pull data from the Virtual Profile application to create new records (within that system) for profiles that already exist within the CHP application.

The Virtual Profile system's security component determines who and what data specified user types can view.

#### ***SYSTEM ROBUSTNESS AND FLEXIBILITY***

The key mapping aspect of the Virtual Profile system makes it highly flexible. The definition of a health profile is table (data) driven. Modifying the definition of a profile should be accomplishable merely by changing how the profile is defined within the profile definition table.

A Virtual Profile system should be fairly robust. The system can be designed to retrieve only partial information if one or more of the native systems it accesses is off-line. The internal organization of the Virtual Profile system is reasonably simple, resulting in greater ease of maintenance and fewer potential failure points.

#### ***IMPACT ON EXISTING SYSTEMS AND BUSINESS PROCESSES***

Under a Virtual Profile solution all data comprising health profile information continues to reside within its native framework. No changes to current business processes should be needed to implement this solution.

Because the Virtual Profile system will access data within Utah's native systems, an analysis of these systems should determine whether they are capable of handling additional demand (especially during predicted peak times). No other impacts to existing organization or business processes are anticipated.

***DEVELOPMENT CONSIDERATIONS/LEVERAGE OF EXISTING ARCHITECTURE***

The creation of records within the key map table will be driven by new record creation in one of Utah's existing systems. Preliminary analysis indicates that the Vital Records application would be an excellent source for driving the creation of new health profile key map records. Nightly batch processing could create new key map records based on new records entered to the Vital Records database during the prior day. More or less frequent batch processing may instead be implemented based on Utah's need for the immediacy of new health profile data.

Implementation of a Virtual Profile should be able to leverage existing Utah technology and expertise. The current Oracle database server should be sufficient for implementation of a Virtual Profile application provided sufficient capacity exists. Like the other solutions recommended in this document, web access to the application can be provided using one of Utah's existing web servers.

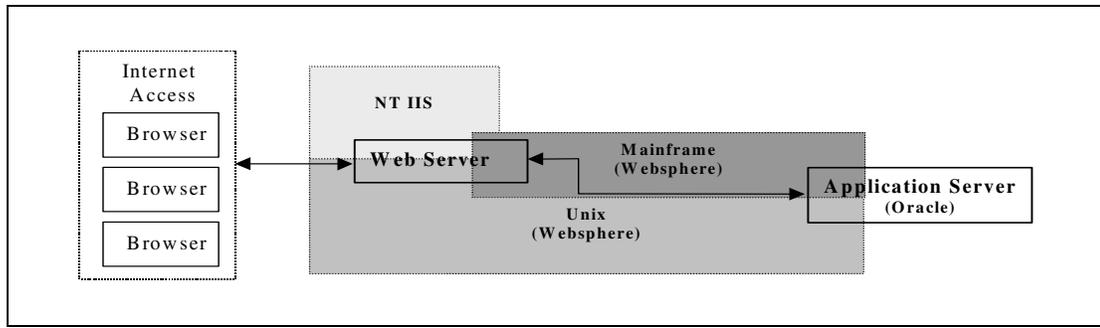
Communication interfaces between the Virtual Profile system and Utah's native systems can be developed jointly: application experts for the existing systems can be tapped for creating programs for retrieving specified information from their native data sources and Virtual Profile developers can develop code for receiving and displaying this information. This allocation of programming responsibilities should speed development and ensure that existing system knowledge is fully leveraged in the development of a Virtual Profile system.

The read-only nature and small footprint of the Virtual Profile solution necessitates only a limited security/user definition interface. Utah may be able to enhance an existing user definition application (preferably one associated with web application access) to meet this requirement. Leveraging such an existing system would reduce both overall development time and cost.

## Implementation Alternatives Comparison

Option	Ownership of Data	Length of Development Cycle	Cost of Development	Flexibility	Robustness	Impact on Existing Processes	Reliance on Existing Systems
Option 1: Unified Application	High	High	High	High	High	High	N/A
Option 2: Data Warehouse	High	Medium	Medium	Medium	High	Medium	Low
Option 3: Core Data Access	Medium	High	High	Low	Medium	Medium	Medium
Option 4: Virtual CHP	Low	Low	Low	High	Medium	Low	High

## Suggested Implementation Architectures



**Figure 5** Architecture Implementation Options

Any of the options proposed within this document should be implementable within Utah's existing technical infrastructure. Below are listed the different combinations possible for implementation. It is suggested that when considering an NT-based implementation the solution incorporate an "all-Microsoft" approach to avoid software conflict issues. Because of data security concerns, an NT-based solution is not recommended. Development of software components can be done in any combination of HTML, XML, Java, Visual Basic script, Java Script and any other languages compatible with Utah's expertise and architecture.

### **Implementation Architecture Alternatives**

Implementation Options	Browser	Web Server	Application Server
Implementation 1	Internet Explorer	NT / IIS	RS 6000 / Oracle
Implementation 2	Internet Explorer	NT / IIS	OS390 / Oracle
Implementation 3	Internet Explorer/Netscape	RS 6000 / Websphere	RS 6000 / Oracle
Implementation 4	Internet Explorer/Netscape	RS 6000 / Websphere	OS390 / Oracle
Implementation 5	Internet Explorer/Netscape	OS390 / Websphere	OS390 / Oracle

## Summary

All of the proposed Child Health Data Integration solutions share a number of common attributes.

### **The proposed system will have the ability to:**

- ❑ Allow anyone with internet or intranet access and defined security rights to view data mapped within the CHP system
- ❑ View real-time or near real-time data stored within the relational database systems accessed by the CHP system
- ❑ Search the CHP system to view children matching specified criteria
- ❑ Track who and when specific data is accessed

### **The proposed system will not:**

- ❑ Modify data residing on any of the systems accessed by the CHP system
- ❑ View data not residing on a relational database system
- ❑ Produce complex aggregate or statistical reports

All discussed alternatives for implementation of the proposed Child Health Data Integration effort are designed to leverage the existing technical architecture within the state of Utah. This includes the use of existing database servers, networking infrastructure and web and application servers with available capacity.

## Recommendations

This report concludes the needs assessment phase of the child health data integration effort. The next step for the project team is to review and evaluate the solution alternatives proposed in the preceding section. To determine which child health data integration solution is the best fit for Utah a number of factors need to be considered:

- ❑ The priorities for the systems to be integrated
- ❑ The length of time available before a solution must be implemented
- ❑ The feasibility that one of the proposed solution alternatives can be successfully implemented
- ❑ The quantity and skill level of resources available for implementing the child health data integration requirements (including time, money, equipment and expertise)

- ❑ Existing system utilization requirements/desirability
- ❑ Technical resources available to maintain the solution after its implementation
- ❑ The level of buy-in and ownership a proposed solution can amass

A structured approach for evaluating these considerations will help to keep the momentum going and support a smooth transition to the next phase. We recommend that this project's management team perform the following:

- ❑ Complete the Needs Assessment follow-up items (see below)
- ❑ Develop a department-wide Technology Architecture
- ❑ Complete an Organizational Impact Assessment
- ❑ Define Project Management and Communication Guidelines for the remaining phases of the integration effort
- ❑ Conduct a pilot/proof-of-concept project prior to planning for the integration's implementation phase. This project will "test" the INFORMATION defined to be included in the Child Health Profile (see Appendix B) as well as the selected technical strategy.

Completing these activities should enable the team to gather the necessary information for determining the best strategy for implementing a Child Health Profile Integrated solution. The following sections discuss each of these activities in detail.

### **Needs Assessment Follow-up Items**

This Needs Assessment includes findings and suggested implementation alternatives based on activities conducted during the assessment. To evaluate which solution, or combination of solution alternatives, is the best fit for Utah a number of activities need to be conducted. Completing these activities will help to garner buy-in, collect feedback and resolve open issues for the Child Health Profile Integrated application. The following activities are suggested to validate Utah's ability to implement its preferred solution:

- ❑ Solicit input from providers to determine their unique requirements for an integrated child health system
- ❑ Select an appropriate audience and distribute assessment findings
- ❑ Develop scenarios to test the Needs Assessment team's conception of the elements comprising a Child Health Profile (use during the testing phase of the pilot project)

- ❑ Resolve issues determining “interactive” or “view only” update capabilities to the CHP system (based upon a specific implementation solution). These should be addressed during the assessment of the technical alternatives.
- ❑ Determine how to uniquely identify a child within an integrated database. This will involve proposing candidate identifier(s), e.g., last name, first name, DOB, and mother’s maiden name, and selecting the one(s) that meets minimum criteria such as compliance with legal requirements and potential to uniquely identify a child. Although the overall purpose for the identifier is to increase the likelihood of uniquely identifying an individual child, storing key identifying information about an individual in a single place proposes security and confidentiality risks in the event that unauthorized users gain access to the system. These risks need to be evaluated against the potential benefits before an identifier strategy is finalized.
- ❑ Research the available capacity of key elements of the proposed technical architecture (e.g., server capacity, and bandwidth capacity). Metrics to be utilized in estimating capacity should include total system volume (1,000,000 child health records) and number of database hits per day (1,000)
- ❑ Legal liabilities (beyond those identified in the requirements section above, see “Requirements: Security, Privacy and Confidentiality Requirements”) for integrating data need to be investigated. This may require involvement of UDOH attorneys. It would probably also be a good idea to identify the ethical responsibilities of users of an integrated system. The attorneys may have some knowledge these as well.

### **Development of a Department-wide Technology Architecture**

Although it is outside the scope of this project, it is recommended that the department develop agency-wide technical architecture standards as soon as possible. The findings of this assessment confirm that there is a wide diversity of software and hardware in UDOH’s existing technical environment. Given the department’s goals for integration, the establishment of these standards will provide guidelines for future IT projects, thus preventing future and hopefully some “in-progress” projects (depending upon where they are in the system development life cycle) from having to do costly “retrofitting”. It will also eliminate the need for future system development project teams to assess/select technologies, develop an infrastructure to support the technologies, etc. Formally defining an architecture will also ensure that the department’s standards are in alignment with any existing state level architectural standards. It is recommended these standards be completed prior to the beginning of the Child Health Data Integration Planning Phase.

At a minimum, the Technical Assessment should include: 1) developing an inventory of the department’s existing systems<sup>4</sup>, 2) proposing a desired technical architecture that aligns with the agency’s strategic goals, IT budget, technical

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<sup>4</sup> The current systems technical inventory for this project can serve as a guideline for this work, see Appendix D.

resources, etc., and 3) a migration strategy (driven by these strategic goals). Appendix C contains a sample worksheet for capturing the elements of a Technical Assessment.

As part of the Assessment UDOH should examine its software development environment to determine how it supports the goals of coordination of services, information integration and user access. The assessment may also include an evaluation of software development tools (both back and front end, including web-based tools), database access tools, hardware, networks, security, and infrastructure. At the end of this effort a technical architecture report providing recommendations based on business objectives, project requirements, budgetary limits, and timeliness should be created. The recommended technical alternatives should provide the capabilities for security, scalability, reliability, manageability, maintainability, ease of use, transportability, and conformity with industry accepted conventions.

### **Completion of an Organizational Impact Assessment**

The purpose of an Organizational Assessment would be to examine UDOH's software development and support environment. Current roles and responsibilities should be mapped to those required by the proposed technical architecture. Additionally, the department may want to develop an "object sharing" strategy. Topics included in an Organization Impact Assessment might include:

- ❑ Object/model Management Strategies
- ❑ Version Control Procedures and Technologies
- ❑ Data Reusability -both logical and physical
- ❑ Development Standards, Guidelines, and Best Practices

To implement a component development infrastructure UDOH may wish to also develop a strategy for identifying, managing and reusing components and services. New standards for development must be outlined and existing standards enhanced to successfully implement a component development approach.

### **Project Management & Communication**

Establishing clear channels for communication is essential to the implementation of any complex system and is particularly applicable to the Child Health Integration effort. Standards and procedures for communicating management goals, tasks and timelines must be clearly defined and communicated. Conversely, design, development and test team progress must be systematically reported and mapped to established project milestones. Recommendations for

establishing an effective project management and communication infrastructure for the child health data integration effort include:

- ❑ Appointing a technical project manager to work with the program project manager
- ❑ Selecting a team to develop plans for implementing the requirements defined in the Needs Assessment
- ❑ Designating an advisory board to serve as the guidance and decision making body for the duration of the project (through implementation). Membership of this group can be drawn from the CHARM Core Council or the Grants Oversight Team.
- ❑ Appointing a dedicated workgroup of both technical and non-technical team members (with assigned project roles and responsibilities) to ensure project progress and success
- ❑ Establishing regular stakeholder communication (including email, status reports, and regularly scheduled meetings) to impart project status and progress
- ❑ Several issues and items for follow-up have been identified during the Needs Assessment. Progress toward completing these items should be tracked and the resolutions of the issues documented. Ideally an issue log could be implemented in a PC database to provide phase-to-phase tracking.
- ❑ Tracking the risks identified during the Focus Group Sessions. Ideally, the project team will develop a Risk Management Plan that fully describes each risk and identifies prevention and mitigation strategies.

### **Pilot Project/Proof-of-Concept Implementation**

Implementing a small portion of the proposed solution as a pilot application should:

- ❑ Verify the technical solution's feasibility
- ❑ Ensure UDOH's underlying technical infrastructure is capable of supporting a preferred solution
- ❑ Help to verify design and implementation time and resource estimates
- ❑ Identify procedural, organizational, or technical issues that may hinder the implementation of the entire system
- ❑ Validate the Child Health Profile data definition

- ❑ To be effective the pilot project should incorporate a subset of each of the major functional and technical areas identified with the Child Health Profile Integration effort. To measure the value to be gained from a pilot project the following areas must be identified:
  - ❑ Critical Success Factors
  - ❑ Quantified expectations in efficiency, information availability, usability and performance
  - ❑ Resources (both time, equipment and personnel) needed to implement
  - ❑ Native systems to be included in the pilot
  - ❑ Technical alternatives for the Child Health Profile Integrated solution (should the pilot project invalidate the preferred solution)
  - ❑ Establish priority of systems to roll into the Child Health Profile Integrated application (after a successful pilot implementation)

The following table can serve as a guide to creating a Roles and Responsibilities document for the implementation of a pilot application.

<b>Pilot Project Phase</b>	<b>UDOH Participant Roles</b>
Initiation	Project Managers, Project Advisory Board & IT Consultants
Visualization & Concept of Operations	Project Advisory Board, UDOH IT, CSHCN IT, & IT Consultants
Review & Validate Requirements	Project Manager, Directors
Complete Analysis	Project Manager, GSDI Grant Manger and Project
Finalize Design Specifications	
Pilot Project Version Development	UDOH Consultant Systems Developers, User testing groups
Establish Production Environment	UDOH DBA & Technical Support
Close Project	Project Manager

The successful implementation of a pilot project should be usable in the first phase of the Child Health Profile Integrated solution. Experience gained from the pilot should facilitate refinement of a comprehensive project plan and identify areas of technical infrastructure needing additional attention.

If a pilot effort is not successful UDOH should be able to identify the barriers to the pilot’s implementation, better identify alternate solutions more appropriate to Utah’s architecture, and revise its estimates of resources and expertise needed to implement a Child Health Profile Integrated solution.

## **Conclusion**

**“To develop and manage systems which provide information to facilitate decision making, policy development, and service delivery, by providing leadership that assures collaboration with**

**stakeholders, adherence to common standards, integration of information systems components, and innovation”.**

***-Utah Department of Health Information Systems Vision***

Based on findings collected during the Needs Assessment, the Utah Department of Health’s mission statement should prove to be technically feasible, realistic and practical.

Weighing which solution is the best fit for Utah rests on four main factors:

- ❑ Tolerance for risk
- ❑ Development resources and technical expertise
- ❑ Management and communication infrastructure
- ❑ Acceptable time to delivery

This Needs Assessment identifies implementation options based on varying degrees of acceptability for each of these factors. The outlined activities in this recommendation are designed to establish which implementation alternative is best suited for Utah’s Department of Health.

Solicitation of feedback from stakeholders and completion of an Organizational Assessment will gauge both the risk/reward tolerances for each of the Child Health Profile Integrated solutions and discern an acceptable rollout schedule. Completion of a department-wide Technology Architecture sets the direction for a CHP solution and confirms the necessary technical infrastructure is in place. Establishment of management and communication protocols and definition of participant roles and responsibilities reduces risk to implementation and ensures a robust project development environment. Lastly, defining and implementing a CHP pilot validates the direction of the Child Health Profile Integrated solution and substantiates development, resource and delivery estimates.

To minimize risk to the implementation of the Child Health Profile Integration effort (and to maximize the value of Utah’s preferred implementation solution) it is crucial that each of these preparatory activities be rigorously conducted and completed. Premature application development poses one of the largest risks to the successful deployment of the Child Health Profile Integration effort.

This Needs Assessment has discovered no insurmountable barriers to the Child Health Profile Integration effort. Ultimately, the issue is not whether UDOH can implement a Child Health Profile Integrated solution, but rather by which method it will choose to do so. A systematic and intelligent drive to build not only the Child Health Profile Integration application but also a solid foundation on which to support it will indeed realize Utah’s mandate to Protect, Prevent, and Promote the health of its children.

# Appendix A - Questions

## List of Posed Questions Used in Defining and Refining the Proposed Child Health Profile System

1. What is the current state of the data warehouse development effort? How is the Child Health Data Integration effort to be incorporated into the data warehouse data set?
2. What is the common envisioned interface?
3. What technologies can be leveraged to access and manipulate data?
4. Are all existing points of data entry going to be maintained?
5. Will the common interface allow data modifications to data obtained from another source?
6. Do all sites desiring access to the data have a common method for accessing it (i.e. Internet or Intranet access)?
7. Is audit information being kept? If not, will it need to be?
8. Are the existing web applications and data storage on a common platform? Can this platform be leveraged?
9. Is the integrated data truly a “join” of an existing data or is the data to be scrubbed and copied to a central database?
10. How frequently must data changes be updated to the common view?
11. Where will the “composite” data reside?
12. Who is responsible for maintaining and enhancing the proposed system?
13. How are data replication and contention issues to be managed?
14. What data sources must be included and what are considered “nice-to-haves”?
15. Can an individual “opt out” of the state’s tracking system?
16. Where is MS Access, FoxPro, Paradox and other stand-alone environments data maintained (network, stand-alone machine,)?
17. What is the envisioned security? Will existing security be replaced with a unified system?
18. Will Excel spreadsheets be replaced with a relational database interface?
19. How will Excel and Word data be incorporated and migrated to the data repository?
20. What licensing issues are relevant when pulling data from proprietary systems?
21. Which data sources can not be accessed via ODBC or JDBC?
22. Are all machines containing information accessible from a network?
23. Are there any systems that cannot export data electronically?

# **Appendix B – Information Requirements for Child Health Profile**

## Child Health Profile Data

Must Have	Nice to Have	Does not Belong
<b>DEATH DATA</b>		
Date of Death	Time of Death	Found By
Cause of Death	Age of Death	
Medical Examiner Number	City of Death	
Position Found <sup>5</sup>	County of Death	
Detailed Death Data <sup>6</sup>	Place of Death	
	Death Certificate Number	
<b>CHILD HISTORICAL DATA</b>		
Previous SIDS in Family		
		<b>BREASTFEEDING DATA (CHILD)</b>
<b>FEEDING/NUTRITION</b>		Breastfeeding at Birth
Bottle Y/N		Currently Breastfeeding
		Ever Breastfed
Breast Y/N		Breastfeeding Frequency
Special formula/diet Y/N		Breastfeeding Begin Date
		Breastfeeding Ceased Date
		Breastfeeding Ceased Reason
		Breastfeeding Duration
		First Formula at Weaning
		<b>LACTATION DATA (MOTHER)</b>
		Currently Breastfeeding
		Previous Breastfeeding Experience
		Breastfeeding Frequency
		<b>Lactation data (Mother) Cont.</b>
		Breastfeeding Ceased Date
		Breastfeeding Ceased Reason
		Breastfeeding Duration
<b>BIRTH DATA</b>		
Date of Birth	Birth Length	
City of Birth	Birth Certificate Number	
State of Birth	Hospital Chart/MR Number	
	Delivery Attendant	
	Type of Delivery (c-section or Vaginal)	
Birthplace	Maternal Mortality	
Delivery Complications (Y or N)	Date of Hospital Discharge (Mother and Baby)	
Birth Facility Name <sup>7</sup>		
Birth Facility ID Number		
Birth Weight (Grams)		
Head Circumference		
Multiple Birth		

<sup>5</sup> For SIDS Program only

<sup>6</sup> For SIDS Program only

<sup>7</sup> Can be either Birth Facility Name or Birth Facility ID#

<b>Must Have</b>	<b>Nice to Have</b>	<b>Does not Belong</b>
Prematurity (Weeks at gestation)		
Abnormal Birth Conditions (Neonatal)(Y or N)		
Abnormal Birth Conditions (Maternal)		
Pediatric Care Provider		
NICU (Y or N)		
Number of Days in ICU		
Transfusion (Y or N)		
Antibiotics (Y or N)		
Apgar (1 min)		
Apgar (5 min)		
<b>PREVIOUS PREGNANCY DATA</b>		
		Age of Mother at First Delivery
		Age of Mother at Current Delivery
		Gravida
<b>PREVIOUS PREGNANCY DATA (Cont)</b>		Number of Previous Pregnancies
		Number of Pregnancy Terminations
		Number of Premature Pregnancies
		Number of Live Births
		First Pregnancy – 17 or younger
		Infant Weight < 5.5 lbs.
		Year of Birth
		Place of Birth
		Birth Outcome (Code)
		Birth Outcome (Risk)
		Sex
		Birth Weight
		Delivery Method
		Delivery Method Risk
		Anesthesia
		Length of Gestation
		Labor Length
		Obstetrical Problems
		Obstetrical Risk
		Neonatal Problems
		Neonatal Risk
		Intended or Not Intended
<b>ELIGIBILITY STATUS FOR OTHER PROGRAMS</b>		
		Household Income
		Proof of Income
		Household Size
<b>SPECIALTY VISIT DATA/ASSESSMENT</b>		
Health History (Medical Diagnosis)	Medications	Date of Visit
	Allergies	Pediatric Exam
		Known Risk Factors
<b>SPECIALTY VISIT DATA/ASSESSMENT (CONT)</b>		Lab (Date of specimen, Specimen ID, Hemoglobin, Hematocrit)



<b>Must Have</b>	<b>Nice to Have</b>	<b>Does not Belong</b>
Current Pregnant Y/N		EDD Date
If yes, High Risk?		Last Menstrual Period
		Month Prenatal Care Began
		Number of Prenatal Visits
		Pregnancy Complications
		Chronic Medical Conditions
		Tobacco Use During Pregnancy
		Alcohol Use During Pregnancy
		Planned Pregnancy
		Method of Delivery
		Testing and Screening (e.g., Hepatitis)
<b>PARENT/GUARDIAN DATA</b>		
Mother/Guardian First Name	Mother's Occupation	
Mother/Guardian Last Name	Mother's Marital Status	
Mother/Guardian Middle Initial	Mother's Birthplace	
Mother's Maiden Name	Mother's Country	
Mother's Date of Birth	Mother's Social Security Number	
Mother/Guardian Address	Father's Occupation	
Mother's Phone Number	Father's Social Security Number	
Mother/Guardian City	Mother's Education in Years	
Mother/Guardian State	Father's Education in Years	
Mother/Guardian Zip Code	Mother and Father's Primary Language	
Mother's Race	Need for Accommodation (Interpretation, Translation, Transportation, Physical)	
Father's First Name		
Father's Last Name		
Father's Middle Initial		
Father's Date of Birth		
Father's Ethnicity		
Father's Race		
Father's Address		

# Appendix C – Technical Architecture Sample Worksheet

	Servers & Operating Systems	Network Access & Protocols	Database Management	Office Automation Software	Application Development Methods & Tools	Internet	Security
<b><i>Current State</i></b>							
<b><i>Migration Strategy</i></b>							
<b><i>Future Strategy</i></b>							

## Appendix D – Current Environment Table

Technical Data Current System	Hrdware Deployed On	Operating System	Deployment Software (Prgramming Language)	Database And/Or File Type	Location Of Deployed System	# Of Total Users	# of Con-current Users	# of Database Hits Per Day	Volume of Data Stored	Usual Volume of Real Time Data Retrieved	Any Peak Volume Periods	What is Used as Unique Data Identifier?	Any Batch Processing?	Notes
Hearing Screening	Novell Server Pentium II	Novell 5.x	Access 2000/ Visual Basic	SQL	44 Medical Dr.	60	45 to 60	60 to 120	10% of Annual Births	1% of Annual Births	End of Month, End of Year & Quarter	System generated unique ID	Data sent from hospitals once per month	
Metabolic Screening	Pentium III	NT	Access 2000 / Visual Basic	SQL	46 Medical Dr.	12	12	10 to 20	100 % of Annual Births (multiple records per birth	10 to 12	End of Day & Early Morning	Patient ID – system generated	lab testing equipment sends batches of 55 – 60 records of data	
Vital Records	Novell Server Pentium II	Novell 5.x	Visual Basic	Btrieve	Cannon Health Building	40	25	1500 - 2500	100 % of Annual Births, multiple years are on line.	5 %		State File Number	Batch Transfers to Other Programs (1000/day)	
Early Intervention	(13)	(14)	(15)	Oracle	(16)	3 (17)	3 (18)	Up to 1,000	5,000 per year	25	June, Dec. & End of Month	(19)	(20)	(21)
Utah Statewide Immunization Information System (USIIS)	RS6000 (1)	(1)	(2)	Oracle	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)
Birth Defects Registry	Novell Server Pentium II	Novell 5.xx	Access 2000	Access 2000	44 Medical Dr.	2	2	10	approxim ately 2,000 Records per year  estimate 200 MB	Data Retrieved to Generate Reports	END OF REPORTING YEAR	System generated	No	System has field for Vital Records State File

Technical Data Current System	Hrdware Deployed On	Operating System	Deployment Software (Prgramming Language)	Database And/Or File Type	Location Of Deployed System	# Of Total Users	# of Con-current Users	# of Database Hits Per Day	Volume of Data Stored	Usual Volume of Real Time Data Retrieved	Any Peak Volume Periods	What is Used as Unique Data Identifier?	Any Batch Processing?	Notes
														Number

- (1) Database deployed on IBM System 390 running Oracle 8.1.7 "Processes" run on IBM?RS6000 – Aix
- (2) Client/Server app – Oracle forms accessing Personal Oracle & "links" to host database. We benabled – Java applett – JDK 1.1.7 – hosted on Sun Server – IBM Websphere server. Host software PL?SQL & Java Serveletts.
- (3) UDOH – Cannon Building & State of Utah Office Building – Database & Web server)
- (4) < 500
- (5) < 50 will increas in next two years – maybe < 100
- (6) 100,000
- (7) 2-4 GB
- (8) < 1,000 bytes / transaction
- (9) Pretty consistent throughout the year
- (10) "USIIS – ID" internal generated number to uniquely identify a "person" in the Immunization Registry
- (11) Yes significant processing – all data loaded into database in a "batch" cycle.
- (12) Contains the Vital Records Birth Certificate #. Contains the Medicaid unique identifier.
- (13) Oracle on State ITS Server (IBM Mainframe or Sun Solaris). Information system ? possibly IBM Websphere – a web application
- (14) NT or Sun Solaris
- (15) ?? IBM Websphere ? Java?
- (16) State ITS Servers probably
- (17) < 50
- (18) < 25
- (19) To be determined
- (20) ?? Report generation?
- (21) The database is in design phase – no existing electronic system

# **Appendix E – Focus Group Session Notes**

## **Focus Group I and II Session Notes**

### **CRITICAL SUCCESS FACTORS FOR INTEGRATED CHILD HEALTH PROFILE**

- ◆ Money
- ◆ Buy-in and shared ownership from agencies involved
- ◆ Top management commitment
- ◆ Honoring/respecting families right to privacy
- ◆ Time commitment for implementation and on-going support
- ◆ Adequately trained staff
- ◆ Commitment from legislature for the long haul (need to educate)
- ◆ Educate public to help people understand the value and ensure their sense of security about the data
- ◆ Make sure this is a profile – not a medical record
- ◆ Committed team
- ◆ Commitment to use data
- ◆ Development of technical skills Commitment to use data (training)
- ◆ Link to healthy people 2010 and not Public Health Performance standards
- ◆ Early success

## **BENEFITS OF INTEGRATED CHILD HEALTH PROFILE**

- ◆ Reduce turnaround time for early intervention eligibility for federal compliance
- ◆ Decrease costs (eliminate unnecessary treatment /evaluation; eliminate redundant data entry)
- ◆ Makes life easier for families
- ◆ Improves overall healthcare, coordination
- ◆ Increase access for families
- ◆ Increase awareness/referrals
- ◆ Enhances policy making capabilities and forecasting trends
- ◆ Enhance marketing abilities for immunization tracking system
- ◆ Improve public health surveillance
- ◆ Makes information sharing user friendly

## ROAD BLOCKS TO INTEGRATED CHILD HEALTH PROFILE

- ◆ Lack of funding
- ◆ People unwilling to allow information to be shared
- ◆ Must be flexible as data, regulations are constantly changing
- ◆ Overcoming technical security constraints
- ◆ Poor data integrity (garbage in/garbage out)
- ◆ Lack of commitment of staff
- ◆ Attitude problems (getting people to work a different way)
- ◆ Technology phobias
- ◆ Past failures resulted in built in resistance

## ISSUES CONCERNING INTEGRATED CHILD HEALTH PROGRAM

- ◆ Should sharing of information through outreach be allowed?
- ◆ Should social security number be in child health profile?
- ◆ How is “Public Assistance” defined in the demographic data?
- ◆ Referred “to” and “by” doesn’t belong on a child health profile.
- ◆ Determine what compromises: name – legal name, also known as
- ◆ Need to determine standards for race.
- ◆ Financial information needs protected fields.
- ◆ Need to determine what fields are updated by what group(s) of users for all categories.
- ◆ Informed consent
  - ◆ Sources of information (e.g., lab, clinical doctor’s office)
- ◆ Will families be able to access their own data?
- ◆ Is an integrated system better for the Department or better for the consumers?
- ◆ How do we define child? 0 – 18 or 0 – 21? Will determine whether “armed forces” is part of demographic data for child. If coordinating service with special ed – age would be 22.
- ◆ Should adoption information be part of demographic data? No
- ◆ Where is “referred to” and “referred by”?
- ◆ Who’s the “source” and “when” for data categories in child health profile – need to consider adding these elements.
- ◆ Should tobacco, alcohol, and drug use be a part of the child health profile?

## DEATH DATA

- ◆ Date of Death
- ◆ Time of Death
- ◆ Age of Death
- ◆ City of Death
- ◆ County of Death
- ◆ Cause of Death
- ◆ Place of Death
- ◆ Found By
- ◆ Death Certificate Number
- ◆ Medical Examiner Number
- ◆ Position Found
- ◆ Detailed Death Data

## CHILD HISTORICAL DATA

- ◆ Previous SIDS in Family

## BREASTFEEDING DATA (CHILD)

- ◆ Breastfeeding at Birth
- ◆ Currently Breastfeeding
- ◆ Ever Breastfed
- ◆ Breastfeeding Frequency
- ◆ Breastfeeding Begin Date
- ◆ Breastfeeding Ceased Date
- ◆ Breastfeeding Ceased Reason
- ◆ Breastfeeding Duration
- ◆ First Formula at Weening

## LACTATION DATA (MOTHER)

- ◆ Currently Breastfeeding
- ◆ Previous Breastfeeding Experience
- ◆ Breastfeeding Frequency
- ◆ Breastfeeding Ceased Date
- ◆ Breastfeeding Ceased Reason
- ◆ Breastfeeding Duration

## BIRTH DATA

- ◆ Date of Birth
- ◆ City of Birth
- ◆ State of Birth
- ◆ Birthplace
- ◆ Delivery Complications
- ◆ Birth Facility Name
- ◆ Birth Facility ID Number
- ◆ Birth Weight (Grams)
- ◆ Birth Length
- ◆ Head Circumference
- ◆ Multiple Birth
- ◆ Prematurity (Weeks at gestation)
- ◆ Abnormal Birth Conditions (Neonatal)
- ◆ Abnormal Birth Conditions (Maternal)
- ◆ Birth Certificate Number
- ◆ Hospital Chart/MR Number
- ◆ Delivery Attendant
- ◆ Pediatric Care Provider
- ◆ Maternal Mortality
- ◆ Infant Mortality
- ◆ Transfusion (Y or N)
- ◆ Antibiotics (Y or N)
- ◆ Apgar (1 min)
- ◆ Apgar (5 min)
- ◆ Type of Delivery (C-section or Vaginal)
- ◆ Date of Hospital Discharge (Mother and Baby)
- ◆ NICU (Y or N)
- ◆ Number of Days in ICU

## PREVIOUS PREGNANCY DATA

- ◆ Age of Mother at First Delivery
- ◆ Age of Mother at Current Delivery
- ◆ Gravida
- ◆ Number of Previous Pregnancies
- ◆ Number of Pregnancy Terminations
- ◆ Number of Premature Pregnancies
- ◆ Number of Live Births
- ◆ First Pregnancy – 17 or younger
- ◆ Infant Weight < 5.5 lbs.
- ◆ Year of Birth
- ◆ Place of Birth
- ◆ Birth Outcome (Code)
- ◆ Birth Outcome (Risk)
- ◆ Sex
- ◆ Birth Weight
- ◆ Delivery Method
- ◆ Delivery Method Risk
- ◆ Anesthesia
- ◆ Length of Gestation
- ◆ Labor Length
- ◆ Obstetrical Problems
- ◆ Obstetrical Risk
- ◆ Neonatal Problems
- ◆ Neonatal Risk
- ◆ Intended or Not Intended

## ELIGIBILITY STATUS FOR OTHER PROGRAM

- ◆ Household Income
- ◆ Proof of Income
- ◆ Household Size

## SPECIALTY VISIT DATA/ASSESSMENT

- ◆ Health History (Current tobacco & alcohol use, Prior hospital admissions, Recent illnesses, Well child care)
- ◆ Date of Visit
- ◆ Medications
- ◆ Allergies
- ◆ Pediatric Exam
- ◆ ***Health Programs Participating In***
  - ◆ Developmental/Psychological
  - ◆ Hearing & Speech
  - ◆ Neurological
  - ◆ Ophthalmological
  - ◆ Nutrition
  - ◆ Dental
  - ◆ Occupational Therapy
  - ◆ Social Work
  - ◆ Developmental
  - ◆ Skin
  - ◆ Vision
- ◆ Known Risk Factors
- ◆ Lab (Date of specimen, Specimen ID, Hemoglobin, Hematocrit)
- ◆ Anthro Prometric (Height, Weight, OFC)
- ◆ Safety Information?

## DEMOGRAPHIC DATA

- ◆ Unique Participant Number
- ◆ Unique Case Number
- ◆ Name: First, Last, Middle, and “Also Known As”
- ◆ Sex
- ◆ Address (Residence)
- ◆ City (Residence)
- ◆ State (Residence)
- ◆ Zip (Residence)
- ◆ County (Residence)
- ◆ Address (Mailing)
- ◆ City (Mailing)
- ◆ State (Mailing)
- ◆ Zip (Mailing)
- ◆ Date of Birth
- ◆ Phone Number
- ◆ Phone Number (Work)
- ◆ Social Security Number
- ◆ Race
- ◆ Hispanic Origin
- ◆ Primary Language
- ◆ Need for Accommodations
- ◆ Child’s Age at Entry
- ◆ School District/School
- ◆ Public Assistance
- ◆ Residential Status
- ◆ Referred By
- ◆ Referred To
- ◆ Primary Care Provider
- ◆ Usual Source of Health Care
- ◆ Armed Forces
- ◆ Marital Status
- ◆ Occupation
- ◆ Education
- ◆ Country of Residence
- ◆ Ethnicity
- ◆ Another Source of Contact
- ◆ All Programs Participating In
- ◆ Last Date Updated and By Whom
- ◆ Living in Same Household

## IMMUNIZATION DATA

- ◆ Immunization Status
- ◆ Immunization History, Data
- ◆ Other (USIIS Tracking)

## INSURANCE DATA

- ◆ Carrier
- ◆ Coverage (Medicaid, Mental Health, CHIP, or Other)
- ◆ Depth and complexity to which the Department is willing to go?

## CURRENT PREGNANCY DATA

- ◆ EDD Date
- ◆ Last Menstrual Period
- ◆ Month Prenatal Care Began
- ◆ Number of Prenatal Visits
- ◆ Pregnancy Complications
- ◆ Chronic Medical Conditions
- ◆ Tobacco Use During Pregnancy
- ◆ Alcohol Use During Pregnancy
- ◆ Planned Pregnancy
- ◆ Method of Delivery
- ◆ Testing and Screening (e.g., Hepatitis)

## PARENT/GUARDIAN DATA

- ◆ Mother/Guardian First Name
- ◆ Mother/Guardian Last Name
- ◆ Mother/Guardian Middle Initial
- ◆ Mother's Maiden Name
- ◆ Mother's Date of Birth
- ◆ Mother's Occupation
- ◆ Mother's Marital Status
- ◆ Mother's Birthplace
- ◆ Mother/Guardian Address
- ◆ Mother's Phone Number
- ◆ Mother/Guardian City
- ◆ Mother/Guardian State
- ◆ Mother/Guardian Zip Code
- ◆ Mother's Country
- ◆ Mother's Race
- ◆ Mother's Social Security Number
- ◆ Father's First Name
- ◆ Father's Last Name
- ◆ Father's Middle Initial
- ◆ Father's Date of Birth
- ◆ Father's Ethnicity
- ◆ Father's Occupation
- ◆ Father's Race
- ◆ Father's Social Security Number
- ◆ Father's Address
- ◆ Mother's Education in Years
- ◆ Father's Education in Years
- ◆ Mother and Father's Primary Language
- ◆ Need for Accommodation (Interpretation, Translation, Transportation, Physical)

## WHO SHOULD BE INCLUDED IN FUTURE FOCUS GROUP SESSIONS

- ◆ Schools
- ◆ Parents and Other Consumers
- ◆ Local Health Departments
- ◆ UMA
- ◆ Minorities
- ◆ Academic Researchers
- ◆ Parent Center
- ◆ PTA
- ◆ Headstart
- ◆ Medical Ethicists
- ◆ Insurance
- ◆ Elected Officials

## Focus Group III Session Notes

### CUSTOMERS

- ◆ Migrant parents of children 5 & under
- ◆ Spanish community of Utah
- ◆ Department of Health
- ◆ Department of Human Services
- ◆ Legislature
- ◆ Premature babies at risk for disabilities
- ◆ Service providers (writing grants)
- ◆ Reporters

### CONCERNS/RISKS/ISSUES

- ◆ Being ineligible for certain programs will “flag” individuals
- ◆ How to ensure accuracy of data –that incorrect data gets “fixed” (parents could get involved)
- ◆ Primary provider should not have unlimited access (e.g. financial)
- ◆ Issue of informing people will have tremendous impact on use/access to data
- ◆ How to get private providers to input data into the system
- ◆ Do benefits of integrated system outweigh the risks?
  - ◆ Benefits outweigh risks but safeguards need to be put into place. Need to build in disincentives for people to use the data inappropriately
  - ◆ System must be extremely user friendly

### BENEFITS

- ◆ Convenience to parent (keeps track of medical services –immunization, avoid repetition of providing info)
- ◆ To help babies in critical period birth to 3 years that currently get lost
- ◆ To help families access available resources (from referrals)
- ◆ To aid in referrals –parents should indicate willingness to be contacted
- ◆ To assist medical professionals in becoming more accountable
- ◆ To aid in following a child
- ◆ To identify children with special health care needs (in schools) –diabetes
- ◆ Ensure timeliness of aggregate data
- ◆ Assist private providers in putting in individual child health info (health problems, habits, etc.)
- ◆ Hospital records could be linked with other places where health services are provided
- ◆ Streamline paperwork required at places where health services are provided
- ◆ Readily available info for creating educational plans, special diets, etc.)

### INFORMATION THAT SHOULD NOT BE SHARED

- ◆ Who information is available to is more important than what information is available
- ◆ Who determines what information is available?
  - ◆ The last request will serve as the guideline
  - ◆ Automatically shared unless otherwise specified
  - ◆ Eligibility info can not flag certain people (also, a parent doesn't want to be told multiple times about services)
  - ◆ No financial information

- ◆ No diagnosis information is available

#### **WHO SHOULD BE EXCLUDED FROM ACCESS?**

- ◆ Commercial insurance companies
- ◆ DFS & Child Protective Services (can be helpful or invasive) –can be collected on an option basis.
- ◆ Groups/people other than service providers
- ◆ Corporate entities/businesses
- ◆ Employers having access to their employees' information that is contained in the system

## **Focus Group IV Session Notes**

### **PURPOSE OF CHILD HEALTH PROFILE**

- For families –convenience, to help prevent people falling through the cracks (enable follow-up), improve awareness of services (referrals)
- Info that is being asked for again and again (demographics)
- Readily available info for those who provide services
- Improve integrity of data (if everyone agrees that CHP data is accurate)
- Improve deficiency of program staff
- Provide info (report)
- Populate program database
- Using other program's data to improve ability to do work
- Improve accuracy of data by not having to ask a third party to interpret
- Letting other programs know in what services/programs(s) a child is participating

### **NOT THE PURPOSE OF A CHILD HEALTH PROFILE**

- Electronic record
- Breastfeeding data (most is not needed)
- Not for generating reports (related to services)
- For families eligibility info (a concern for people outside of public health)

# Appendix F – Table of Functional Requirements

Minimum Functional Standards for the Child Health Profile

	Priority
1. Electronically store data on all CHP Committee approved core data elements.	H
2. Establish a CHP record within 6 weeks of birth for each newborn child born in Utah.	H
3. Enable access to information in the CHP at the time of encounter.	H
4. Receive and process CHP information in real time / near real time.	M
5. Protect the confidentiality of medical information.	H
6. Ensure the security of medical information.	H
7. Recover lost data (data recovery).	M
8. Exchange CHP records with external entities using Health Level 7 (HL7) standards.	M
9. Automatically determine when a CHP client needs a screen/procedure as determined by screening standards set by the CHP Committee. Will need the ability to change the standards at any time.	M
10. Automatically identify individuals due/late for any follow up action due to enable the production of reminder/recall notifications.	M
11. Automatically produce reports by specific program areas and across providers by age groups, and geographic areas.	L
12. Consolidate scattered records to create a comprehensive CHP, using deduplication and edit checking procedures to optimize accuracy and completeness.	H
13. Intuitive collection and use of data for users.	M
14. Two way sharing of data and communication of data.	H
15. QA standards to implement, update, and track HP2010 indicators.	M
16. Acceptable user Performance/Response Time	H
17. Give access to those who should have access and deny access to those that should not have access.	H
18. Quality component to maintain accuracy and quality of data.	H
19. Keep data for specified time period and archive records as specified by the CHP committee.	H
20. Intuitive Maintenance of the system.	M
20. System available 24 by 7.	L

# **Appendix G – Supplemental Project Documentation**

AVAILABLE UPON REQUEST ONLY