

Utah

Department
of Health

DATA INTEGRATION PLAN

May 31, 2002

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ACKNOWLEDGEMENTS

This document is submitted as the Data Integration portion of the final report due on May 31, 2002, under the HRSA MCHB Genetic Services and Data Integration Planning Grant # 5 H46 MC 00171-02. The State Genetic Services Plan constitutes the other part of the final report. We would like to thank HRSA for the opportunity they offered Utah to gather the resources and take the time to plan this important integration initiative.

We want to thank all the people who participated in this intensive and interesting effort. None of this would have been possible without their knowledge, dedication and hard work.

EXECUTIVE SUMMARY

BACKGROUND

This report constitutes the final report for a 2-year (6/00 – 5/02) HRSA grant to complete needs assessment and planning activities in the Utah Department of Health (UDOH), focused on Data Integration for early childhood programs and systems. The main content of the report is about the approach and results of the planning activities (grant year 2). The final report for the need assessment phase (grant year 1) was completed last year and is included as an appendix.

Since the HRSA grant targeted two areas, Data Integration and the development of a state Genetic Services plan, another report, issued concurrently with this one, accounts for needs assessment and planning activities focused on the development of a state Genetic Services plan in Utah.

APPROACH

The Data Integration need assessment phase was contracted out to the MTW Corporation who, together with the UDOH project team, planned, conducted and completed the needs assessment activities and report. In year 2, through the use of teamwork and focus groups, the UDOH project team was able to complete the Data Integration planning phase without contracting out to a vendor.

As a first step, the grant project team reviewed the findings of the needs assessment phase and organized them in clusters, by general area of content. This arrangement allowed for a number of salient topics to be identified. Going into the planning focus groups, each of these areas were further defined by a goal statement and were designated as areas needing dedicated resources, attention, and a plan of their own. As these areas clearly had significant interdependencies, they were called threads, that is, interweaving threads. In preparation for the planning focus groups, the project team drafted the plan for the technical thread and for one other thread, as examples for the focus group participants.

The planning focus groups were moderated and included division, bureau, program managers and staff from the programs participating in the Data Integration initiative, IT representatives, parents and parent advocacy groups, partners from Utah State University, and observers. After the sample draft plans for the two selected threads were reviewed with the group, the focus group participants drafted plans for two additional threads and then assigned lead teams for each thread.

Following the focus groups, each lead team drafted plans for their thread and then reviewed them, as a group, in order to identify and reconcile dependencies. Then the plans were revised and refined. They constitute the basis on which the goals and objectives discussed in this report have been based.

RESULTS

The Data Integration planning effort resulted in building a larger project team to take responsibility for the implementation and success of the Data Integration effort. The team has now expanded beyond the technical members and includes program representatives across the organization.

The team has formulated seven specific goals to effect change. A number of objectives have been identified as landmarks under each goal. Each objective lists the parties who have implementation responsibility, the content and timing of the activities to be performed, the deliverables and milestones to be achieved, the objective's significance, and the ways to measure success.

Following are the seven goals:

GOAL A. Communications & Marketing

To improve the ways in which, and the times at which, the various stakeholder groups (parents, providers, legislators, etc.) are engaged, such that they have opportunities for input, validation, adoption and evaluation all along the continuum of the Data Integration effort.

GOAL B. Data-related Rules, Policies and Procedures

To ensure that data is collected, stored, shared and utilized by all the stakeholders in a non-discriminatory manner, in accordance with state and federal laws and with family input and consent.

GOAL C. Data Quality

To improve the accuracy, completeness, timeliness and reliability of the data collected while making it readily available to all stakeholders in a confidential, secure manner.

GOAL D. Organizational Change

To extend the benefits of Data Integration within the UDOH programs by facilitating, promoting and supporting its "adoption" by leveraging activities, techniques, tools and instruments that foster positive change in the organization.

GOAL E. Technical Development

To enhance the value of the technical components developed for the UDOH Data Integration by ensuring that the proper content is being developed, in the right sequence, according to users' requirements and specifications.

GOAL F. Participating Program Technical Development

To improve the ability of the existing systems currently supporting each of the participating programs to work within the integrated Child Health Advanced Records Management (CHARM) environment, without disrupting or disabling their primary functionality. Technical Threads across Participating Programs will be similar.

GOAL G. Program Management

To ensure the timely and quality completion of all the deliverables in all the threads associated with the DI effort by managing the entire program in a comprehensive, coordinated, responsible, safe, flexible and responsive manner. Efforts will be made at all times to ensure that risks are minimized, funding is optimized, stakeholders are satisfied, families are better served, private providers and medical homes are properly engaged, and the organization is better off.

Because of the timing of certain UDOH specific events and the timing of the HRSA Assessment & Planning (A&P) grant, the plans and timelines proposed cover activities at various degree of completion. Some of the activities have already been completed, some are already in progress or partially completed, and some activities will need to take place. Overall, the plan covers the time span from 1Q 1999, when the UDOH Data Integration vision was formulated, to 3Q 2004, when the web version of CHARM is scheduled for rolled out to private providers. Furthermore, it also covers activities whose timeline is ongoing.

SIGNIFICANCE

The planning effort, as conducted, resulted in the definition of a multi-thread plan for UDOH Data Integration initiative as well as in the expansion of the original team to include new members. Many of these new members are now in charge of leading specific areas of the effort. The plan will offer a roadmap for the implementation of various objectives, as identified, and a mechanism for keeping the complexities of the effort in control.

Because of its complexity, the Data Integration will be managed as a program consisting of a number of individual but interrelated projects. Acknowledging the inherent complexity of a Data Integration effort will enhance our ability to manage it appropriately.

The multi-thread concept will be significant in the data integration initiatives of other Departments of Health and will be shared in appropriate settings and venues. For the UDOH, it has been critical in changing the general belief that Data Integration is an Information Technology (IT), that is technical, project. Instead, it is now viewed as a complex, organization-changing initiative. This will ensure the participation of the organization at large and will make the success of the Data Integration initiative more certain.

DEFINING INTEGRATION

It should be acknowledged that the term *integrated health information systems* means different things to different people in different contexts. Public health agencies need to share information between programs and between divisions within their own department, as well as with other agencies within the state, region, and nation. In order to make informed health care decisions, private providers also need much of the same information already collected by public health programs. Additionally, each of these parties makes decisions regarding the clients/families involved, the details and consequences of which should be shared with others.

Although the statements above are admittedly true, many of the systems supporting public health programs have been developed in isolation of one another or with incompatible technologies. This resulted in independent systems that share many common data elements and serve overlapping client bases, yet cannot communicate and share data with one another. Furthermore, they also support duplicate data entry, which hinders agency operations, consumes precious resources, retards timely access and undermines the quality of the data as well as the service delivery process.

Integration encompasses a variety of functions designed to remedy many of these deficiencies and enable timely and efficient sharing of information within and between agencies.

With respect to intra-agency integration, the primary objectives are:

- to eliminate duplicate data entry,
- to provide access to information that is not otherwise available,
- to ensure the timely sharing of critical data, and
- to enable coordinated service delivery.

Beyond improving the internal operations of public health programs, integration is more expansively viewed as enabling the sharing of critical information *between* public health and private providers involved in the health care continuum of the same clients. These integration efforts are often referred to as *horizontal*.

Integration of the information about one segment of the population into data sets or systems containing larger and larger population segments, such as from the county, to the state, the region, the nation, is referred to as *vertical*.

These different definitions of integration highlight not only variations in the objectives sought by participating programs and the functional differences of the systems in design, but also the important differences in the roles and responsibilities of the programs involved.

However, integration, whether horizontal or vertical, generally refers to the ability to access and share critical information, in real time, or at key decision points, throughout the health care service delivery process.

The functions we normally consider in integration efforts between a public health agency's programs include the ability to:

1. Perform identity resolution at a satisfactory level of matching.
2. Automatic query across databases to assess the current screenings, screening results, immunizations, follow-ups, other health status indicators, etc.
3. Record or access key services performed by participating providers.
4. Generate automatic alert notifications, from one program to other programs, based on some predetermined conditions.
5. Request and receive information held by other programs, based on a published list of available information.

Integration efforts are designed to automate many of these operations, reengineer systems and processes, and achieve new capabilities with greater efficiency and effectiveness.

There are a few principles that should be incorporated into the overall integration effort:

- Data should be captured at, or as close to, the originating point as possible, rather than trying to reconstruct it down line or have others collect it again;
- Data should be captured once and used many times, leveraging existing resources and improving data quality; and
- The integrated system should be driven by the operational systems of participating programs, not separate from the systems supporting the programs.

It is important to recognize that building integrated health information systems does not mean that *all* information between programs is shared without regard to the client, the programs involved, or the sensitivity of the information available. Programs need to share key information, on a need to know basis and as allowed by statutes and rules, in real time, at the time of service delivery, or at critical decision points throughout the health care continuum.

HISTORY

Traditionally, public health has been organized around programs, such as Newborn Blood Screening, Immunizations, Newborn Hearing Screening, Vital Records, etc. The program-based model has worked well because it allows specialized focus and resources to be directed towards responding to a well-defined issue. Organizational and funding support has followed the traditional program-based model. The Utah Department of Health (UDOH) has followed the same model.

While this has provided a great focus on specific issues and needs, the program-centered processes and systems have promoted a troubling degree of redundancy and insulation in the collection and use of data. It also led to a fairly limited view of the clients' needs and to an ensuing inability to provide coordinated care.

As in most Departments of Health across the country, local, one-time efforts to link data sets from two or more different programs have also been performed in the UDOH. Not only are such efforts taxing on the organization, they are also subject to resource and skill availability, the quality of the data, and the rigor of the process followed. Because of the related costs, such efforts have been carried out rather infrequently and have always had an analytic and evaluation purpose. In terms of implementation, the linking was done "after the fact" and was not available at the time services were being delivered.

As the complexity and interdependencies of issues and needs have become more apparent, public health organizations, at all levels, as well as the public, have started to identify the emerging need for coordination of care and of services at the time of service delivery. However, they both recognize that this should not be done by taking the program-focus away from the provision of care and services but by adding a layer of coordination and integration.

Public health organizations have become sensitive to these trends and are starting to respond through their own initiatives to address the need for more client-centered services and more population-based integrated assessment capabilities. At the state level, the Utah Department of Health has been among the first to identify this emerging need. The initiative was recognized as a top strategic goal in the department and was championed at the Executive level.

The Data Integration initiative at the UDOH started while Dr. Scott Williams, currently UDOH Deputy Director, was Director of the Division of Community and Family Health Services (DCFHS). As a pediatrician, he became acutely aware of how "silo" systems were hampering our efforts at coordinating service delivery, especially when it was known that many programs shared highly overlapping client bases. He rallied the forces in the Department and articulated what is now referred to as the Information Systems (IS) Vision.

Thus, the IS Vision was formalized in 1997 and identified a number of strategies:

- 1) Identifying and supporting an individual, who is accountable to the Executive Management Team, to implement a process to assure the achievement of the UDOH IS Vision objectives and strategies.
- 2) Establishing processes to develop, implement and monitor data standards, and to integrate information systems.
- 3) Identifying major stakeholders for each Health Information System constituent group and developing a process for their participation in achieving the vision.
- 4) Creating an analytic network to facilitate converting data into useful information.

The IS Vision also called for three major outcomes:

- 1) Public health data to be complete, uniform and accurate;
- 2) Stakeholders to be satisfied with the availability and usefulness of public health data;
- 3) Public health data to be entered only once, and to be readily retrievable by all authorized people.

In early 1999, the first IS Vision strategy was implemented when the UDOH CIO was hired. She was assigned responsibilities over the IS Vision and overall integration initiatives. Through a number of other organized activities, the UDOH continued to pursue its IS Vision and identified Child Health as one of the areas to focus its Data Integration efforts. Furthermore, in late 1999, both program representatives and IT representatives defined a set of new integrative, customer centric initiatives for the Department and assigned champion teams. The Child Health initiative was one of them. During the next six months, the champion teams developed the conceptual level of each initiative and garnered support within the organization. The Child Health integrative initiative became known as the Child Health Advanced Records Management, or CHARM.

In the meantime, on the national front, federal funding, mostly through grants, became available to support integration and coordination initiatives, at community/local, state and federal levels. As programs continue to be funded and evaluated categorically, more and more evaluation outcomes, possible only through integration and coordination of services, are now being expected and measured.

In pursuit of funding to support CHARM, its Data Integration initiatives, the UDOH applied for and received a Needs Assessment Grant (June 2000 – May 2001) and a Planning Grant (June 2001 – May 2002) from HRSA MCHB. Through these grants we developed a State Genetic Services Plan and a Data Integration Plan.

This document covers the Data Integration Plan developed under the MCHB grant. The State Genetic Services Plan is contained in a separate but adjoining document.

NEEDS ASSESSMENT APPROACH

During the first year of the Genetic Services and Data Integration (GSDI) Grant Project, an effort was undertaken to assess the needs for integrating child health data sets within the UDOH and for sharing these sets with entities outside the UDOH. The GSDI Project Team, working with a contractor employed to conduct the needs assessment, determined the concepts which informed the process.

These concepts included such things as the need to:

- Be responsive to all stakeholders;
- Attain compliance with all federal, state and local regulations related to confidentiality and informed consent;
- Identify just what data can be shared and what would constitute a “Child Health Profile” (CHP);
- Obtain input from families and advocacy groups in the community;
- Strive for a community-based approach;
- Gain support for these activities from the highest level possible within the UDOH.

The GSDI contractor, the MTW Corporation, solicited, refined and documented feedback from four focus groups. A Needs Assessment Report was completed by MTW and is attached (Appendix E).

The participants in the focus groups included UDOH Managers from programs that currently have child health data sets; parents of children with special health care needs and representatives from family and other community advocacy groups (See Appendix A for a list of Needs Assessment Data Integration Focus Group Participants).

The first three focus groups were conducted to brainstorm and gather as much input as possible regarding such things as: (See Appendix B for Needs Assessment Focus Groups 1, 2, & 3 Agenda)

- Components of a “Child Health Profile”;
- Purposes of creating such a profile;
- Benefits of integrating data sets;
- Barriers to integration;
- Uses of integrated data;
- Consent and confidentiality approaches;

The fourth and final focus group was held to refine the input and generate a final needs assessment document. (See Appendix C for Needs Assessment Focus Groups 4 Session Agenda)

NEEDS ASSESSMENT FINDINGS

The major findings of these assessment activities were:

1. Throughout the focus group session, a strong need to involve parents and families and to have their voices heard throughout the Data Integration process was identified. Doing so is important so that parents can provide input, participate in direction setting and content definition, and ensure the data is shared and used appropriately. Parents were very supportive of the UDOH integration and data sharing initiative and were very interested in anything that would improve their children’s health and facilitate the process of getting needed services. Parents wanted to be made aware, in a clear and comprehensive manner, of all the service options provided by the Department’s other health programs for which they might qualify. They saw the sharing of their children’s health information with program staff and providers involved in their children’s health care as critical to the process. However, parents were concerned about information, in particular income-related, getting into the “wrong” hands and somehow leading to discrimination and a negative impact on their insurance cost and access to health services.
2. The focus groups also identified a number of critical factors with respect to electronically sharing data with providers. Focus groups pointed out that providers do not easily change their routines and their processes and have limited spare time to learn new procedures. Furthermore, many older providers are not computer savvy. Although the majority of private providers do want to improve children’s health, the UDOH would have to consider all these barriers when approaching providers and would have to make participation very easy and attractive to them.
3. The focus groups found that program staff were very interested and supportive of the Data Integration initiative. While staff identified a need to better understand the benefits of data sharing and to become more familiar with the new, integrated, way of providing services, they did understand that the availability of new data/information – through data sharing – would enable better ways of serving their clients. Program staff identified that they would need training and support as they start to discover and adopt coordinated ways of providing service to children and their families.
4. Program managers entrusted with the data collection and stewardship were concerned about all the state and federal legal issues related to data sharing, including the new HIPAA regulations on Privacy and Security. Problems dealing with the legality of data sharing will have to be a major concern and will have to be considered and implemented accordingly, as well as monitored and evaluated for compliance.
5. Specific to any Data Integration initiative, the program managers also identified correctly that the integration solution should not require the overhaul of their existing systems. In addition, they would

expect that the integrated solution would support a reduction in redundant bio-demographic data collection while, at the same time, improve information currency and accuracy, rather than becoming the perpetuator of all sorts of inaccuracies in the data.

For additional information on the findings of the Needs Assessment, please see Appendix D – Needs Assessment Results and Appendix E – Needs Assessment Final Report.

PLANNING APPROACH

While Needs Assessment was the first major activity to be carried out as part of the definition of need for any major undertaking, Planning was the next major activity that needed to be completed. It started when the Needs Assessment ended and it used the finding of the Needs Assessment to scope out and frame the content of the Plan. When the Planning phase is completed, the team will use the plan to guide the actual Implementation work.

In order to develop the DI plan and the associated planning document, a planning focus group was scheduled for March 22-23, 2002 (See Appendix G for DI Planning Focus Group Agenda).

As part of their preparation for the focus group, the DI planning team had several brainstorming sessions parsing, analyzing, and re-organizing the findings of the Needs Assessment focus groups held during 2001. It became evident that several individual, complex but interrelated themes emerged. The DI planning team summarized the themes in standalone names and definitions and came into the planning focus group looking to achieve the following objectives:

1. Identify and define the various inter-weaving project threads
2. Assign ownership and accountability to each project thread
3. Lay out rough, or draft, project plans for each project thread
4. Identify critical interdependencies between the project threads
5. Detail an overall program plan to coordinate the interdependent project threads
6. Include enough detail in each plan to each thread to be carried into implementation (Note: It is not expected that, at this point, each plan be complete with all levels all detail)
7. Identify major assumptions and constraints
8. Identify and evaluate major risks

All plans have been organized within the framework of much the same components, such as goals, objectives, activities, milestones, deliverables, timelines, resources, etc. What we found to be different about the DI initiative is that, due to its complexity and the number of its themes, it is more like a program than like a project. Therefore, we found that, instead of needing to work on one streamlined project plan, we needed to develop a number of separate, yet interrelated project plans, all coming together under one Data Integration program management umbrella.

The table below shows the individual themes, or threads, that were identified, together with their goal definition.

Theme / Thread	Goal / Definition
Technical Development	To guide the development of the technical components involved in the UDOH Data Integration effort (CHARM) by ensuring the proper content is being developed, in the right sequence, according to users' requirements and specifications.
Participating Program Technical Development	To prepare the systems currently supporting each of the participating programs such that they are ready to work within the integrated CHARM environment but without disrupting or disabling their primary functionality. There will be one for each participating program.

Communication & Marketing	To engage the various stakeholder groups such that they have opportunities for input, validation, adoption and evaluation all along the continuum of the data integration effort.
Data-related Rules, Policies and Procedures	To ensure that data is collected, stored, shared and utilized by all the stakeholders in a non-discriminatory manner, in accordance with state and federal laws and with family input and consent.
Data Quality	To ensure that the data collected is accurate, complete, timely and without duplication and/or redundancy and that it is readily available to all stakeholders in a confidential, secure manner.
Organizational Change	To facilitate, promote and support the "adoption" of CHARM and its benefits within the UDOH programs by leveraging activities, techniques, tools and instruments that foster positive change in the organization.
Data Integration Program Management	To manage the multiple threads of the data integration effort in a comprehensive, coordinated, responsible, safe, flexible and responsive manner, so as to ensure the timely and quality completion of all the deliverables in all the threads. Efforts will be made at all times to ensure that risk is minimized, funding is optimized, stakeholders are satisfied, the families are better served, the private providers and medical homes are properly engaged, and the organization is better off.

Table 1: Individual themes, or threads, and their goal definition.

In planning for our DI CHARM initiative, UDOH decided that a phased/incremental approach is the most appropriate strategy. The complete strategy for CHARM spans several years and breaking it up into releases seems the only practical approach (See Appendix H for the CHARM Strategic Overview).

During the Planning phase, the actual goal was to lay out the tracks for the first two phases of the Data Integration initiative, while “roughing-in” the following few phases. Therefore, the DI plan currently contains considerable more definition for the first one-to-two years of the initiative.

The fact that the Plan for the Technical Development was already sketched was used as an opportunity for the focus group. In addition, it was already clear that the timing of technical milestones and deliverables would be driving many of the activities of the other complementary efforts. The team decided to flesh out the technical plan and go with it into the focus group. They fitted it with additional information, called “triggers” to show how a technical activity could “trigger”, that is “kick in”, an activity in another thread, or how a technical activity could be “triggered” by the completion of a milestone or a deliverable in another thread.

The technical plan that was developed, just like the plans for all the other threads, is a lot clearer in its first year or two than it is further out. All plans will have a better definition in their first year or two, while beyond that, they will be somewhat fluid and open to change due to unanticipated opportunities and barriers. As part of each plan’s project management function, plans will be re-worked and redefined at various points in time.

Planning activities are not trivial and the composition of the focus group was such that no previous planning experience could have been expected (See Appendix F for the DI Planning Focus Group Participants). Because of that, the planning team decided to also develop a draft plan for one of the non-technical threads and use it as a learning opportunity to show the members of the focus group how it was developed. The plan for the Organizational Change Thread (OCT) was chosen for that purpose.

Before the actual focus group planning work actually started, the Technical Development Thread (TDT) plan was reviewed with the participants and the significance of the “Triggers” columns was explained. Then the moderator used the OCT Plan to walk through the complex process of using the triggers in conjunction with the traditional planning process to lay out the plan draft.

The focus group then participated in the development of plan drafts for the Communication & Marketing Thread (CMT) plan and the Data-related Rules, Policies and Procedures Thread (DRPPT) plan. After an expectedly slower start, the group successfully used the remaining focus group time to develop the two plan drafts and cover a lot of content through ongoing questions and answers.

Close to the end of the focus group, the participants assigned point persons for each DI thread and assigned responsibilities for further definition and completion of the plans for all the threads. The point persons met as small teams and followed a similar process for the development of their plans:

1. Identify key activities and associated deliverables
2. Prioritize and sequence the activities
3. Use the triggers already identified in the TDT and the other threads for which drafts had already been developed
4. Scrutinize and question for accuracy and completeness
5. Identify triggers and dependencies with other threads
6. Add (rough) start and end times, resources needed, party responsible, techniques to be used, tracking and evaluation mechanisms.
7. Add one time and recurrent activities that are part of each project plan, such as:
 - Assess risks and develop risk management strategies (one time)
 - Re-assess risks and develop risk management strategies (ongoing)
 - Perform project management activities: track progress, assign resources, evaluate output, coordinate with other plans, identify and resolve issues, etc. (ongoing)

Once the plan drafts were completed, the point persons used meetings and other forms of communication to reconcile their plan against every other plan and to resolve any cross-thread dependencies or inconsistencies. While the plans will remain independent and at a low level of detail for execution and management purposes, they have been somewhat consolidated and rolled up in this final report.

The table below shows the point persons identified for each thread.

Thread	Point Person(s)
Technical Development	Don Gabriele* Stephen Clyde
Participating Program Technical Development	USIIS – Joe Nay Early Intervention – Don Gabriele Vital Records (Births & Deaths) – Mark Jones Newborn Hearing Screening – Stephen Clyde Newborn Blood Screening – Jane Johnson
Communication & Marketing	Nancy Pare* Christine Perfil
Data-related Rules, Policies and Procedures	Marcia Feldkamp* Sandra Schulthies
Data Quality	Barry Nangle* Sharon Clark
Organizational	John Eichwald*

Change	Lynn Martinez
Data Integration Program Management	Rhoda Nicholas* George Delavan Margaret Lubke

Note: * designates the main point person

Table 2: Point persons for each thread

PLANNING RESULTS

VISION

The UDOH Data Integration initiative will achieve useful and viable integration of the child health programs within UDOH and between UDOH programs and their outside partners, and will be adopted as the system of choice in providing coordinated care to our clients and their families.

MISSION

The UDOH Data Integration initiative is a complex, multi-release program conceived with an overarching purpose in mind – to achieve and institutionalize a holistic, client-centric way of fulfilling the mission of public health. Because its entire focus is so vast, this initiative has been compartmentalized so as to facilitate its framing, planning, management and realization. The initial Data Integration focus will be on child health and is referred to as Child Health Advanced Records Management, or CHARM.

The mission of the CHARM is to integrate child health service delivery and to support care coordination by integrating the systems and the data currently collected and used by the child health programs within the UDOH and their external partners.

SWOT ANALYSIS

STRENGTHS

The following are situations which have been created as a result of internal efforts within the UDOH and which have become assets to the DI Initiative. The UDOH will work hard at maintaining these conditions:

1. The DI initiative is recognized as the highest level strategic initiative for the Department.
2. The holistic, 360-degree view of the client is a critical Business Principle for the UDOH, adopted in June 1999.
3. CHARM and the DI program have highest level executive sponsorship.
4. UDOH CIO is dedicated to the DI effort.
5. CHARM and the DI program have a management team that is supportive and engaged.
6. UDOH and its people have an entrepreneurial spirit.
7. Staff is creative.
8. Staff is excited about the DI effort.
9. UDOH has forged strong partnerships in support of its DI effort.
10. UDOH and Utah have strong parent advocacy that is supportive of the DI effort.
11. The UDOH DI initiative is based on a solid conceptual and technical architecture.

WEAKNESSES

The following are conditions specific to the UDOH and which are reducing the Departments ability to respond to and support the DI Initiative. The UDOH will work hard to eliminate these conditions or to reduce their impact.

1. The UDOH has not typically been engaged in large scale IT or business reengineering efforts.
2. Limited IT resources.
3. Generally, staff is not used to following rigorous development approaches and project management methodologies.
4. Staff is, as a rule, overloaded and over-committed.

5. Because of several years of consecutive budget cuts, there are no internal funds to support the project.

OPPORTUNITIES

The following are situations and conditions outside the UDOH creating a favorable and supportive climate for carrying out DI initiatives. The UDOH is taking advantage of as many of these opportunities as possible and will look out for any new favorable conditions that may develop.

1. General recognition, at the state and federal levels, that the time for integration has come.
2. Technology solutions for data and systems integration have started to become more commonplace and allow implementation with limited disturbance to existing investment in legacy systems.
3. Customer centric, web enabled solution are becoming more and more prevalent.
4. Federal funding is made available to incentivize integration initiatives.
5. Several noteworthy integration initiatives are underway at leading DOHs around the nation.
6. A Communities of Practice for leading integration initiatives in public health around the country has been underway since June of 2001, under the aegis of AKC Center for Innovation in Health Information Systems.
7. States are collaborating and sharing best practices.
8. CDC, HRSA, and CMS have agreed to support cross-programmatic data sharing and integration initiatives.
9. CMS has started a renewed campaign in support of data sharing between Medicaid and Public Health.
10. A number of the HP2010 health outcomes can only be accomplished through data sharing, collaboration and cooperation.

THREATS

The following are situations and conditions outside the UDOH undermining our ability to carry out a DI initiative. The UDOH is on the lookout for such new and existing conditions in order to minimize their impact on the project.

1. Dogmatic interpretations of the HIPAA ruling.
2. Misinterpreting data sharing for an OK to arbitrarily disclose data and misuse it.
3. Lobbyists on ultra-conservative agendas.

PRINCIPLES & VALUES

The UDOH Data Integration initiative is guided by a set of principles and values. These have been defined early on in the vision formulation stage. In June 1999, the UDOH formulated and adopted its centerpiece business principle of customer centricity. It calls for the department and its programs to:

- **Strive to provide an integrated view of its services to all its customers.**
An integrated view of UDOH services is one that enables the customer to know that one or more services exists to address the customer's initial reason for contacting UDOH and that other services exist that may address other related or pertinent needs the customer might have.
- **Strive to provide an integrated view of the customer to all its employees.**
An integrated view of a UDOH customer is one that enables an employee to be aware of and to access any information about that customer which may exist in UDOH databases and which is appropriate for the employee to use in helping the customer.

Throughout the following vision formulation stage, a number of value statements have surfaced and have been collected. They will guide the work of the team during the planning, definition and realization of the solution.

- Integration should enhance rather than deflect programmatic focus. Each program has a focus that is well defined, both from an organizational and from a public health perspective. Programs have been designed and work best when staying on focus.
- The department entrusts the programs and the program managers with the appropriate stewardship and management of the data. The UDOH recognizes that it is the client who owns the personally identifiable health data. However, when such data is being collected as part of the department's fulfillment of its mission, it is being collected under the department's authority and it is the department who is ultimately responsible for the proper use and safekeeping of this data.

- Internal data sharing is critical to a data integration initiative but should be based on need to know and appropriate use. Access to and use of the data is covered by an employee’s employment agreement and will be subject to audits.
- External data sharing is necessary to support the continuum of care and the concept of medical home. Access to and use of the data is covered in Confidentiality Agreements developed for, and executed by external users.
- Partnerships are critical in resource constrained projects and should be based on a win-win strategy.

PROGRAM ORGANIZATION

PROGRAM MANAGEMENT

During the Needs Assessment and the Planning phases, the UDOH Data Integration initiative has been deemed a very complex and multi-faceted organizational and technical endeavor. Because of that, the initiative has been planned, and will be managed, as a program, where the program is the overall umbrella under which all the interrelated and interdependent projects are managed and coordinated. The program management will have the breadth of the full superset of all the component plans and will be responsible for the overall framing, planning and integration of the component plans.

PROJECT MANAGEMENT

Each component thread will have the breadth of its content and the depth of detail needed to define, plan and realize the activities required for its implementation. Each project, or thread, will be guided by a project plan that will include among its activities project management, risk management, and evaluation management, in addition to strictly implementation related tasks. The project managers will work together, among themselves, as well as with the program managers.

GOALS

- GOAL A. To improve the ways in which, and the times at which, the various stakeholder groups (parents, providers, legislators, etc.) are engaged, such that they have opportunities for input, validation, adoption and evaluation all along the continuum of the Data Integration effort. (This is the equivalent of the Communication & Marketing Thread goal).

Rationale: The first and foremost responsibility of the UDOH and its programs is towards the clients and citizens they are meant to support. As part of the government of the people and for the people, UDOH is designed to serve, and is accountable to, its constituency. Additionally, as service providers, the programs need to be responsive to their clients’ needs, which can only be ensured by listening to the voice of the client and doing what is best for the client.

- GOAL B. To ensure that data is collected, stored, shared and utilized by all the stakeholders in a non-discriminatory manner, in accordance with state and federal laws and with family input and consent. (This is the equivalent of the Data-related Rules, Policies and Procedures Thread goal).

Rationale: For as long as the data has been collected, stored, and utilized according to the stovepipe or silo metaphor, there has been an assumption of control and safety, by virtue of raising walls around each individual system. Whatever technical solution will be implemented, data sharing and system integration will in effect lower the walls around these systems, or somehow open communication “holes” in these walls. There is an associated assumption that this will come at the price of compromising the safety and security of the data. The truth is that safety has never been achieved by locking anything behind a wall. Technology and administrative process should be defined and implemented to ensure that the data is safe and that it is used to the highest possible benefit to the client. That means

listening to the needs and voices of families and providing opportunities for informed consent, as well as observing the limitations prescribed by statutes and laws.

GOAL C. To improve the accuracy, completeness, timeliness and reliability of the data collected while making it readily available to all stakeholders in a confidential, secure manner. (This is the equivalent of the Data Quality Thread goal).

Rationale: Again, as a result of decades of stovepipe operation, each program / system had to, and did, develop its own mechanism for collecting bio-demographic information about their clients, to be used for client identification and contact. In addition, each program also gathered program specific information and tracked service specific information through time. Although many of the programs in the UDOH have largely overlapping client bases, the clients had to provide the same bio-demographic information over and over again, to each individual program in which their children were enrolled. Data Integration will address these issues by reducing duplicate data collection, by providing newly updated and more accurate information across all programs and providers with a need to know, and by doing so in a safe and confidential manner.

GOAL D. To extend the benefits of Data Integration within the UDOH programs by facilitating, promoting and supporting its "adoption" by leveraging activities, techniques, tools and instruments that foster positive change in the organization. (This is the equivalent of the Organizational Change Thread goal).

Rationale: As a rule, the UDOH responds well to change and is eager to adopt forward thinking solutions. However, due to many years of budget cuts and limited resources, program staff have grown averse to taking on new things without relief somewhere else. Data Integration will, as a rule, transform the organization by introducing new responsibilities that come with data sharing, such as performing service coordination activities. The initiative has to plan for and implement ways to make this as easy and rewarding as possible for staff and not call for a radical overhaul in operations.

GOAL E. To enhance the value of the technical components developed for the UDOH Data Integration by ensuring that the proper content is being developed, in the right sequence, according to users' requirements and specifications. (This is the equivalent of the Technical Development Thread goal).

Rationale: While, to some, developing the technical solution for the initiative seems like the most difficult goal to achieve, the reality is that it is not. It may be the most expensive goal to achieve, but not the most difficult. With today's technology, it is all within reach. However, the UDOH technical team will have to take on the challenge of listening to the stakeholders and providing them ample opportunity to provide input, to review and validate progress and to evaluate results, as the project is going through its development phases. Developing a Data Integration solution that is the figment of some technologist with no, or not enough, input and validation from the stakeholders would be like "building it and wishing they'd come".

GOAL F. To improve the ability of the existing systems currently supporting each of the participating programs to work within the integrated CHARM environment, without disrupting or disabling their primary functionality. Technical Threads across Participating Programs will be similar. (This is the equivalent of the Participating Program Technical Development Thread goal).

Rationale: The existing systems supporting each of the programs targeted for the CHARM DI had been developed according to the silo-based model. Each one is on a different platform, use different technologies, and is maintained by different IT resources, usually associated with the programs they support. The effort of analyzing, preparing and executing the changes that best accommodate their integration into CHARM is the responsibilities of the IT resources currently maintaining these systems.

GOAL G. To ensure the timely and quality completion of all the deliverables in all the threads associated with the DI effort by managing the entire program in a comprehensive, coordinated, responsible, safe, flexible and responsive manner. Efforts will be made at all times to ensure that risks are minimized, funding is optimized, stakeholders are satisfied, families are better served, private providers and medical homes are properly engaged, and the organization is better off. (This is the equivalent of the Program Management Thread goal).

Rationale: To first timers, a data integration effort sounds like a technical project. While it is true that Data Integration initiatives usually have, at their core, a technical solution, it is the non-technical representatives who should be in the driver's seat. Data Integration is primarily a programmatic, organizational and executive initiative. Data Integration must involve clients, clients' families, providers, and various other stakeholders. Data Integration needs to deal heavily with legal issues regarding patients' rights, privacy, security, etc. Data Integration is unquestionably one of the most complex initiatives to hit silo-based public health to date: many stakeholders; highly political, legal, technical, financial, and territorial issues. As such, a considerable amount of effort will have to go into meeting the goal of managing and coordinating this set of related and concurrent efforts, which we have called threads, so that they all converge towards the common goal of achieving Data Integration.

GOALS & OBJECTIVES

GOAL A – Communication & Marketing

To improve the ways in which, and the times at which, the various stakeholder groups (parents, providers, legislators, etc.) are engaged, such that they have opportunities for input, validation, adoption and evaluation all along the continuum of the Data Integration effort.

Objective A.1. To identify the appropriate governance and participation structure for all stakeholder groups, formalize it, and maintain it.

Activities: The C&M staff will work with the CCC and will identify representative members for each stakeholder group. They will contact the parties, explain the purpose of the involvement and obtain commitment for participation. A schedule for regular participation will be prepared. A procedure for extraordinary sessions will also be prepared and communicated. As participants need to be replaced, these activities will be carried out on an as needed basis.

Timelines: 3Q and 4Q 2002

Responsible Party: Nancy Pare and C&M staff.

Deliverables: Stakeholder list, organized by groups, with contact information for main representatives; Stakeholder representatives' commitment; Rough schedule of activities involving stakeholders; Communication Strategy and Process for stakeholder notification, involvement and participation;

Expected Outcome: Stakeholder governance and participation will be ensured. This includes parents, families, providers, etc.

Evaluation Strategy: The CCC and PM will perform an initial review of lists and procedures. This will be repeated on an annual basis.

Objective A.2. To provide opportunities for parents, parent advocates, providers, and other stakeholders to define the content and other parameters of the data sharing process (what, with whom, for what purpose, etc.) and of the system being developed. This would be accomplished by organizing reviews, demos, focus groups, etc., during the definition, design, development and deployment phases.

Activities: The C&M staff, as the primary liaison between the CCC, the project team, and the other stakeholders, will define communication mechanisms, schedules, and participation for how most major decisions regarding the content and direction of the CHARM DI project will be made and formalized (sign off). The C&M staff will also

organize such meetings and reviews and will make sure that Issue Logs, Action Items, Evaluation Reports and Improvement Plans are being generated and passed on to the responsible parties.

Timelines: ongoing

Responsible Party: Nancy Pare and C&M staff.

Deliverables: Schedule of activities involving stakeholders; Actual meetings and other formats for involving stakeholders; Review Checklists and Guidance Documents for Stakeholders; Lists and documentation of stakeholders' input, comments, issues, remediation requests, and action items.

Expected Outcome: The CHARM project will receive appropriate guidance and controls so as to understand and implement users' and stakeholders' requirements.

Evaluation Strategy: Schedules and participation lists previously developed vs. actual schedules and participation. Stakeholder surveys.

- Objective A.3. To establish and enhance CHARM project's visibility among UDOH staff, other agencies, Governor's office, community-based organizations, current and potential funding organizations, and USIIS Oversight Committee.
- Activities: The C&M staff will develop CHARM project logo and "glossies", will prepare, schedule and conduct informational presentations and brown-bags, and will issue a newsletter for the user community. C&M staff may involve other resources, as needed, to hold such presentations.
- Timelines: 2002-2003 and ongoing
- Responsible Party: Nancy Pare and C&M staff.
- Deliverables: CHARM project logo and glossies; Presentation materials (PowerPoint, etc.); Brown bags and presentations.
- Expected Outcome: Project will get wide-base recognition, support and adoption. Resources might be easier to obtain.
- Evaluation Strategy: Limited release evaluation. Before-and-after surveys/polls of UDOH staff on the UDOH Intranet.
- Objective A.4. To ensure that the CHARM system, as developed and deployed, meets users' expectations and is used appropriately.
- Activities: The C&M staff will identify necessary resources, as well as guide and be responsible for the development of User Acceptance Test (UAT) plans, UAT data, and User Manuals. Preparation of the UAT material will follow the same order as the schedule for Participating Programs inclusion. In addition, the CMT team will also rally the necessary resources from the Participating Programs and will organize and oversee the User Acceptance Testing.
- Timelines: 1H 2003
- Responsible Party: Nancy Pare and C&M staff.
- Deliverables: User Acceptance Test (UAT) plans; UAT data; User Feedback Report; User Manuals.
- Milestones: Completion of UAT plans and data.
- Expected Outcome: System will be tested according to the users' expectations. System will get the users' vote of confidence.
- Evaluation Strategy: Reviews by, and recommendation lists from the CCC and the technical staff, prior to the start of UAT. Number of problems discovered after official general release date that should have been tested and discovered during UAT.
- Objective A.5. To enroll as many providers as possible to use the CHARM Information Systems (CIS - the web-based release of CHARM) and raise their level of regular system use.
- Activities: The C&M staff will prepare marketing material for CIS and will use the USIIS model to plan a rollout campaign for CIS. They will work with Dr. Scott Williams, the UDOH liaison with the USIIS Oversight Committee to expand the committee's role and mission in order to take on CIS rollout and adoption issues. The C&M staff will develop and produce a newsletter for CIS users and use it as a vehicle to expand adoption and use.

Timelines: 4Q 2003 – 1Q 2004 and ongoing

Responsible Party: Nancy Pare and C&M staff.

Deliverables: Marketing glossies and brochures targeted to private providers; New name and mission document for the USIIS Oversight Committee; CIS Newsletter.

Milestones: USIIS Oversight Committee takes CHARM and CIS on as part of its mission.

Expected Outcome: CIS will be able to build on USIIS successes and follow its market penetration strategy. CIS will have the backing and support of a very powerful, community-based stakeholder group, such as the USIIS Oversight Committee.

Evaluation Strategy: Track CIS penetration and compare with USIIS penetration. Identify CHARM and CIS related items on the USIIS Oversight Committee meeting agendas. Review minutes.

GOAL B – Data-related Rules, Policies and Procedures

To ensure that data is collected, stored, shared and utilized by all the stakeholders in a non-discriminatory manner, in accordance with state and federal laws and with family input and consent.

Objective B.1. To establish the UDOH internal policies, processes and procedures needed to facilitate and manage the data-sharing environment predicated in the Department IS Vision and the CHARM DI system.

Activities: The DRPPT team together with the UDOH CIO and other resources in the Department will draft a Policy to spell out how data sharing will be conducted within the Department. The Policy will also define the roles and responsibilities of each party involved in the collection, use and sharing of data, including those of the Data Stewards, the decision-makers closest to the data. Other resources will be rallied to develop a web-based, easy to maintain, data system inventory and to train the Data Stewards on how to use and maintain the system.

Timelines: 2Q 2002 – 3Q 2002

Responsible Party: DRPPT Team and UDOH CIO

Deliverables: UDOH Data Sharing Policy; Data Stewards List; Data System Inventory

Milestones: Adoption of the UDOH Data Sharing Policy; Completion of Data Steward Assignments

Expected Outcome: Cross-program data sharing will be easier to set up and manage.

Evaluation Strategy: Data Steward Survey; Data Sharing and Data Use Audit.

Objective B.2. To formalize the content and conditions of use for the data to be shared among programs within the UDOH.

Activities: The DRPPT team will work with the participating programs and their data stewards to identify all the data elements to be shared and will develop data models representations. They will also identify, review and approve all the proposed uses of such data. They will engage legal counsel to review and advise on the legality of the proposed data sharing, in terms of privacy and confidentiality. They will draft, finalize and get signatures on any documentation that might need to be filed and will prepare user authorization matrices to be used by the TDT team in granting or limiting access to data.

Timelines: 1Q 2002 – 3Q 2002

Responsible Party: DRPPT team and representative of the Data Resources Group

Deliverables: Data Models of the Shared Data; Catalog of the Shared Data; User Authorization Matrix

Milestones: Reached agreement on all shared data

Expected Outcome: The extent of the sharing of data will be known

Evaluation Strategy: Walkthroughs; Reviews

Objective B.3. To provide a reliable, repeatable process to identify and share the data that is the most accurate and reliable.

Activities: The DRPPT team will work with other resources from the Participating Programs and will compile the rough parameters of a process to be used in establishing the order of data precedence, in terms of quality and reliability, especially in situations when data from different systems show different values. They will then review the process with the CCC in order to get it refined and approved. The DRPPT team will then use the process to identify, for each shared core data element, its order of precedence across participating programs. These decisions will become business rules to be used by the TDT in determining what data to provide and in what sequence of reliability.

Timelines: 3Q 2002

Responsible Party:

Deliverables: Precedence Decision Criteria & Process; Data Precedence Lists

Milestones: Completion of Data Precedence List

Expected Outcome: The most reliable sources of data will be used when sharing data.

Evaluation Strategy: Procedure to track expected vs. actual variances in data quality

Objective B.4. To formalize the content and conditions of use for the data to be shared between the UDOH programs and external users, in particular, providers.

Activities: The DRPPT team will work with the participating programs and their data stewards, provider representatives, and parents to identify all the data elements to be shared with providers and how such data will be used. They will engage appropriate reviewers to advise on the legality of the proposed data sharing and will prepare user authorization matrices to be used by the TDT team in granting or limiting access to data. They will draft and finalize any binding documentation (Confidentiality Agreement) that might need to be executed and filed. The DRPPT team will work with the C&M team to get Confidentiality Agreement signed by providers, as the CIS is being rolled out.

Timelines: 3Q 2003 – 3Q 2004

Responsible Party: DRPPT team and C&M staff

Deliverables: Catalog of the Shared Data; User Authorization Matrix; Confidentiality Agreement

Milestones: Reached agreement what data will be shared with private providers; Signed Confidentiality Agreements

Expected Outcome: The limits of the data sharing with private providers will be known

Evaluation Strategy: Walkthroughs; Reviews

Objective B.5. To correctly frame the content and parameters for executing the queries, alerts, and other services to be provided by each of the Participating Program for the benefit of the other programs.

Activities: The DRPPT team will work with the participating programs to identify all the services they could provide to, or get from, the other programs. These lists will be developed into rough specifications and then, they will be reconciled into a consolidated list across all programs and reviewed by the CCC. The DRPPT team will further define the requirements for each of the remaining services and will provide the information to the TDT staff and the PPTDT staff for design and implementation.

Timelines: 3Q 2002 – 4Q 2002

Responsible Party: DRPPT team

Deliverables: List of Services (queries, alerts, etc.); Service Content and Execution Requirements

Milestones: Completion of the Consolidated Services List and Requirements

Expected Outcome: Concrete uses of the shared data will be identified

Evaluation Strategy: Walkthroughs; Reviews; Cross-validation between the data to be shared and the services to be shared.

Objective B.6. To correctly frame the content and parameters for executing the queries, alerts, reports, and other services to be provided by CHARM to partnering private providers.

Activities: The DRPPT team will work with private provider representatives to identify the queries, alerts, reports, and other services that they would be interested in getting

from and giving to CHARM. The identified services will be developed into rough specifications and will be reviewed and approved by the CCC. The DRPPT team will further define the requirements for each service and will provide the information to the TDT staff and the PPTDT staff for design and implementation into the CIS.

Timelines: 3Q 2003 – 3Q 2004

Responsible Party: DRPPT team and C&M staff

Deliverables: List of Services; Service Content and Execution Requirements

Milestones: Completion of the Consolidated Services List and Requirements

Expected Outcome: Concrete uses of the shared data will be identified

Evaluation Strategy: Walkthroughs; Reviews; Cross-validation between the data to be shared and the services to be shared.

- Objective B.7. To ensure that parents and families are informed about the data collected and shared by CHARM and the use of the shared data and that they are given the choice to opt out.
Activities: The DRPPT team will consult with the managers of the Participating Programs, parents, the CCC, and Legal Counsel to identify the best opportunity, timing, procedure, format and content to provide parents and families with informed consent without doing so repeatedly, for each portion of the CHARM integrated system. The DRPPT team will draft the content of the Informed Consent documentation and will conduct reviews with the CCC and Legal Counsel for revisions and final approval. The DRPPT team will then implement the new Informed Consent process for CHARM at the appropriate time.
Timelines: 2Q 2003 - 3Q 2003
Responsible Party: DRPPT team and Legal Counsel
Deliverables: Informed Consent Policies; Processes; Procedures; Informed Consent Document
Milestones: Approval of the CHARM Informed Consent Document and Process
Expected Outcome: Meet legal requirements regarding providing proper notification and options
Evaluation Strategy: Parent Survey; Review of Signed Informed Consent Forms vs. new Clients in CHARM
- Objective B.8. To develop, adopt and promote a UDOH Privacy Policy that respects the individuals' legal rights to privacy while supporting the use of authorized data sharing.
Activities: The DRPPT team will review any Privacy Policies currently in use across the Department and will work with the UDOH Privacy Officer to draft a Privacy Policy that would serve the needs of CHARM. If possible, the team will attempt to develop one Privacy Policy that could serve the needs of the entire Department. The team will also develop a proposal identifying the circumstances when and how the Privacy Policy should be used. Legal Counsel and the CCC will review and approve the proposal.
Timelines: 1Q 2003 – 2Q 2003
Responsible Party:
Deliverables: Privacy Policy; Recommendation Regarding the Use of the Privacy Policy
Milestones: Approval of the Privacy Policy
Expected Outcome: Compliance with HIPAA requirements; Meeting the requirements of Informed Consent
Evaluation Strategy: Selected Audit of the Privacy Policy Use process; Parent Survey regarding the usefulness and clarity of the Privacy Policy; Evaluation of Privacy Policies of other state DOHs.
- Objective B.9. To provide a supportive legal environment for the DI initiative.
Activities: The DRPPT team will work with UDOH Legal Counsel to identify any rules that might need to be revised or introduced to support the data sharing and data use proposed by CHARM. The team will provide support to UDOH Legal Counsel in revising or introducing the necessary rules. They will also rally the CMT team to initiate lobbying activities, as needed.

Timelines: 3Q 2002 – 2Q 2003

Responsible Party: DRPPT team and Legal Counsel

Deliverables: Rules that need to be changed or introduced

Milestones: Adoption of rules revision or introduction

Expected Outcome: Data Sharing in the context of the CHARM system will have the needed legal support

Evaluation Strategy: Legal Compliance Audit

GOAL C – Data Quality

To improve the accuracy, completeness, timeliness and reliability of the data collected while making it readily available to all stakeholders in a confidential, secure manner.

Objective C.1. To determine the nature and the magnitude of the data quality issue within and among the Participating Programs and make recommendations to improve the current level of data quality.

Activities: The DQT team will work with the Participating Programs' data stewards to identify and document data quality issues and will prepare a report on the scope of the inconsistency and duplication found. The DQT team will consult with the TDT team and the PPTDT teams and will prepare a Remediation Recommendation guidance document. The guidance document may include organizational and process related recommendations as well as technical recommendations.

Timelines: 2Q 2002 – 3Q 2002

Responsible Party: The DQT team

Deliverables: Data Quality (DQ) Assessment Report; DQ Remediation Recommendation Document

Milestones: Completion of DQ Remediation Recommendation Document

Expected Outcome: Staff will understand where the issues with DQ are.

Evaluation Strategy: Compare DQ findings with DQ problems as documented by the Participating Programs.

Objective C.2. To ensure the data quality remediation process is properly championed, executed, overseen, monitored and evaluated for success.

Activities: The DQT team will work with all the parties identified in the DQ Remediation Recommendation Document and will prepare a plan for the completion of the remediation effort. The DQT team will use the plan and the DI Governance structure to ensure that resources are assigned and the effort is completed.

Timelines: 3Q 2002 – 4Q 2003

Responsible Party: The DQT team

Deliverables: DQ Remediation Plan

Milestones: Completion of the Data Quality Remediation

Expected Outcome: CHARM will start out with cleaner data

Evaluation Strategy: Remediation Reports

Objective C.3. To recommend and establish a proactive solution that will prevent data quality issues from becoming a problem.

Activities: The DQT team will research and recommend data quality standards and workable solutions designed to eliminate or minimize the deterioration of data quality in CHARM. They will work with the OCT team and the DI Governance to design and institutionalize new behaviors and performance measures that will keep data quality on the human / operational side of the equation from slipping. They will also work with the TDT and PPTDT teams to enable and enforce data quality standards and will champion the acquisition of the best person matching software CHARM can afford.

Timelines: 3Q 2002 – 3Q 2003

Responsible Party: DQT team

Deliverables: DQ Standards; DQ Performance Measures; Person Matching Software; DQ Solution Design Document

Milestones: Completion of Proactive DQ Solution Design

Expected Outcome: Data Quality will be addressed not only from a remediation point of view but also from a prevention point of view.

Evaluation Strategy: Process Audit

- Objective C.4. To ensure the data quality is measured and evaluated on an ongoing basis and recommendations for improvement are made and implemented.
- Activities: The DQT team will work with the TDT and PPTDT teams to develop a set of measures to be used in evaluating DQ. They will also develop testing and evaluation tools as well as DQ test data. They will schedule and coordinate periodic tests to be run against the CHARM data intake process and against the existing data. The DQT Team will issue recommendations for improving the technical and operational aspects impacting DQ.
- Timelines: 2Q 2003 - ongoing
- Responsible Party: DQT team
- Deliverables: DQ Measures; DQ Testing and Evaluation Tool; DQ Test Data; DQ Performance Reports
- Milestones: Completion of the First Evaluation - Recommendation - Improvement Cycle
- Expected Outcome: DQ issues will not spiral out of control
- Evaluation Strategy: Comparison of the number and types of DQ issues found over time

GOAL D – Organizational Change

To extend the benefits of Data Integration within the UDOH programs by facilitating, promoting and supporting its "adoption" by leveraging activities, techniques, tools and instruments that foster positive change in the organization.

- Objective D.1. To ensure that adjustments to the job descriptions of Participating Program staff will set new job expectations and performance standards to leverage the data sharing and care coordination possible through CHARM.
- Activities: The OCT team will work with the Office of Human Resource Management (HRM) to select a representative to participate on the CHARM Core Council. The OCT team will work with the HRM representative and with the Participating Program managers and staff to find the appropriate language to use in revising existing job descriptions and job performance standards such that they include functions and standards achievable only through the data sharing enabled by CHARM. The team will also draft language that will formalize the Data Steward's duties. They will also propose when the new job descriptions will become official and will present to the CCC for approval. The team will also monitor how the CHARM system will actually support the enhanced job descriptions and will recommend revisions, as needed. As a by-product of these activities, the OCT team will start documenting the benefits to be derived from using CHARM.
- Timelines: 3Q 2002 – 2Q 2003 and ongoing
- Responsible Party: OCT Team and HRM
- Deliverables: Revised Job Descriptions; Revised Performance Standards; Body of Knowledge on the Benefits of Data Integration - Draft
- Milestones: Completion of New Job Description and Standards; Implementation of the New Job Description and Standards.
- Expected Outcome: Staff will understand there are new job and behavioral expectations associated with Data Integration
- Evaluation Strategy: Observation of staff at work; Staff Surveys; Job Performance Evaluation

- Objective D.2. To motivate Participating Programs' staff to become frequent users of CHARM and to use the new tools which enable data sharing and care coordination.
Activities: The OCT team will engage the Participating Program managers and staff and the HRM staff to draft an appropriate and reasonable incentive and reward system. They will also work with the DI program governance bodies in order to obtain approval and funding. The OCT team will also work with the CMT team to properly communicate the special incentive system to staff. The OCT team will work with managers and staff from the participating programs to develop a performance baseline for staff in all areas where data sharing and care coordination is expected to improve. The team will also develop Informational Tests and other ways to measure staff performance towards data sharing and care coordination and will provide rewards based on measured performance.
Timelines: 1Q 2003 – 3Q 2003 and ongoing
Responsible Party: OCT team and HRM
Deliverables: New Incentive and Reward System; Action Plan for Barrier Removal; Staff and Measure Performance Baseline; Actual Performance against Baseline Reports
Milestones: Approval of the New Incentive & Reward System; Completion of Performance Baseline
Expected Outcome: Staff will not see the new job requirements as a typical add-on and will feel more apt to perform.
Evaluation Strategy: Staff Surveys; Job Performance Evaluation; Actual Performance against Baseline Reports; Informational Test Scores; Review of the Reward Justification Documentation
- Objective D.3. To guide the attention and the effort of the Participating Programs' staff towards those areas where using the data sharing and care coordination enabled by CHARM could improve client outcomes and HP2010 indicators.
Activities: The OCT team will work with the UDOH Office of Public Health Assessment (OPHA) and with the Data Resources group to identify the most likely HP2010 health outcomes to be improved through data sharing and care coordination. These groups will work together to develop a schedule for measuring these indicators through time, to take baseline those indicators prior to turning CHARM into production, and to set achievable yet challenging targets. They will oversee the scheduled measurement of the selected indicators, will recommend action based on results, and will oversee the implementation of such recommendations. The OCT team will also perform, or commission others to perform, Contextual Inquiries as an ongoing process to observe how the system is being used in its natural environment. Findings will be used to enhance the UDOH ability to share data and provide coordinated care.
Timelines: 3Q 2002 – 2Q 2003 and ongoing
Responsible Party: OCT team and OPHA staff
Deliverables: Selected HP2010 Indicators, Baseline Measurements; Schedule and Protocols for Ongoing Measurements; Measured HP2010 Outcomes; Action Items and Recommendations; Contextual Inquiries Reports
Milestones: Completion of Baseline Measurements
Expected Outcome: Measurable results in areas of national concern will be achieved through Data Integration
Evaluation Strategy: Actual Outcomes against Baseline and Target Measures; Contextual Inquiries Reports
- Objective D.4. To assist the Participating Programs' staff in gaining expertise, becoming the standard carriers in data sharing and care coordination, and in achieving HP2010 targets.
Activities: The OCT team will work with the TDT and PPTDT teams to draft an outline for the training manual and will oversee the development of the training manual. Special attention will be given to identify and train how to use the CHARM system to perform one's job and provide coordinated care at the same time. It will also teach specific changes in behavior and job execution where the use of data sharing and care coordination could help achieve the selected HP2010 targets. When the Participating

Programs are integrated into CHARM, the OCT team will schedule and oversee the training to be delivered to the appropriate staff. It is envisioned that the team will commission a Technical Writer to produce the Training Manual and a Training Specialist to conduct the initial training. The OCT team, in cooperation with the Participating Programs' staff, will draft a charter proposal for a CHARM User Group (CHUG); the group will further the expertise, cooperation and data sharing between staff. In addition, in order to support the internal users with CHARM related questions and problems, an internal Help Desk will be created and staffed, on a rotation basis, with staff that have reached a certain level of expertise. Staff on the Help Desk will be identified and will be providing help desk service from their desks.

Timelines: 3Q 2002 – 3Q 2003 and ongoing

Responsible Party: OCT team

Deliverables: Training Manual; Training Schedule; Staff Training; CHUG; Internal Help Desk Proposal

Milestones: Completion of the Training Manual; Completion of Staff Training; Formation of the CHUG; Formation of the Internal Help Desk

Expected Outcome: Staff will be helping and pushing each other. Data sharing and care coordination will be adopted faster.

Evaluation Strategy: Testing of Knowledge Before- and After-Training; CHUG Meeting Surveys; HP2010 Measures

Objective D.5. To refine the organizational model and the DI governance structure, as needed, to better reflect the new and evolving service delivery model and to maximize its benefits.

Activities: The team will use input from various groups involved in the DI initiative and will draft proposal for organizational changes which would better support data sharing and care coordination. This will happen after CHARM has been in use for some time and various patterns will emerge. They will work with the various levels of the DI governance to have these proposals reviewed, approved, and implemented.

Timelines: 3Q 2004 – 2Q 2005 and ongoing

Responsible Party: OCT team

Deliverables: Organizational Change Proposals

Milestones: Approval of Organizational Change Proposals

Expected Outcome: The organization will be better aligned with, and more supportive of, the collaborative, coordinated care model

Evaluation Strategy: Staff Surveys; Job Performance Evaluations

Objective D.6. To develop a DI specific Body of Knowledge (BOK) by documenting the benefits of data sharing and care coordination to clients and their families, providers, Participating Programs, and the organization as a whole.

Activities: The OCT team will work with CHUG and document the benefits of data sharing and providing coordinated care, as observed by staff on the job. This will include new ways of doing things that were discovered by staff. When CHARM becomes available to private providers, the team will work the CMT team to survey samples of providers on what benefits have accrued to their clients, their staff, and their practice in general. The BOK will also include provider benefits. The OCT team will also work with the UDOH Analytic Network Coordinating Team to identify any benefits that have accrued across programs, for the entire Department, and that might not be noticeable to Participating Program staff, on a day-to-day basis.

Timelines: 2Q 2003 – 1Q 2004 and ongoing

Responsible Party: The OCT team

Deliverables: BOK Documenting the Benefits of Integration

Milestones: Issuance of the first version of the BOK on Benefits of Integration

Expected Outcome: Benefits of Integration will become more concrete and more compelling

Evaluation Strategy: Staff Reviews

GOAL E – Technical Development

To enhance the value of the technical components developed for the UDOH Data Integration by ensuring that the proper content is being developed, in the right sequence, according to users' requirements and specifications.

- Objective E.1. To ensure that the system will meet the needs of the user and of the stakeholders.
Activities: The TDT staff, together with resources from the UDOH Data Resources group, will conduct interviews and focus groups to gather and document requirements from users and other stakeholder groups. During the system's design and construction, the TDT team will conduct design reviews, walkthroughs and proof of concept demos to validate that requirements are being reflected and will use prototyping techniques in order to capture the users' usability requirements. At system hand-off time, the TDT team will guide the users through the systems User Acceptance Testing and will resolve any technical deficiencies as identified. While the TDT team will start working on the next release of the CHARM DI system, they will continue to resolve issues identified by users while in production.
Timelines: 3Q 2001 – 3Q 2003
Responsible Party: Don Gabriele and the TDT team
Deliverables: Requirements Document; Demos, Walkthroughs, Prototypes, Issue Resolution
Milestones: Completion of the Requirements Document
Expected Outcome: The completed system will have high chances of being accepted and used
Evaluation Strategy: Review and Approval of the Requirements Document; User Satisfaction Survey
- Objective E.2. To validate the technical feasibility of the DI concept for CHARM.
Activities: The System Architect on the TDT team will take the high level architectural concept and the high level requirements and will specify a technical architecture design able to support the desired functionality. The System Architect will further refine the design by identifying and defining the required lower level components.
Timelines: 2Q 2001 – 3Q 2001
Responsible Party: System Architect and the TDT team.
Deliverables: Technical Design and Component Specifications
Milestones: Completion of the Technical Design
Expected Outcome: High level of confidence that the concept is technically sound.
Evaluation Strategy: Review by the Technical Review Board
- Objective E.3. To ensure that the technology selected will support the needs of the CHARM system architecture.
Activities: The TDT team will research, benchmark, and demo various technical products that could fit the architecture. They will use demo versions of the products to build proof-of-concepts and test product performance. They will share knowledge with other projects using similar technologies (such as NYC DOH) and will work with Utah State ITS to identify technologies already owned by and available. The TDT team will then select remaining products based on fit and the performance/cost ratio and will work with ITS to set up the development and production environment for CHARM.
Timelines: 3Q 2001 – 2Q 2002
Responsible Party: Stephen Clyde (System Architect), Don Gabriele (Project Lead) and the TDT Team
Deliverables: Technology Selection Document, Tools and Technologies
Milestones: Completion of Technology Selection, Acquisition of needed Tools and Technologies, Completion of Development Environment.
Expected Outcome: Development can start.
Evaluation Strategy: Review by the Technical Review Board.

- Objective E.4. To deliver a system with all the functionality needed to support the requirements of the CHARM.
Activities: The TDT team will develop and use physical specification to engineer the various components and functions that the CHARM system will have to provide. Prototypes will be developed, as needed. Unit and system testing will be performed to ensure all the components and functions perform as specified.
Timelines: 3Q 2002 – 3Q 2003
Responsible Party: Don Gabriele and the TDT team
Deliverables: Complete Executable System
Milestones: Completion of CHARM System Engineering and Testing
Expected Outcome: The entire system is ready for the Users' Acceptance Testing, prior to turning into production.
Evaluation Strategy: System Testing Problem & Resolution Log; Users' Acceptance Testing
- Objective E.5. To facilitate the transition of the system from development to production.
Activities: The TDT will work with ITS to set up a secure and optimized production environment for CHARM. They will develop the system manual to document the system "as built" in order to facilitate ongoing maintenance efforts in the face of unavoidable turn over in personnel. The team will also prepare operations procedures and instructions for the daily operation, backup and restore. They will work with assigned support staff from ITS to train them in the operation of the system. They will also work with ITS and develop a Service Level Agreement (SLA) that will meet the users' performance requirements.
Timelines: 1Q 2003 – 3Q 2003
Responsible Party: Don Gabriele, the TDT team, and the State ITS support team.
Deliverables: Production Environment; System Documentation (Manual); Operations Instructions/Procedures (Manual); Service Level Agreement.
Milestones: CHARM System Release 1.0 in Production
Expected Outcome: Program staff in five UDOH programs can now provide coordinated care.
Evaluation Strategy: Usability Review; User Satisfaction Survey

GOAL F – Participating Program Technical Development

To improve the ability of the existing systems currently supporting each of the participating programs to work within the integrated CHARM environment, without disrupting or disabling their primary functionality. Technical Development Threads across Participating Programs will be similar.

- Objective F.1. To prepare the technical environment of the participating program's system to enable its integration into CHARM.
Activities: The participating program's technical team will complete the Technical Readiness Assessment prepared by the CHARM technical team. They will use the results of this assessment to identify technical incompatibilities with the CHARM operating environment and other technical readiness issues. The team will then make needed adjustments to address these issues and incompatibilities. They will also work with the DRPPT team to construct and validate their program's actual data model and "to be shared" data model. They will also work with the DQT team to identify and remedy data quality issues in their system, prior to data migration and integration into CHARM.
Timelines: 3Q 2002 – 1Q 2003
Responsible Party: Participating Program's Technical Lead
Deliverables: Technical Readiness Assessment; Change/Upgrade Recommendations
Milestones: Completion of Technical Readiness Assessment; Completion of Change/Upgrade Recommendations

Expected Outcome: Participating Program will be technically ready to integrate into CHARM

Evaluation Strategy: Completed Assessment; System Review

- Objective F.2. To enable the access of other participating programs' staff to specific data, services, and alerts offered by their own program's system.
Activities: The participating programs' technical team will work in collaboration with their program's Data Steward and other staff to identify all the data, services and alerts their system is to make available to the integrated CHP. They will complete and validate the design of the coded procedures needed to provide these services and will implement and test them. They will also implement the secure access and views required for CHARM users to get to the shared data and services. The team will implement necessary security measures and will enhance their system's own audit trail as needed. They will prepare migration strategies and programs to support the migration of their program's CHP data to the CHARM Core database. They will also work in collaboration with the CHARM technical team to design and implement the CHARM Agent for their participating program. The team will also perform system and regression testing to make sure the system's pre-integration functionality continues to perform as expected.
Timelines: 3Q 2002 – 2Q 2003
Responsible Party: Participating Program's Technical Lead
Deliverables: Design Document; Coded & Tested Procedures; Migration Strategy Document; Migration Program; CHARM Agent
Milestones: Completion of Design Document; Completion of the CHARM Agent
Expected Outcome: Participating Program's system will be able to provide information to the integrated CHP
Evaluation Strategy: Design document walkthrough and signoff
- Objective F.3. To enable seamless access to Child Health Profile information for their program staff.
Activities: The participating programs' teams will design and implement access and display mechanisms that will enable their program staff to benefit from an integrated CHP and to provide coordinated care while best meeting their own needs and workflow requirements. In certain instances, a workflow review will be conducted. They will also provide additional functionality, as required by their users, to update the program's own data with selected CHP data, if desired. The team will also conduct system and regression testing to make sure that pre-integration functionality continues to perform as expected.
Timelines: 3Q 2002 – 2Q 2003
Responsible Party: Participating Program's Technical Lead
Deliverables: Workflow Model; Design Document; Coded & Tested Program Changes
Milestones: Completion of Design Document
Expected Outcome: Participating Program's system will be able to get information from the integrated CHP
Evaluation Strategy: Design document walkthrough and signoff
- Objective F.4. To ensure that their participating program's system is ready for, and operates correctly in production.
Activities: The participating programs' technical team will work together with the CMT team and their own program staff to develop UAT test plans and test data to test their own systems performance in the CHARM integrated environment, both in an "ON" and an "OFF" state. The "ON" state is achieved when the participating program is "plugged" in to CHARM and CHARM is active. The "OFF" state is achieved when either the participating program is not plugged in to CHARM, or CHARM is not active, or both. Once UAT is completed, the main activity will be to move all the data and program changes in the production environment. The team will also make necessary updates to the system documentation and to the operations manual. Once in production, the team will implement any system changes recommended by the Quality Improvement Reviews.

Timelines: 4Q2002 – 3Q 2003 and ongoing
Responsible Party: Participating Program’s Technical Lead
Deliverables: System Test Problem and Resolution Log; User Acceptance Testing Plan and Test Data; Updated System Documentation and Operations Manual
Milestones: Completion of UAT; System in Production
Expected Outcome: The participating program will operate in an integrated environment
Evaluation Strategy: Quality Improvement Reviews

GOAL G – Program Management

To ensure the timely and quality completion of all the deliverables in all the threads associated with the DI effort by managing the entire program in a comprehensive, coordinated, responsible, safe, flexible and responsive manner. Efforts will be made at all times to ensure that risks are minimized, funding is optimized, stakeholders are satisfied, families are better served, private providers and medical homes are properly engaged, and the organization is better off.

Objective G.1. To provide an overarching concept and a vision for a strategic Data Integration in UDOH that is realistic and achievable within the current local and federal conditions and that has strong executive and programmatic sponsorship, as well as community-based partnerships.

Activities: In line with her mission, the UDOH CIO will use focus groups during specially scheduled retreats to develop the vision and conceptual architecture for a Child Health Services integrative solution. The solution will use advances in technology to achieve data sharing and enable care coordination while leveraging investment in existing systems. The CIO will work with UDOH executive and management staff to broaden the base of the CHARM DI initiative by making presentation on the concept and discussing implementation strategies. She will initiate the formation of the CHARM Core Council and draft its initial charter.

Timelines: 4Q 1999 – 3Q 2000

Responsible Party: Rhoda Nicholas, UDOH CIO

Deliverables: Vision Document; Conceptual Architecture; CHARM Core Council Charter

Milestones: Attaining highest level of strategic importance among UDOH initiatives

Expected Outcome: The UDOH has a strategic direction to achieving Data Integration

Evaluation Strategy: Reviews with Executive Director and in Executive Management Team (EMT) Planning Retreats

Objective G.2. To frame the high level parameters of the CHARM DI solution such that it will be consistent with the initial vision and concept.

Activities: Members of the UDOH programs, the client community, and the provider community will be invited to participate in specially scheduled focus groups to provide input on their needs with respect to data sharing and care coordination in providing child health services. Based on this input and additional research of the DI experience of other states (e.g. Missouri), the CIO and other technical resources will identify and document the underlying high level design and the high level functionality to be supported by the CHARM solution.

Timelines: 4Q 2000 – 2Q 2001

Responsible Party: Rhoda Nicholas and Lynn Martinez

Deliverables: Needs Assessment Document; High-Level Requirements Document; High Level Design and Architecture Document; Project Charter

Milestones: Completion of the Needs Assessment Document; Completion of the Project Charter

Expected Outcome: The technical solution will faithfully reflect the approved vision and concept.

Evaluation Strategy: Walkthroughs and Reviews

- Objective G.3. To provide an organized, deliberate, disciplined, and measurable approach to achieving the goals of the CHARM DI initiative.
Activities: Rhoda Nicholas and Lynn Martinez will review the findings of the Needs Assessment and will identify ways in which to parse the effort needed to address them. Based on the findings of this analysis, they will recommend what threads will need to be identified. During special facilitated focus groups with program managers and staff, parents, and other stakeholders, the rationale for the approach and the mechanics of plan development will be discussed. Focus group activities will also be used to develop draft plans for each of these threads and to assign point persons for planning, management, and overall completion responsibility of each thread. Each of these teams will further develop the plans for their own areas while working with the teams of all the other threads to identify and resolve all the points of dependencies and hand-offs. The PMT team will guide and manage the plan development process and will synchronize and manage the complexities of the program on an ongoing basis.
Timelines: 3Q 2001 – 3Q 2002 and ongoing
Responsible Party: The PMT team and Lynn Martinez
Deliverables: Project Plans for each Thread; Overall Data Integration Plan
Milestones: Completion of the Data Integration Plan
Expected Outcome: The resources involved will understand their roles and responsibilities in the DI initiative
Evaluation Strategy: Tracking of Actual vs. Planned; Feedback from Funding Source
- Objective G.4. To limit the risks that could delay, derail, or cancel the CHARM DI initiative.
Activities: The PMT team will organize a focus group with the point persons assigned to each thread to conduct a comprehensive risk assessment across the entire program. The PMT and assigned resources will develop a Risk Management plan for the entire program. This will be in addition to the Risk Assessment and Management activities to be included in, and carried out, within each thread plan. The PMT will use the plan to proactively manage program risks and will conduct regular reassessment and plan adjustments, on an ongoing basis.
Timelines: 4Q 2002 – 1Q 2003 and ongoing
Responsible Party: The PMT team
Deliverables: Risk Assessment Document; Risk Management Plan
Milestones: Completion of the Risk Assessment; Completion of Risk Management Plan
Expected Outcome: Risks to the DI Program will be reduced and proactively managed
Evaluation Strategy: Tracking of Risk Management actions taken; History of Risk Management Plans
- Objective G.5. To maintain a high level of quality in the performance and completion of project deliverables that are being approved and funded.
Activities: The PMT team will ensure that all deliverable reviews, walkthroughs, demos, etc. involve the most appropriate stakeholders and provide a true opportunity for understanding, whether it be necessary time, explanations, guidance, checklists, etc., and that signoffs are a true reflection of quality work and acceptance. Otherwise, punch lists and action lists will be drafted to enable remediation. In addition, the PMT team will commission an independent technical & usability review of the CHARM integrated system and of the web-based CHARM Information System (CIS).
Timelines: ongoing
Responsible Party: PMT team
Deliverables: Signoffs; Approvals; Punch Lists, Technical & Usability Review Report
Milestones: Acceptance of Major DI Program Deliverables
Expected Outcome: The DI program will have a higher chance of meeting expectations
Evaluation Strategy: Walkthroughs; Reviews; Demos; Testing; Reviewer Feedback; Technical & Usability Review Report; Budget Tracking

- Objective G.6. To ensure the CHARM DI Program is adequately funded and has a broad basis of support.
- Activities: The PMT team and the Grant Oversight Team (GOT) will hold regular meetings to review and approve requests for funding for the CHARM DI program. The GOT manages and is accountable for several grants UDOH has received that have a DI component. Central coordination of funds will enable the CHARM program to maximize its existing funding. The PMT team will also look for additional funding opportunities that fit the vision of UDOH DI effort and will rally the effort needed to put together winning applications. The PMT together with the CMT team will meet with our existing partners, the Utah State University, and ensure that we share and pursue a win-win strategy. Together with the CMT team, the PMT team will plan to meet with the existing USIIS Oversight Committee (UOC), which is a very powerful and generous community-based group, in order to expand CHARM support and sponsorship basis.
- Timelines: ongoing
- Responsible Party: PMT team
- Deliverables: Funding Approvals; Grant Applications
- Milestones: Adoption of CHARM by the UOC
- Expected Outcome: The CHARM DI Program will be able to realize its goals
- Evaluation Strategy: New Grants Awarded; Partner Feedback; Partner Letters of Support

GOVERNANCE

Below is the governance structure UDOH has in place to lead and manage the CHARM project, the UDOH Data Integration initiative.

LEADERSHIP

The Data Integration initiative is one of the ten highest strategic initiatives of the UDOH. The Executive Director, the two Deputy Directors and the entire Executive Management Team (EMT) have responsibility for its outcome and success. They ensure the project has the right visibility within the department and the state and they provide the point of ultimate accountability for the project. In particular, the DI initiative is the foremost responsibility of the UDOH CIO who has direct implementation accountability for all integration initiatives within UDOH.

MANAGEMENT

The team currently managing the UDOH Data Integration initiative has very much the same composition as the team identified in the HRSA grant proposal. Alongside Rhoda Nicholas, the UDOH CIO, is Dr. George Delavan, Director of the Division of Community and Family Health Services (DCFHS), where most of the child health programs targeted for integration in CHARM reside. Dr. Delavan has long been a proponent of integration and is an integral part of the CHARM management team.

Chart 1 shows the organizational distribution of the programs targeted for CHARM.

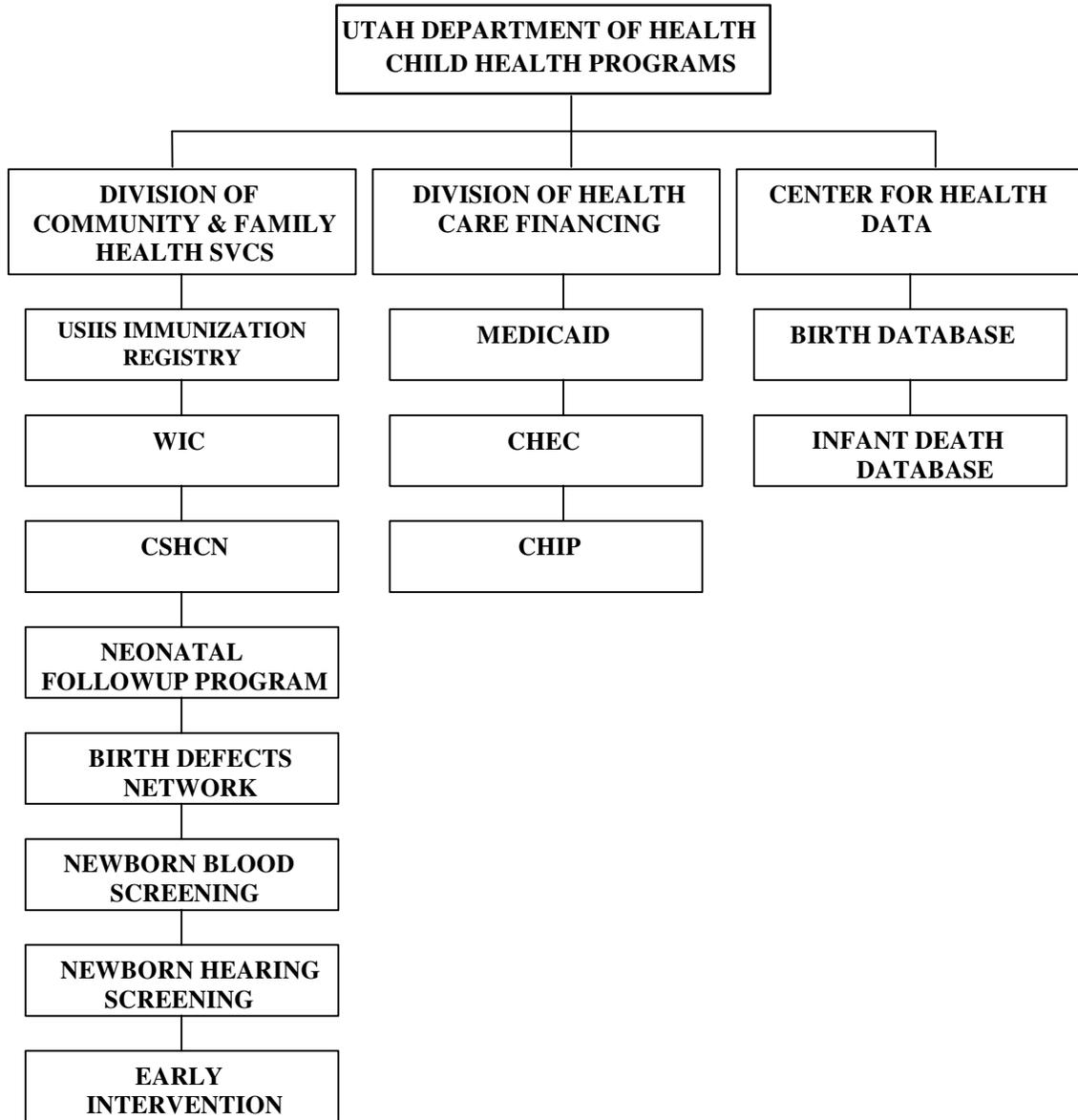


Chart 1: Organizational distribution of the programs targeted for integration into CHARM

CHARM CORE COUNCIL

Decisions regarding the degree and content of the CHARM Data Integration initiative are made by consensus in the CHARM Core Council, or the CCC. The CCC is made up of the managers of the child health programs in UDOH. The council has been in existence since June of 2000 and has been meeting every other month since November 2002. Its involvement is critical to the progress and success of the Data Integration initiative. This committee works in collaboration with the Grant Oversight Team, which coordinate the activity of systems integration projects currently funded by grants.

The CCC is chaired by Dr. George Delavan, Division Director, Community & Family Health Services and is co-chaired by Dr. Barry Nangle, Director, Office of Vital Records and Statistics. The table below lists the member composition of the CCC.

NAME	REPRESENTING:
George Delavan, MD, Director	Division of Community & Family Health Services
Barry Nangle, PhD, Director	Office of Vital Records Utah Statewide Immunization Information System (USIIS)
Fan Tait, MD, Director	Bureau of CSHCN
Fay Keune, Manager	Newborn Blood Screening
Jan Bagley	Newborn Blood Screening
John Eichwald, Clinical Administrator	Bureau of CSHCN
Tom Mahoney, MD, Manager	Newborn Hearing Screening Program
Nita Owens	HI*Track - NHS System
Susan Ord, Manager	Baby Watch / Early Intervention
Marcia Feldkamp, Manager	Birth Defects Network
Rhoda Nicholas, UDOH CIO	CHARM Program Management
Don Gabriele, Manager	CHARM Technical Development

Table 3: Member Composition of the CHARM Core Council

It is anticipated that the composition of the CCC will change through time to include managers of other programs, as they are being closer to their integration timeline. Based on availability of future grant funding, the UDOH plans on adding a parent advocate to the composition of the CCC. As CHARM gets closer to its web development phase, where access to the integrated child profile will be opened to private providers, the CCC will also open its ranks to private provider representation.

GRANT OVERSIGHT TEAM

The Grant Oversight Team (GOT) addresses issues related to how various financial needs of the Data Integration initiative could be met. The GOT consists of the Principal Investigators and Budget Coordinators of all grants received by the UDOH that have a Data Integration component and are pursuing similar or complementary purposes. The GOT has been meeting monthly, since October 2000, to review progress of deliverables committed under each grant, so that each grant can make good on its promise. The GOT also coordinates and optimizes funding streams, so that more can be achieved with less and that one common solution is pursued for Data Integration. In time, this team may expand membership and focus to include the coordination of other integration related grants, such as NEDSS, etc.

The GOT is chaired by Dr. George Delavan, Director of the CFHS Division. The table below lists the member composition of the GOT.

Name	Representing
George Delavan, MD	All CFHS grants
John Eichwald	All CFHS grants
Karen Zinner	SSDI Grant Coordinator
Suzanne Knight	CFHS Budget Coordinator
Rhoda Nicholas	UDOH CIO - IS Vision & Data Integration Program
Karl White, MD	USU - EHDI + CDC + SBIR + SPRANS Grants
Margaret Lubke, PhD	USU - CDC EHDI Grant Coordinator
Steve Clyde, PhD	USU - Technical Specialist

Table 4: Member Composition of the Grant Oversight Team

PROGRAM MANAGEMENT

The DI program management will be carried out through team and committee work of the Program Management Team and the Project Management Teams. The three sections below describe the composition and roles of each.

PROGRAM MANAGEMENT TEAM

This team is comprised of:

- Rhoda Nicholas
- George Delavan
- Margaret Lubke

The Program Management Team is responsible for the overall success of the CHARM Data Integration initiative. The team will be meeting as needed, but no less frequently than once a month, either by themselves, or as part of a Program Management Committee (PMC) meeting.

PROJECT MANAGEMENT TEAMS

These teams are comprised of the point persons identified during the planning focus group to manage each of the underlying DI projects or threads. They will report progress on their plans and work out related issues with the Program Management Team.

The table below lists the project management teams for all the DI project thread plans.

Thread / Project	Project Management Team
Technical Development	Don Gabriele* Stephen Clyde
Participating Program Technical Development	USIIS – Joe Nay Early Intervention – Don Gabriele Vital Records (Births & Deaths) – Mark Jones Newborn Hearing Screening – Stephen Clyde Newborn Blood Screening – Jane Johnson
Communication & Marketing	Nancy Pare* Christine Perfili
Data-related Rules, Policies and Procedures	Marcia Feldkamp* Sandra Schulthies
Data Quality	Barry Nangle* Sharon Clark
Organizational Change	John Eichwald* Lynn Martinez

Note: * designates the main point person

Table 5: Member Composition of the DI Project Thread Teams

These teams will meet independently, as needed, to manage their own projects, but no less frequently than once a month.

The chart below shows the Governance structure hierarchy, spanning across the executive level through the Project Management Teams.

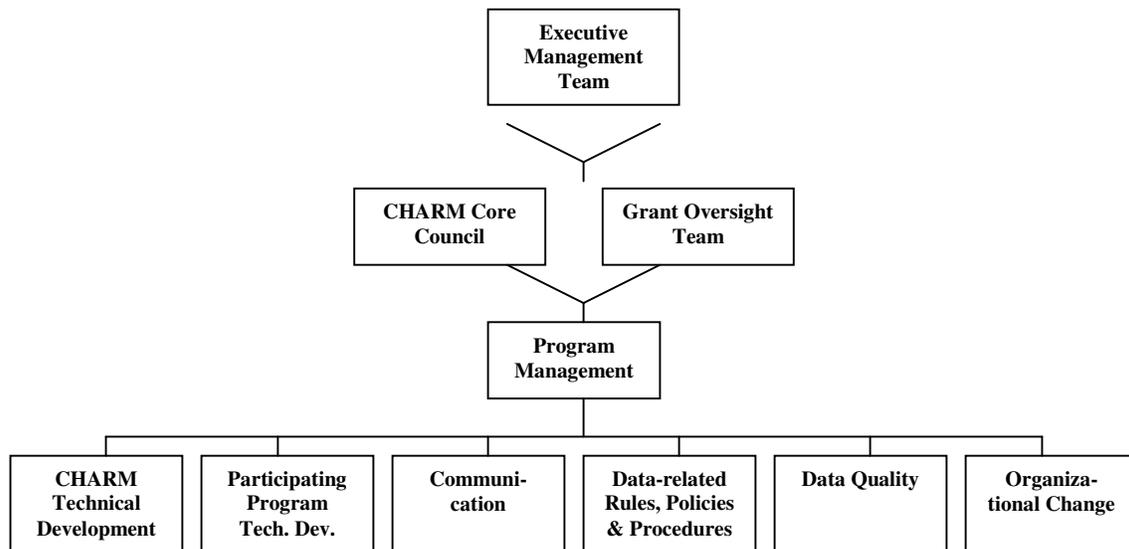


Chart 2: CHARM Governance Structure Hierarchy

PROGRAM MANAGEMENT COMMITTEE

The Program Management Committee (PMC) is comprised of the point persons (teams) of each of the DI projects and the Program Management team. This committee will meet, as needed, to resolve issues related to project coordination, synchronization, resource identification, etc., but no less frequently than once every other month.

STAKEHOLDERS

A stakeholder is defined as anyone who can impact the success of the Data Integration initiative or anyone impacted by the initiative. Stakeholders are identified so that we can take action to assure appropriate involvement from each of them.

- UDOH Executive Leadership
- UDOH Program Managers and Staff involved in Child Health Services
- Local Health Department (LHD) Program Staff involved in Child Health
- Private Providers involved in Child Health
- Parents/Families
- Community-oriented organizations and partners (e.g. IHC, USU)
- Programs tied to child health preventive services – Epidemiology & Surveillance (NEDSS)
- UDOH Data Warehouse project
- Other state agencies
 - Department of Human Services (DHS)
 - State Office of Education (SOE)
 - Department of Administrative Services (state Information Technology Services - ITS)
- Other states (regional efforts)
- Grantors and other funding sources
 - CDC
 - HRSA
 - CMS
 - AKC Connections
 - USIIS Oversight Committee
- Governor, Legislators, state CIO

The figure below shows the various levels and relationships within the UDOH CHARM Data Integration program governance structure.

UDOH CHARM Governance Model

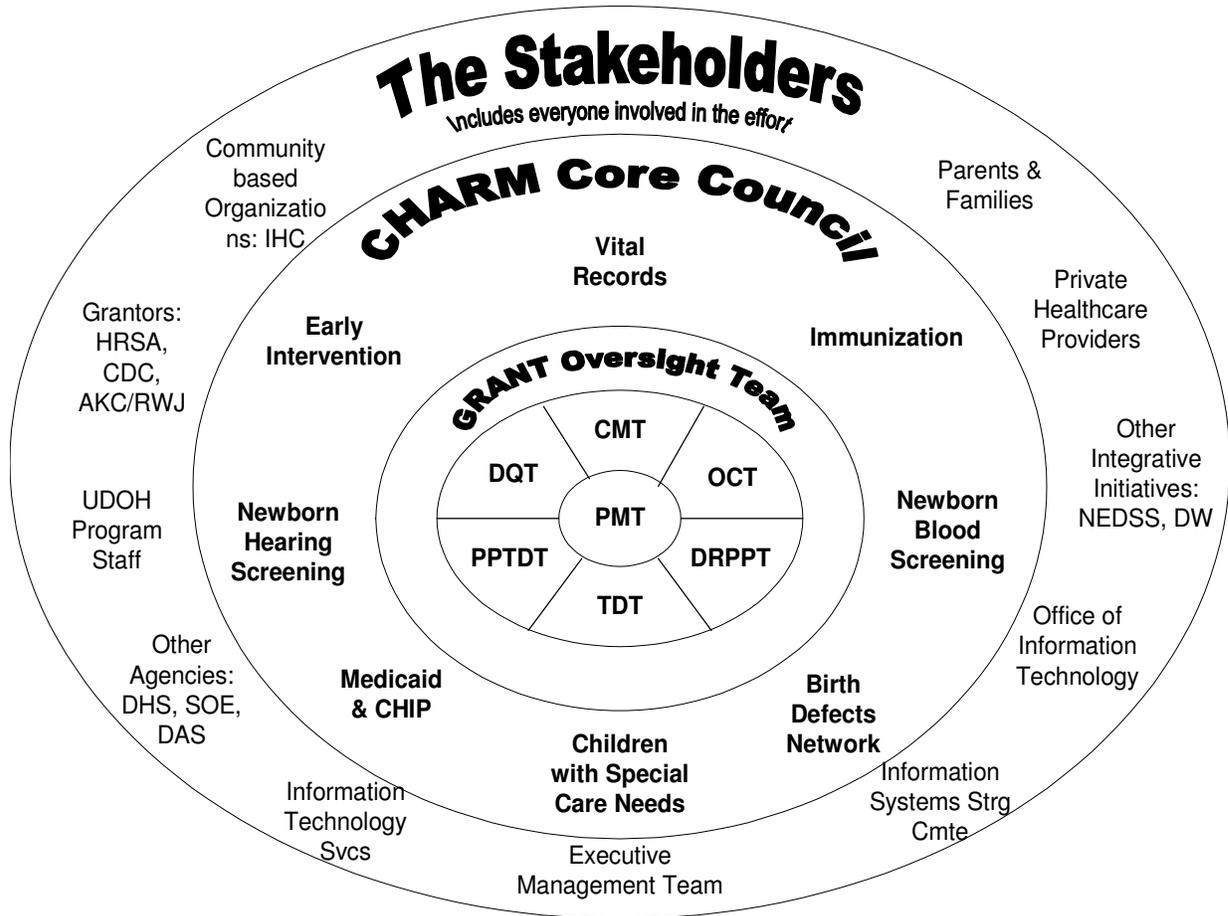


Figure 1: Levels and Relationships within the UDOH CHARM Data Integration Program Governance Structure

CRITICAL SUCCESS FACTORS

Critical success factors are the foundation of an initiative’s success. If these are overlooked, the solution delivered may not reflect the true need, may not be adopted, may lead to no growth and improvement, may even to subject to sabotage.

The following factors have been identified as being critical to the success of the UDOH Data Integration initiative:

1. Any solution IT delivers must be a Program solution, first and foremost.
2. No initiative can succeed unless the Programs own it.
3. The solution must lead to and enable organizational change.
4. Resistance and denial, the usual symptoms facing any innovation, need to be overcome.

5. Broad support from executive and senior management, as well as “adoption” by line management is essential to the credibility and success of the Data Integration initiative.
6. The voice of the client (parents/families) must be heard.
7. Funding must be optimized and coordinated.
8. Governance structure is in place and at work.
9. The Utah Statewide Immunization Information System (USIIS), which is doing trailblazing work for its web-based acceptance with private providers, continues on a path of success. CHARM will be leveraging and building on USIIS’ successes.

ASSUMPTIONS AND CONSTRAINTS

ASSUMPTIONS

In our understanding, assumptions are situations that are assumed to be true but are under someone else’s control. Assumptions are identified and listed so that they can be validated. The success of the CHARM project, our Data Integration initiative, is based on the following major assumptions:

1. Funding sources, as intermittent and unpredictable as they may be, will continue to be available in the future to enable the UDOH to complete the Data Integration initiative.
2. Data Integration is a long-term initiative. It is assumed that UDOH executive leadership, even if different in future administrations, will continue to support DI as a worthy effort.
3. The Connections collaboration currently sponsored by the AKC Center for Innovation in Health Information Systems will continue to identify best practices in integration initiatives across the country and share the body of knowledge with its members. CHARM is constantly learning and improving as a result of the Connections sponsored visits.
4. Our partners at the USU will continue to contribute to and support CHARM.

CONSTRAINTS

Constraints are situations under someone else’s control that limit the project’s range of choices. Below we have identified the major constraints so that they can be validated and accommodated as needed.

1. The Data Integration initiative is subject to financial constraints. That limits the size of its technical team and the extent to which other UDOH resources can be freed to engage in the project. The pace of the project is expected to be slow.
2. CHARM is subject to the technical standards developed and instituted by state ITS. The technology choices will be limited by what ITS will offer and will support.
3. State ITS is still operating in a reactive mode with respect to meeting agencies’ needs and expectations. Because of that, CHARM might have to find alternative development environments at its partner, USU. When they do catch up, state ITS might not be able to replicate the same environment set up at the USU. This might set CHARM back as it might require a certain amount of re-work.
4. Since integration funding is often targeted to the integration of a certain program, CHARM will not always be able to pursue the development of the segment that makes best sense from a project point of view. At times, CHARM will have to change gears, lose momentum, and re-engage in certain areas, as opportunistic funding may become available.
5. Because of its reliance on its partners at the USU, the CHARM technical team is fragmented and separated by hours of driving. Often communication suffers which leads to a certain amount of misunderstandings and rework.

RISKS

Risks are potential problems that could have a significant adverse affect on the initiative. Usually, certain assumptions involve substantial risks, if they lose their validity. By disclosing the possibilities of risk, the stakeholders know up-front that there are risks associated with the venture. It is the responsibility of the project and program managers to continuously reassess and mitigate these risks.

Tasks related to the identification and management of project thread specific risks have been incorporated in each project thread plan. Tasks related to the identification and management of overall risks have been incorporated in the program plan.

Some of the major overall risks have also been listed here:

- Executive Sponsorship and Governance
 - The DI initiative loses its executive level champions
- Resources
 - Funding stops
- Organizational Commitment
 - UDOH Programs lose interest in and no longer support the DI initiative
- Stakeholder Involvement:
 - Parents and community at large fail to be properly involved
 - Stakeholders become unhappy with how DI is being implemented
 - UDOH fails to get Providers on board
- Legal Implications
 - Aspects of the data sharing, as implemented in CHARM and CIS, are challenged as un-statutory
- Program Management
 - Partnership with USU disintegrates
 - Program Coordination is too cumbersome and gets stressed out

Since any one of the risks identified above has the potential of making or breaking the DI initiative in the UDOH, the CHARM Program Management will make continuous efforts to control, mitigate and manage these risks.

FINANCIAL SOURCES

The table below identifies the financial sources and amounts the UDOH Data Integration project has been able to get so far. The management of the program will continue to pursue other funding, as it may become available.

Source	Grant Name/Purpose	Grant Period	Amount ¹
CDC	EHDI Cooperative Agreement	10/01/2000 - 09/30/2005	\$233,552
HRSA	Genetic Services and Data Integration Planning Grant	06/01/2000 - 05/31/2002	\$75,500
AKC/RWJ	Connections TA	09/01/2001 - 08/31/2002	\$51,980
HRSA	SSDI	10/01/2001 - 09/30/2002	\$89,900
HRSA	MCH Block Grant - One Time	07/01/2001 - 06/30/2002	\$35,000

Table 6: Funding Sources for the CHARM Data Integration Project

¹ This amount reflects the amount earmarked for integration related work. In other words, this is the amount that has been available for program/system enhancement and integration.

APPENDICES

APPENDIX A – Data Integration Needs Assessment Focus Group Participants

December 5

Lynn Martinez	GSDI Project
Nita Owens	Newborn Hearing Screening
Jan Bagley	Newborn Blood Screening
Linda Abel	Immunizations Program
Susan Ord	Early Intervention
Marcia Feldkamp	Birth Defects Network
Barry Nangle	Vital Records
Jane Johnson	CSHCN IT
Sandra Schulthies	USIIS
Marie Nagata	WIC
Julie Olson	Medicaid

December 6

Holly Balken	CSHCN Clinical Programs
Tom Mahoney	Hearing Speech and Vision Services
Fay Kuene	Newborn Blood Screening
Martee Hawkins	Immunizations Program
Sue Olsen	Early Intervention
Wu Xu	USIIS
Don Johnson	WIC
Joyce Gaufin	Medicaid

February 20

Anthony Smith Health Program	Indian Walk-In Center 120 West 1300 South SLC, UT 84115
Judi Hilman Health Advocate	Utah Issues 330 West 500 South Salt Lake City, UT 84101
Steve Briles Health and Nutrition Centro de la Familia de Utah Salt Lake City, UT 84101	320 W. 200 So. Salt Lake City, UT 84101
Chris Chytraus Utah Children	757 East South Temple #250 Salt Lake City, UT 84102
Terry Haven Utah Children	757 East South Temple #250 Salt Lake City, UT 84102
Vivian Garcia Parent and U of U Health Ed student	1411 Utah St. Salt Lake City, UT 84104
Gina Pola-Money Family Voices Joyce Dolcourt Governor's Council for Persons with Disabilities	

February 21

Barry Nangle	Vital Records
Julie Olson	Medicaid
Tom Mahoney	Hearing Speech and Vision Services
Fay Kuene	Newborn Blood Screening
Linda Abel	Immunizations Program
Marcia Feldkamp	Birth Defects Network
Don Johnson	WIC

Jane Johnson
Sue Olsen

CSHCN IT
Early Intervention

APPENDIX B – Needs Assessment Focus Groups 1, 2, & 3 Agenda

Introduction:

- Introduce Focus Group Participants
- Introduce Needs Assessment Team (UDOH & Consultant)
- Discuss meeting logistics (e.g., how long, lunch, phones, bathrooms, etc.)

Why we are here:

- Discuss purpose/overview of Child Health Data Integration Initiative (project background, objectives, major tasks, etc.)
- Discuss overall benefits
- Discuss benefits to various stakeholder groups
- Explain why we need stakeholder input
- Recap first two Focus Group sessions

Focus Group Session Topics:

- Discuss approach to be used to gather information (e.g., pre-developed questions to drive out the needed information; fast-moving agenda to ensure that everything is covered; controlled discussion of issues--unresolved issues will be assigned for resolution, etc.)
- Identify the kind of input needed from participants (e.g., what information would be helpful to them, what information should NOT be contained in a Child Health Profile (CHP), confidentiality/security/privacy concerns, accessibility, data retention requirements, archival storage and retrieval requirements, timeliness of data, system environmental considerations, etc.)
- Gather information from participants
- Assign issues for resolution
- Explain what will be done with Focus Group Session findings

Where do we go from here?

- Discuss next steps (e.g., complete Focus Group Sessions, compile results, make recommendations, document findings, feedback, etc.)
- Discuss timeline for the remainder of the project
- Ask about further input from others---have we forgotten anyone?
- Identify who to contact if Focus Group Participants have questions

APPENDIX C – Needs Assessment Focus Groups 4 Session Agenda

Introduction:

- Introduce any new Focus Group Participants

Why we are here:

- Recap Objectives of Needs Assessment & this session
- Recap findings from meetings with Scott, George and Focus Group sessions 1, 2, & 3 (from Focus Group 3 - discuss information participants did NOT want to include in a Child Health Profile, or CHP)
- Discuss purpose for this meeting, why participants were asked to attend another meeting, how they can help the Needs Assessment team nail down requirements, identify most critical issues to address, & identify topics to be addressed in this session

Focus Group Session Topics:

- Discuss meeting logistics (e.g., how long, lunch, phones, bathrooms, etc.)
- Review refinements made to strawman CHP since the first Focus Group sessions
- Nail down the info to be contained in the CHP, determine existence of unique identifier across programs for each child, identify mandated data sharing restrictions, etc.
- Discuss how the CHP should be used
- Review findings from systems requirements questionnaires, e.g., data currency requirements, history data requirements, privacy/security/confidentiality requirements, peak usage of system, etc.)
- Address questions arising from technical review of current systems
- Gather any other information needed for preparation of Needs Assessment Document

Where do we go from here?

- Discuss next steps (compile results, make recommendations, draft findings, get feedback from participants, finalize document, etc.)
- Discuss timeline for the remainder of the project
- Discuss future involvement of these participants in the project
- Identify who to contact if Focus Group Participants have questions

APPENDIX D – Needs Assessment Results

Appendix D contains the summarized list of issues and needs identified during the focus groups conducted during the grant's Needs Assessment phase. It also contains the list organized according to topic.

Summary of Issues and Needs Identified During the GSDI Data Integration Year 1 Grant ** Needs Assessment **

- Data Integration Projects are complex (lots of issues, stakeholders, highly political and turf, legal, technical, funding, etc.)
- Data Sharing is controversial and needs buy-in from parents. In addition to buy-in the parents need to be among the planners and the drivers of any data sharing system that is established as well as its users.
- Parents are concerned about issues related to discrimination based on sharing data inappropriately. Parents are also very interested in making sure their children's care providers have all the information they need to better treat their children; this includes the results of screens, diagnostic tests as well as immunization records.
- Data Sharing needs to be regulated and controlled.
- Program managers entrusted with collection and stewardship of the data are concerned about legal issues related to data sharing.
- Program Managers are also concerned about making sure inaccuracies in the data are not perpetuated.
- State and federal laws need to be observed.
- Data needs to be shared with Private Providers but Private Providers have little time to spare. (Marketing, penetration, developing "carrots" strategies, strengthening USIIS, building on USIIS, growing the USIIS Oversight Committee, etc.)
- Bio-demographic data, whose currency is often critical, is collected redundantly yet, in many systems, it remains out-dated.
- Benefits of data sharing are obvious to some but remain obscure to others, at least in the beginning.
- The availability of new data/information (through data sharing) enables new and better ways of serving our clients and dealing with issues. These have yet to be discovered or thought out.
- HIPAA Privacy and Confidentiality issues need to be addressed.
- Program representatives are already squeezed to do more with less. Working as part of an integrated system should not burden them or require them to know, or be trained in, the specifics of other programs. Nor should it require them to overhaul their existing systems.
- More...Parents need to have 'control' of their families' data. They want the ability to opt out of some parts, or all, of the data sharing activities. For example, some may want sharing of clinical, but not financial, data, while others may not want sharing of clinical, but are willing to have eligibility information shared. They want a system that is flexible enough to allow that kind of opting out. Parents also want to be made aware of their options in a clear and comprehensive manner. They expressed concern that they often aren't given information about *other* health dept programs and services for which they may qualify when they interact with a particular health dept program.

- Parents also expressed interest in web-based information, particularly results of screens, resources for which they may qualify, impact of the condition(s) for which their child has screened positive and means to mitigate that impact.
- The WIC program was concerned about what was seen as its statutory inability to share with anyone, including other dept programs. This issue will need to be addressed before any sharing with WIC can be accomplished.
- NBS staff are concerned about genetic discrimination. This issue needs to be revisited in view of the new anti-discrimination legislation passed this year.
- Program staff will likely have a long 'learning curve' as regards any new computer system or way of accessing a new system (e.g., the CHARM agent, etc.).

Summary of Issues and Needs Organized by Topic/Threads

**** Planning ****

Communication & Marketing

- Data needs to be shared with Private Providers but Private Providers have little time to spare. (Marketing, penetration, developing "carrots" strategies, strengthening USIIS, building on USIIS, growing the USIIS Oversight Committee, etc.)
- Data Sharing is controversial and needs buy-in from parents. In addition to buy-in the parents need to be among the planners and the drivers of any data sharing system that is established as well as its users.
- Parents are also very interested in making sure their children's care providers have all the information they need to better treat their children; this includes the results of screens, diagnostic tests as well as immunization records.
- Benefits of data sharing are obvious to some but remain obscure to others, at least in the beginning.
- The availability of new data/information (through data sharing) enables new and better ways of serving our clients and dealing with issues. These have yet to be discovered or thought out.
- Parents need to have 'control' of their families' data. They want the ability to opt out of some parts, or all, of the data sharing activities. For example, some may want sharing of clinical, but not financial, data, while others may not want sharing of clinical, but are willing to have eligibility information shared. They want a system that is flexible enough to allow that kind of opting out. Data sharing agreements, informed consent etc.
- Parents also want to be made aware of their options in a clear and comprehensive manner. They expressed concern that they often aren't given information about *other* health dept programs and services for which they may qualify when they interact with a particular health dept program.
- Parents also expressed interest in web-based information, particularly results of screens, resources for which they may qualify, impact of the condition(s) for which their child has screened positive and means to mitigate that impact.
- Both the program and the parent participants expressed interest in ensuring on-going input from the parents into the development, implementation and evaluation of any shared data system.

Data-related Rules, Policies and Procedures

- Data Sharing is controversial and needs buy-in from parents. In addition to buy-in the parents need to be among the planners and the drivers of any data sharing system that is established as well as its users.
- Parents need to have ‘control’ of their families’ data. They want the ability to opt out of some parts, or all, of the data sharing activities. For example, some may want sharing of clinical, but not financial, data, while others may not want sharing of clinical, but are willing to have eligibility information shared. They want a system that is flexible enough to allow that kind of opting out. Data sharing agreements, informed consent etc.
- Parents identified a strong need for a privacy policy. They encouraged the sharing of medical information to benefit the child, but were more cautious about sharing family financial information.
- Parents are concerned about issues related to discrimination based on using data inappropriately.
- Data Sharing needs to be regulated and controlled.
- Program managers entrusted with collection and stewardship of the data are concerned about legal issues related to data sharing.
- State and federal laws need to be observed.
- HIPAA Privacy and Confidentiality issues need to be addressed. Data sharing should be governed by data sharing agreements internally among programs and confidentiality agreements externally between public health and private providers.
- The WIC program was concerned about what was seen as its statutory inability to share with anyone, including other dept programs. This issue will need to be addressed before any sharing with WIC can be accomplished.
- NBS staff are concerned about genetic discrimination. This issue needs to be revisited in view of the new anti-discrimination legislation passed this year.

Organizational Change

- The availability of new data/information (through data sharing) enables new and better ways of serving our clients and dealing with issues. These have yet to be discovered or thought out.
- Program representatives are already squeezed to do more with less. Working as part of an integrated system should not burden them or require them to know, or be trained in, the specifics of other programs. Nor should it require them to overhaul their existing systems.
- Program staff will likely have a long ‘learning curve’ as regards any new computer system or way of accessing a new system (e.g., the CHARM agent, etc.).

Data Quality

- Parents are very interested in making sure their children’s care providers have all the information they need to better treat their children; this includes the results of screens, diagnostic tests as well as immunization records.
- Program Managers are also concerned about making sure inaccuracies in the data are not perpetuated.
- Bio-demographic data, whose currency is often critical, is collected redundantly yet, in many systems, it remains out-dated.

APPENDIX E – Needs Assessment Final Report

APPENDIX F – DI Planning Focus Group Participants

Below are the participants in the Data Integration Planning Final Focus Groups, held on March 22 and 23, 2002, at the Homestead Resort.

Participant	Representing
Rosemary Thackaray	Moderator
John Eichwald	GSDI Project Team Member, CSHCN
Rhoda Nicholas	GSDI Project Team Member, EDO
Margaret Lubke	USU
Marcia Feldkamp	Birth Defects Network
Jane Johnson	CSHCN IT
Sandra Schulthies	USIIS
Marie Nagata	WIC
Julie Olson	Medicaid
Wu Xu	USIIS
Vivian Garcia	Parent, CHIP participant and Family Voices
Gina Pola-Money	Parent Spina Bifida Association
Kathie Peterson	Family Voices
Dr. George Delavan	CFHS Division Director
Ladene Larsen	Health Promotion Bureau Director
Ellen Wild	All Kids Count - Observer
Nicole Fehrenbach	All Kids Count - Observer
Ruth Gubernick	All Kids Count - Observer

APPENDIX G – DI Planning Focus Group Agenda

GENETIC SERVICES/DATA INTEGRATION PLANNING PROJECT Final Focus Group Meeting

March 22nd and 23rd 2002 - Homestead Resort

FRIDAY, MARCH 22

- 10 AM: Registration
- 10:30 to Noon: Overview of GSDI Planning Project and Presentation of Draft Plans
- Noon: Lunch and discussion
- 1:30 to 4: Break-out Focus Groups on Data Integration and Genetics
- 6 PM: Dinner

SATURDAY, MARCH 23

- 8 to 10: Focus Groups
- 10 to 10:15: BREAK
- 10:15 to Noon: Focus Group Reports
- Noon: Lunch
- 1 to 3 PM: Finalize Genetics and Data Integration Plans

APPENDIX H – CHARM Strategic Overview

Appendix H contains a standalone document describing the CHARM initiative. It contains the long-term “rough-in” plan for CHARM.

Child Health Advanced Records Management (CHARM) **Utah Department of Health Integration Initiative**

Background

Over the past few years, the Utah Department of Health (UDOH) has made significant progress in developing a public health information infrastructure. Most local health departments are now linked to the State’s Wide Area Network and Internet access to key health indicators is available and being expanded.

In the area of child health systems, several successes have been achieved. For the early childhood stages, UDOH has developed an Electronic Birth Registry (EBR), an Early Hearing Detection & Intervention (EHDI) surveillance and tracking system using HI*Track, and a Newborn Blood Screening program and system. Utah also has a birth defect program and registry, called the Birth Defect Network and a Statewide Immunization Information System (USIIS). Utah is currently developing a system for its Baby Watch - Early Intervention program.

Until recently, Utah, like many other states, was caught in the paradigm of categorical funding and considered an integrated approach to child health virtually impossible. However, new integrative initiatives in federal funding and federal grants have started to change this paradigm. New thinking at the UDOH business and IT leadership have added critical mass to federal efforts and guided the Department to formulate and pursue a long-term integration architecture. This calls for the integration of relevant databases and information systems into a system that can be used to improve services to children and families, make better public health policy decisions, and advance our knowledge about children with health, developmental, and genetic conditions.

The CHARM Initiative

Charter

The UDOH system that will integrate child health related programs and systems is called the Child Health Advanced Records Management or CAHRM. The CHARM charter is to create a virtual health profile for every child and to allow real-time data sharing across health-care programs and partners. This will provide for immediate access to information that is stored in specific databases to track and monitor screening results, immunization status, referrals, follow-ups, assessment, treatment, and outcomes for children and their families. The integrated system will reduce or avoid redundant data entry, increase accountability, and reduce the fragmentation of data and health care services.

The ultimate goal of CHARM is to increase the effectiveness of our child health services by providing an easy to adopt, easy to use, sustainable, technology-based way of providing access to integrated information at the point of service.

Governance

Many child health programs within UDOH have embraced CHARM. Management of the Division, bureaus and programs within the purview of CHARM sit on the CHARM Core Council (CCC). The CCC meets every other month and makes content and policy decisions regarding the CHARM scope, goals and objectives, programmatic integration sequence, issues about data access and authorization, privacy and confidentiality, and client consent.

Functional Requirements

The CHARM Core Council defined the functional requirements for CHARM following the minimum requirements model developed and published by the CDC for Immunization Registries. Table 1 lists the proposed minimum high-level functional requirements for CHARM.

Provide for client participation in CHARM based on parent/guardian informed consent.	Enable access to CHARM information at the time client oriented activities (e.g. encounter) are performed.
Establish the backbone of a CHARM record as soon as a newborn's record is created in the central Birth Registration System.	Protect the confidentiality of personally identifiable medical information.
Grow to include all children 0-21.	Ensure the security of medical information.
Collect the shared core data elements approved by the CHARM Core Council and store it centrally.	Provide recovery procedures for lost data.
Identify the child across multiple programs.	Automatically detect "out of the norm" situations (due or late for any screening or follow up action) with a CHARM client based on standards and thresholds.
Create a comprehensive CHARM profile, using de-duplication and edit checking procedures to optimize accuracy and completeness.	Provide intuitive, easy-to-use prompts, scripts, referrals and reminder/recall notification procedures.
Receive, process, and provide access to CHARM information in real time or near real time.	Automatically produce reports by specific program areas, across program areas and across providers by age groups, and geographic areas.
QA standards to implement, update, and track HP2010 and other indicators.	Support table driven standards and threshold values that are set by the CHARM Core Council but can be easily updated.
Support secure, role-based, authorized access to CHARM information.	Extend the longest programmatic record retention requirements to all the segments of the integrated record.
Provide two-way access to and sharing of CHARM records.	

Table 1: CHARM Minimum High-Level Functional Requirements

Integration Architecture

Unlike the more traditional approach to integration, the Utah solution is not predicated on an architecture that targets existing systems for replacement by including their data and their functionality in a unified, monolithic system. Instead, Utah has developed a conceptual architecture that builds loosely on the notion of a federation. With today's technology, solutions that were not possible just a few years back are now well established.

By developing and/or acquiring a core collection of software components, CHARM will build the "brain" of the integrated system, or its integration infrastructure. It will act as a broker, dispatcher, traffic cop, conflict manager, policy enforcer, as well as many other roles for the integrated system. The participating programs will be fitted with their own "agent", or "adapter", and front-end to "plug in" to the CHARM infrastructure. The agents and front-ends will help the programs translate and format their communications, as well as define and manage the rules under which they are operating and sharing data.

While programs and their systems have been evaluated for integration readiness, they will be periodically re-assessed, as readiness parameters may change through time. Many times, the availability of new grant funding will allow programs to participate in the integration effort earlier rather than later. Table 2 lists the programs that have expressed an interest and have been evaluated for readiness to be included in the early integration efforts. Table 3 lists other programs and systems that will be considered for inclusion in later releases.

<p>Vital Statistics—Birth Registration Newborn Hearing Screening Newborn Blood Screening Early Intervention (Baby Watch) Immunization Registry</p> <p>Table 2: Programs/systems targeted for early integration</p>

<p>Children with Special Health Care Needs Birth Defects Network Lead Screening Women Infants & Children (WIC) Vital Statistics--Electronic Death Certificate Neonatal Followup Program Medicaid Child Health Evaluation and Care or CHEC (Utah version of EPSDT) Child Health Insurance Program (CHIP) DHS/DCFS SAFE - Health Services for Children in Foster Care</p> <p>Table 3: Programs/systems targeted for later integration</p>

Figure 1 shows the UDOH programs targeted for CHARM as well as programs from other agencies, such as DCFS (Health Services for Children in Foster Care). It also shows the CHARM Information System, which is our planned access option via the web.

The figure also includes planned integration with other major initiatives the UDOH is currently working on, such as the National Electronic Disease Surveillance System (NEDSS) and the UDOH Data Warehouse.

CHARM will be a rich source of integrated data to store in a data warehouse. The Data Warehouse will serve as a repository for historical and statistical data and will allow for longitudinal studies, analysis, research, reporting, and policy development. Building the UDOH data warehouse is a different initiative from CHARM. Started under the aegis and funding of our Medicaid program, the UDOH Data Warehouse is already adding Vital Records data and an algorithm to support client matching.

CHARM Overview

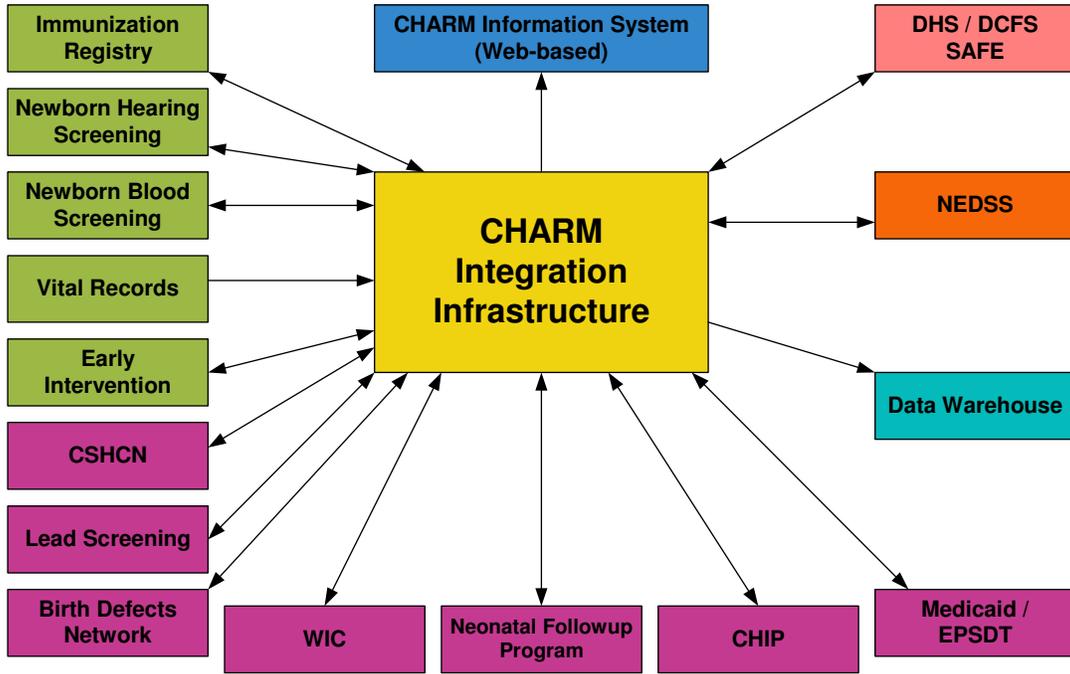


Figure 1: CHARM Overview and Participating Programs

Figure 2 shows a very high level, simplified conceptual architecture depicting just three systems and how they integrate into CHARM through their agents.

CHARM Architectural Overview

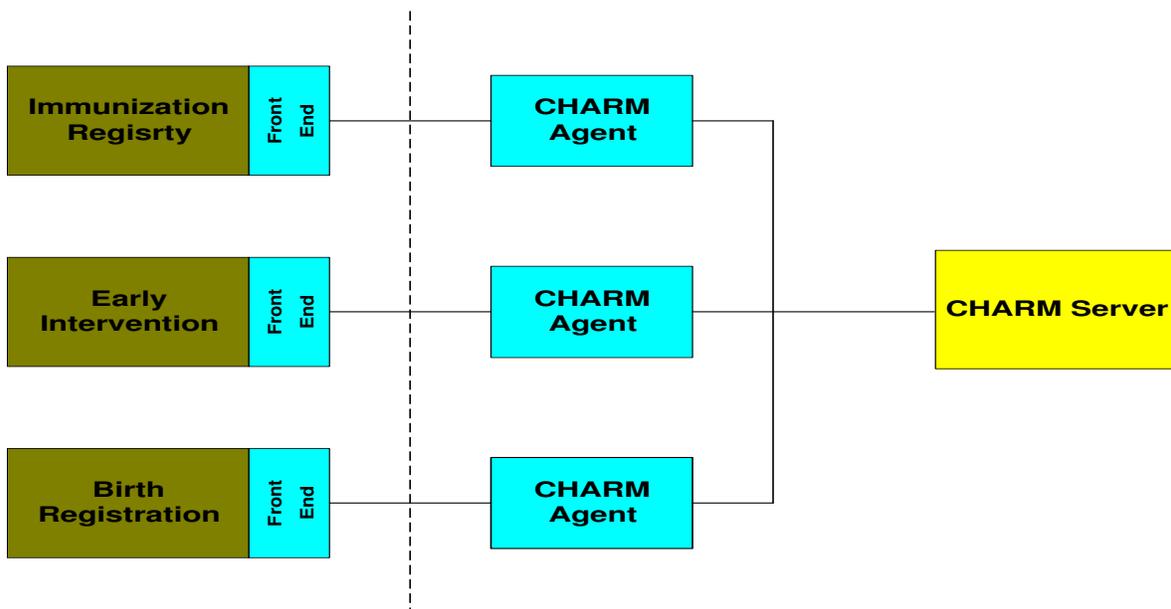


Figure 2: CHARM Conceptual Architecture

Integration Philosophy

One of the unique concepts to be implemented as part of the Utah integration project is that of a "permissive" solution. The permissive solution allows the participating programs to maintain focus on their specific functions, to enhance their own information systems and to grow in scope and size independent of other participating programs, and independent of the core integration component of the system. This independence will ensure that participating programs retain stewardship and responsibility of the data in their purview. It will allow them to define which data they are able to share with others and describe the intended use and meaning of that data.

In addition, the permissive solution allows the participating programs to move along the integration continuum, from looser integration to tighter integration, at their own pace. We call this the "low bar - high bar" entry. Low bar entry allows new programs to easily be added to the system, by requiring only a minimum of effort. As programs develop more resources and expertise and as the level of confidence with the integrated system grows, the bar of integration could be set higher, and programs can move deliberately towards an enhanced integration formula.

Project Structure

CHARM is currently under development and has a team of full time and part time program and IT resources that have dedicated time, knowledge and energy to this effort. CHARM is under the direct accountability of the UDOH CIO and is managed as a high level priority for the Department.

Partnering and sharing is very much at the basis of our successes so far and we believe that it is the best way for resource-constrained organizations to achieve more than they could otherwise. Most notably, UDOH has developed a strong partnership with the Utah State University (USU) where many programs have public and community health-oriented goals. In addition, UDOH is one of the original eight teams working together on developing best practices and knowledge sharing environments as part of the RWJ funded "Connections" integration collaboration sponsored by The Center for Innovation in Health Information Systems.

The CHARM project is structured in three main Programmatic Integration (PI) releases, in addition to five basic, or enabling releases, such as the Integration Infrastructure (II), Web-Access (WA), Content

Enhancement (CE) Extended Integration (EI), and Data Warehouse (DW) releases. Below is a time driven list showing the planned sequence of these releases.

CHARM Release 0.1 – Integration Infrastructure (II):

During this release, the team will design, architect, build and test the middle-tier of the integration architecture, otherwise known as CHARM Integration Infrastructure, or CHARM II. This will include a group of components upon which the rest of the participating programs will integrate and which will perform a variety of functions, such as:

- identify the child,
- manage the sending and receiving of information requests and information responses to and from the participating systems,
- identify and notify of alert conditions,
- manage and enforce security and access to data, and
- other functions.

Status: The team has completed the design specifications for most of its Integration Infrastructure components and is currently developing several architectural prototypes to help decide its final architectural choices.

CHARM Release 1.0 – Early Programmatic Integration (PI):

During this release, the team will integrate the programs/systems targeted for early integration. This will include development of CAHRM Agents and Front Ends for each of the programs, to allow them to "plug-in" to CHARM, as well as modifications to each program to allow them to ask for and use newly shared data. Currently, the programs/systems targeted for early integration are:

- Vital Statistics—Birth Registration
- Newborn Blood Screening
- Newborn Hearing Screening
- Early Intervention (Baby Watch)
- Immunization Registry

Status: Work to identify specifically what data elements will be shared by each program and with whom and under what conditions is currently underway. Work on developing data sharing agreements and mechanisms for gathering client consent is also underway. A proof of concept will be developed to demonstrate how the real-time exchange of information between USIIS and the Early Intervention systems will work.

CHARM Release 2.0 – Web Access (WA):

During this release, the team will develop the CHARM Information System (CIS) which will provide web-based access to CHARM and will open CHARM to external (non-UDOH) users. This is envisioned as a web portal architecture where users have access to the information in CHARM through single sign-on and context management. Single sign-on technology will eliminate the need for users to identify themselves to each program/application integrated within CHARM. Context management will allow the users to navigate across the various application integrated within CHARM and carry the identification of the child they are reviewing information for until they identify another child.

The web-based module will allow CHARM to start penetrating the private providers' practices by providing them easy and timely access to the integrated child health profiles in CHARM. As the web-based access stabilizes and matures, and security concerns are properly addressed, CHARM will make inroads into other external user groups, eventually targeting schools and even families.

Status: Work on this release has not started. The team will be using the state's experience with its Immunization Registry and building on its success in penetrating the private providers' community through the web-based module of USIIS.

CHARM Release 3.0 – Mid Programmatic Integration (PI):

Expand the programmatic content of the integrated child health profile in CHARM by integrating additional programs/systems. The current thinking is that the following systems will be targeted for integration during the Mid PI Release:

- Birth defects network (this includes tracking fetal alcohol syndrome)
- Lead screening
- WIC
- Neonatal follow-up program
- CSHCN

Status: Work on this release has not started. The team will be using the experiences of the Early PI Release to develop similar information regarding data sharing and to leverage technical integration solutions used and validated during that release.

CHARM Release 3.1 – Content Enhancement:

During this release, the team will revisit the “plug-in” architecture and the quantity and quality of the content (data and services) currently published and shared by the participating programs. The team will work on solution to enhance the integration between individual programs by expanding the CHARM II functionality as well as improving each system's ability to deal with and use the shared information they exchange. The initial low-bar entry will be raised to a higher level, leading to an enhanced programmatic integration.

Status: Work on this release has not started.

CHARM Release 4.0 – Later Programmatic Integration (PI):

During this release, the team will again expand the programmatic content of the integrated child health profile in CHARM. This will be done by integrating programs/systems whose complexity would require more time and work as well as programs under the control of other agencies, such as Division of Children and Family Services in the Department of Human Services:

- Child Health Evaluation and Care or CHEC (Utah version of EPSDT)
- Child Health Insurance Program (CHIP)
- Medicaid
- SAFE (Health services for children in foster care)

Status: Work on this release has not started.

CHARM Release 5.0 – Extended Integration:

During this release, the team will identify and implement a solution for the integration of the clinical information in CHARM with the epidemiological and surveillance information in NEDSS. NEDSS is the major federal initiative, sponsored by the CDC, to integrate public health epidemiological and surveillance systems and establish a more patient-centered approach to these traditional public health functions. The NEDSS initiative is currently underway in the UDOH.

Status: Work on this release has not started but both CHARM and NEDSS are pursuing development according to their own schedules, while being aware of each other’s requirements and progress.

CHARM Release 6.0 – Data Warehouse:

During this release, the team will develop the modules to bring copies of integrated child health profile data into the UDOH Data Warehouse to enable and support longitudinal analytical studies.

Status: Work on this release has not started.

Funding

Since the year 2000 when the CHARM initiative started, various funding sources have contributed to its advance. State general funding is sustaining the UDOH CIO, whose mission is primarily to architect and

implement a client-centered cross-programmatic systems integration within the Department and then expand it to include Public Health's traditional stakeholders. State funding also sustains the Department's Office of Information Technology (OIT) who provides infrastructure support.

Federal and Private Foundation funding has been the main source for moving the development of CHARM forward. Table 4 lists the main sources of funding:

Source	Grant Name/Purpose	Grant Period	Amount ²
CDC	EHDI Cooperative Agreement	10/01/2000 - 09/30/2005	\$233,552
HRSA	Genetic Services and Data Integration Planning Grant	06/01/2000 - 05/31/2002	\$37,500
AKC/RWJ	Connections TA	09/01/2001 - 08/31/2003	\$51,980
HRSA	SSDI	10/01/2001 - 09/30/2002	\$89,900
HRSA	MCH Block Grant - One Time	07/01/2001 - 06/30/2002	\$35,000

Table 4: CHARM main sources of funding to date

Through its partnership with Utah State University, the Department has been able to utilize Computer Science graduate students skilled in new technologies. While this sometimes generates logistical difficulties and planning issues, it allows UDOH to maximize our funding and we are hopeful that this collaboration will be sustained.

² This amount reflects the annual amount not otherwise earmarked for non-integration related work. In other words, this is the amount that was available for program/system enhancement and integration.

APPENDIX I – Acronyms

Appendix I lists and defines all the acronyms used throughout this document.

A&P	Assessment & Planning
AKC	All Kids Count
BOK	Body of Knowledge
BT	Bio-Terrorism
CCC	CHARM Core Council
CDC	Center for Disease Control and Prevention
CFHS	Community and Family Health Services
CHARM	Child Health Advanced records Management
CHEC	Child Health Evaluation and Care
CHIP	Child Health Insurance Program
CHUG	CHARM User Group
CIO	Chief Information Officer
CIS	CHARM Information System
CMS	Center for Medicaid and Medicare Services
CMT	Communication & Marketing Thread
C&M	Communication & Marketing
DAS	Department of Administrative Services
DCFHS	Division of Community and Family Health Services
DHS	Department of Human Services
DI	Data Integration
DOH	Department of Health
DQ	Data Quality
DQT	Data Quality Thread
DRPPT	Data-related Rules Policies & Procedures Thread
DW	Data Warehouse
EHDI	Early Hearing Detection and Intervention
EMT	Executive Management Team
EBR	Electronic Birth Registry
GOT	Grant Oversight Team
GSDI	Genetic Services & Data Integration (Grant)
HP2010	Healthy People 2010
HRM	Human Resource Management
HRSA	Health Resources and Services Administration
IHC	Intermountain Health Care
ISSC	Information Systems Steering Committee
IT	Information Technology
ITS	Information Technology Services
LHD	Local Health Department
MCH	Maternal and Child Health
MCHB	Maternal and Child Health Bureau
MTW	Making Technology Work (Vendor)
NEDSS	National Electronic Disease Surveillance System
OCT	Organizational Change Thread
OPHA	Office of Public Health Assessment
PMC	Program Management Committee
PMT	Program Management Thread
PP	Participating Program
PPTDT	Participating Program Technical Development Thread
RWJ	Robert Wood Johnson
SLA	Service Level Agreement
SOE	State Office of Education
SSDI	State Systems Development Initiative

SWOT	Strengths, Weaknesses, Opportunities, Threats
TA	Technical Assistance
TDT	Technical Development Thread
UAT	User Acceptance Test
UDOH	Utah Department of Health
UOC	USIIS Oversight Committee
UofU	University of Utah
USIIS	Utah Statewide Immunization Information System
USOE	Utah State Office of Education
WIC	Women Infants & Children
USU	Utah State University