Utah’s Statewide Integrated and Coordinated Developmental Screening Data System and Data Systems Analysis
Statewide Integrated and Coordinated Developmental Screening Data System
Diagram Symbols

Colors indicate teams or organizations who are responsible for database and software components:

- **Brooke’s**
- **CHARM**
- **USIIS**
- **DOHMPI**
- **Other Screening Data**
- **Other Components**

Symbols:
- **Database**
- **Software component**
- **Data synchronization**
- **Retrieval of data via real-time queries**
- **Data pushes**
- **Data queries and data pushes**
- **User redirection to a website**
High-level Overview of Primary Data Flows

**Parents**

Brooke’s ASQ Enterprise System

**CHARM**

* a secure information broker of identified child data

Medical information systems and web portals

*for accessing identifiable child-level ASQ screening data as part of the child’s medical records*

**Health Care Providers**

**Public Health Programs**

**Home Visitors**

**Health Care Providers**

**Schools, and Early Care and Education Users**

**Administrators**
High-level Overview

- **Parents**

  Brooke’s ASQ Online Enterprise

- **CHARM**
  a secure information broker of identified child data

  Medical information systems and web portals
  for accessing identifiable child-level ASQ screening data as part of the child’s medical records

  - Public Health Programs
  - Home Visitors
  - Health Care Providers
  - Schools, and Early Care and Education Users
  - Administrators
Overview of Primary and Secondary Components and Data Flows

Parents

Brooke’s ASQ Online Enterprise

CHARM

a secure information broker of identified child data

CHARM WebIF
USIS Immunize
SAFE
EMR
CHARM Reports
ECIDS
UDRC

Health Care Providers and Public Health Programs
Health Care Providers, Schools, and Early Care, Education Users
Home Visitors
Health Care Providers, Schools, and Early Care, Education Users
Administrators

DOHMP provides ASQ for longitudinal studies

Parents

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Health Care Providers, Schools, and Early Care, Education Users
Home Visitors
Health Care Providers, Schools, and Early Care, Education Users
Administrators

DOHMP provides ASQ for longitudinal studies
Additional details about Primary Components and Data Flows

- Sync done by CHARM’s ASQ Data Monitor
- Real-time queries through CHARM’s ASQ Query Agent using Brooke’s API

CHARM’s ASQ Data Monitor and Query Agent

CHARM Core
(sync server, matcher, query manager, etc.)

CHARM’s Updaters and Query Agents

- Only demographics and record linkages

Webservice API

CHARM Web Page for USIS

CHARM Web Page for SAFE

CHARM WebIF

USIS Immunize

SAFE

Home Visitors

EMR

- An EMR only queries ASQ data through Webservice API
- An EMR downloads and stores ASQ data

Health Care Providers and Public Health Programs

Health Care Providers, Schools, and Early Care and Education Users

Parents

Those involved in doing ASQ screenings

Administrators

Reporting Features:
- Child identities are de-duplicate across enterprise accounts
- Pre-defined reports for common use cases
- Users can define their own reports, within the constraints of their access rights

EMR integration options:
- An EMR only queries ASQ data through Webservice API
- An EMR downloads and stores ASQ data

Health Care Providers, Schools, and Early Care and Education Users
Additional about Secondary Components and Data Flows

Parents

Sync done by DOMPI's ASQ data monitor using Brooke’s API

Stored identified ASQ Data

UDRC

Governor’s Office, Legislators, Researchers, and Longitudinal Child Outcome Data Reports

DOHMPI

Stored de-identified ASQ Data

ECIDS

Statewide Users of Early Childhood Integrated Data Systems’ Reports, Longitudinal Studies and Research

Sync done by DOMPI’s ASQ data monitor using Brooke’s API

Stored identified ASQ Data
Possible Extension for other Screening Data
(After the purposed 3-year project)

Future types of screening data may include child-level details of SWYC screenings performed at University of Utah, Intermountain Health Care, and other facilities within the state.
Systems Analysis
Analysis of Systems and Technologies

• The ECU Health Subcommittee reviewed the following:
  • Existing systems and technologies used by the state of Utah;
  • Systems and organization models used by other states and some counties; and
  • Emerging and future systems that may overlap or compliment the proposed system.

Existing Utah Systems and Technologies (in alphabetical order)

- Brookes Publishing’s full product suite
- BTOTS
- CHARM
- cHIE
- DOHMPF
- ECIDS
- EMRs
- HiTrack
- Medical Home Portal
- SAFE
- UDOH Gateway
- USIIS Database
- USIIS-EMR Data Exchange
- USIIS Immunize
- URDC

Other States and Counties

- Alaska
- Kansas
- Michigan
- Orange County, CA
- Vermont

Emerging and future technology

- Data gateway
- DOHMPF data file upload
- Pediatric Patient Summary Portal

Note these lists are not all inclusive, but a sampling of those which come up in discussion most frequently
Brookes Publishing’s Product Suite
For collecting, storing, and managing ASQ online screening data

• Brookes Publishing holds the rights to the ASQ screening tools.
  • All ASQ screenings need to be done using one of their digital or paper products.

• The project team studied their product offerings in the following ways:
  • Through numerous discussions with Brookes Publishing personnel;
  • By analyzing how other states (or large counties) are using their products;
  • By studying their product materials and technical documentation;
  • By studying the technical documentation provided by Brookes Publishing; and
  • Through hands-on experiences with using ASQ screening tools.

• Of all the products, the ASQ Online Enterprise is the best fit.
  • The question of one vs multiple ASQ Online Enterprise accounts is addressed later.
BTOTS
Potential data requestor (user of the shared ASQ screening data)

- BTOTS is a case management system for Earlier Intervention (EI), ages 0-3.
- BTOTS is currently integrated with CHARM as both a data provider and data requestor.
- Children enter the EI through a referral process to Part C. The ASQ screening data is usually shared with Part C when referral for EI are made.
- The team’s investigation determined BTOTS will not benefit from receiving the ASQ screening data from a query through BTOTS systems because most ASQ screenings results will be shared with them when programs refer a child to them.
- Beneficial when used as a child-find tool.
CHARM
Data broker across multiple data providers and data requestors for AQS screening data

• CHARM is an existing data broker for child-health information.
• CHARM’s effort began in 1999 and has been in operation since 2003.
  • Most of the CHARM team remains intact and posses considerable experience with the child-health information data sharing system in Utah.
• CHARM has been enhanced and evolved over to past 2 decades to ensure that its technology meets the ever-changing needs of child-health care.
• CHARM uses a service-oriented architect and arms-length-information-broker approach to complete the following:
  • Match, de-duplicate, and link child identities across data sources;
  • Provide real-time access to child-health data directly from its original data sources;
  • Ensure a high-level of confidentiality and security for child-level screening data; and
  • Support a variety of integration and data access mechanisms.
• CHARM’s mission aligns closely with the goals of the statewide integrated and coordinated ASQ screening data project.
• CHARM is implemented in Java and can run on virtually any operating system.
• UDOH owns the CHARM software.
cHIE

Potential data repository for many data requestors

• The cHIE is a clinical health exchange that collects, de-duplicates, stores, and provides medical records for patients in and around Utah.
  • 1300+ providers
  • 50+ hospital systems

• Unfortunately, the cHIE is currently only allowed to work with data that originates from providers, not from parents.
  • This restriction prevents us from using the cHIE.
  • If an exception can be made in the future for parent provided ASQ screening data to be used, then the cHIE will be a possible channel for making ASQ data available to many providers.

• Also, based on previous experience, integrating with the cHIE could be costly and time consuming.
DOHMP1
Data broker or data transfer system

• DOHMP1 is a data broker with similar functions to CHARM, however, it has very different purposes, many different data sources and different data consumers.

• In the context of ASQ data, DOHMP1 currently supplies de-identified ASQ from one ASQ Enterprise account to ECIDS.

• DOHMP1 does not currently have a medical provider web portal.

• DOHMP1 is not currently integrated with USIIS.

• DOHMP1 is written in C# and uses the .NET platform and therefore needs to run on a Windows server.

• UDOH licenses the DOHMP1 software from a vendor.
ECIDS
Provides de-identified ASQ screening data for end user reports, longitudinal research and data studies

• ECIDS is a data system containing de-identified data to run statewide reports and support researchers in performing longitudinal studies.

• ECIDS is currently receiving de-identified ASQ screening data through DOHMPI from UDOH ASQ’s Online Enterprise account.
EMRs
Potential users of identified ASQ screening data

• Most medical providers in Utah have electronic medical records systems (EMRs).
• There are EMRs from over 90 different vendors in use in Utah and that number will likely grow over time.
• Most EMR can interface with other medical systems to either request data or make real-time queries.
• Providing a standard application programming interface (API) opens the possibility for EMRs to access identified child-level ASQ screening data.
  • A restful Webservice API is recommended.
HiTrack
Potential user of identified ASQ screening data

• HiTrack is Utah’s data system for Early Hearing Detection and Intervention (EHDI).
• HiTrack is currently integrated with CHARM as both a data provider and data requestor.
• After discussions with the EHDI leadership, the team has concluded that there is no need for HiTrack users to access ASQ data at this time.  
  • This decision may be revised in the future, after the proposed 3-year project.
Medical Home Portal
context: potential portal for users to access ASQ data

• The Medical Home Portal is a website that supplies resource information about children and youth with special health care needs to families, medical providers, and caregivers.

• The Medical Home Portal does not collect, store, or provide any child-level individual-specific screening data.

• The Medical Home Portal does not authenticate or authorize users.

• Therefore, the Medical Home Portal is not a feasible way to allow medical providers access to identifiable ASQ screening data.
SAFE
Potential portal for end users to access ASQ screening data and to be a potential ASQ screening data source

• SAFE is a case management system for the Division of Child and Family Services (DCFS).

• Its users would benefit from being able to review ASQ screening data for a child whom they serve, regardless of who or where those screenings were done.

• SAFE could be integrated with CHARM through a simple re-direction link like USIIS Immunize.
  • SAFE would not need to handle any ASQ data or queries directly.

• Currently, DCFS is planning to enter ASQ screening data into their own ASQ Online Enterprise account. They plan to encrypt all identifying information.
  • This may make it difficult to link child identities in their account with identities in other ASQ Enterprise accounts.
UDOH Gateway
Potential portal for users to access ASQ data

• The UDOH Gateway is a data transfer system for automatically moving large amounts of data between information systems, particularly when one of the systems is outside of UDOH.
  • e.g., UDOH is currently being used to move Medicaid histories to the cHIE.
• UDOH Gateway does not de-duplicate the records.
USIIS Database
Potential data storage for ASQ screening data

• USIIS stores identifiable child-level immunization data in an Oracle database.

• This database is currently a functional data source for CHARM.
  • CHARM currently matches child identities in this database with other data sources.

• Current regulations prohibit the USIIS database to store anything but immunization data.

• Therefore, the USIIS will be used in an innovative way to allow end-users to access ASQ screening data through USIIS Immunize.
USIIS-EMR Data Exchange
Data transfer mechanism

• USIIS has a bi-direction data exchange setup with many of the provider EMR systems, which from a technologically perspective could be leveraged to transmit ASQ data to those EMRs.

• However, current regulations prohibit data exchanges outside of storing immunization data.

• Therefore, using the USIIS-EMR Data Exchange will not be used as part of this project.
USIIS Immunize
Portal for end-users to access ASQ screening data

• USIIS Immunize is a web portal used by providers and schools to access immunization data.

• USIIS Immunize is currently integrated with CHARM to make hearing screening and certain birth registry information available to authorized users.

• USIS Immunized will be utilized in the same way as above to share ASQ screening data with end-users.

• The USIIS team plans to extend USIIS Immunize during the 1st year of the project to make ASQ data available to users.

• This exchange will involve redirecting users to a CHARM-supplied webpage, which will in turn request the ASQ data directly from ASQ Enterprise data sources.
UDRC
Potential portal for users to access ASQ screening data

- UDRC is a data system for longitudinal studies.
- The UDRC team would like identified ASQ data so they can perform their own record matching.
- The UDRC only allows its users to see aggregated data.
- The UDRC would like to import the ASQ data just once a year.
Alaska

• Alaska has 17 Enterprise accounts.
• State system fixed cost = $15,450 per year plus variable cost of screenings ($2,840 in 2019) and starter kits.
• The State of Alaska Part C/ILP Office (Division of Senior and Disability Services, DHSS) acts as the Hub with the 16 Infant Learning Programs (ILPs) acting as Enterprises;
  • In 2017, HMG-AK was added as the 17th Enterprise.
• A centralized Hub system such as this has the advantage of the following:
  • Running system-wide aggregate reports,
  • Having a centralized organizing structure, and
  • Potential for coordinated management of the system.
• Current leadership under Part C: “A lead agency should be identified to take the leadership role for oversight of developmental screening efforts in Alaska. It is most appropriate for this leadership to be based within state government, which has the authority to establish policy and regulations. A group of key stakeholders, acting in an oversight capacity, could guide the work, develop and approve a statewide plan, act as liaisons with interested organizations, and champion developmental screening in Alaska. Implementation activity could be contracted out to independent contractors or organizations that have the capacity and skill sets for identified activities.”
Alaska (continued)

- Alaska has no central registry at this time.
- State Enterprise accounts only captures screening data entered into the statewide system and HUD account. Many other entities are conducting developmental screening using tools other than ASQ or using the ASQ and not participating in the statewide online system.

**Recommended restructuring of system:**
- Structuring Enterprises by service types offers the following:
  - Organized by user groups. In this structure, all ILPs could be under one Enterprise with 16 individual programs, one for each ILP.
  - Similarly, medical practices could comprise one Enterprise, with each as an individual program.
  - Early care and learning programs could be in a single Enterprise.
  - Head Start/Early Head Starts could be its own Enterprise with individual programs for each HS/EHS program.
  - Parents as Teachers could be one Enterprise with multiple individual programs, etc.
- There is rich data to be mined in the thousands of child profiles and screening results. However, individuals with the knowledge and skills to analyze and utilize this data do not have access to it. Granting access to Enterprise-level data to a limited number of individuals through data sharing agreements would greatly increase the value of the information currently available in the ASQ online system.
- Alaska's ASQ online system would benefit from consistent pro-active Enterprise account administrators who receive training, remain actively engaged with the programs under an Enterprise account, and maintain regular communication with other Enterprise and Hub administrators.
Kansas

• Kansas has 31 Enterprise Account for each of their local Part C Programs.

• The Part C administrators are being paid a stipend to act as the account administrators for each of the 31 local Part C ASQ Enterprise Accounts. The account administrator duties are being written into their Part C contract.

• All ASQ Enterprise Accounts (the 31 Part-C Enterprises + the KSDE Kindergarten Snapshot Enterprise Account) are connected by a HUB, in which they are able to collect aggregate screening data.

• Once the system was embraced there was initial information sharing through presentations with appropriate groups giving an overview of the system structure and expectations.
  • Conducted initial outreach to all 31 local Part-C programs providing an overview of the structure, stipend, roles and responsibilities of the Part-C program and onboarding new programs into their enterprise system.
  • Developed a FAQ document for Part-C Coordinators that has been helpful in this initial process, which will then work with each Part-C to get their enterprise account set-up and onboarded.
  • Brookes’ services includes ASQ Online questions and supports and will provide TA to account administrators during this process, which includes providing technical assistance, general guidance and resources to Part C administrators for outreach and onboarding to new programs in their community.

• Training in three phases:
  • Initial information sharing,
  • Answering questions, and
  • Account set up and onboarding. Technical assistance and support is provided for outreach and program onboarding.
The OC Children’s Screening Registry is an online database designed to enable primary health care providers and community-based providers to view and/or enter developmental and behavioral screening data and share information on referrals and outcomes. It accommodates four screening tools including the Ages and Stages Questionnaires-Third Edition (ASQ-3), ASQ: Social Emotional-2 (ASQ: SE-2), Parents Evaluation of Developmental Status (PEDS), and Modified Checklist for Autism in Toddler, Revised with Follow-up (M-CHAT R/F).

The intent of the OC Children’s Screening Registry is to communicate screening results between organizations and providers in Orange County, CA, that conduct developmental screening. These types of organizations are not limited to pediatric health care providers, early care and education providers, community-based organizations that conduct developmental screening, service providers, and therapists.

This registry is created and maintained through a collaboration of:
- American Academy of Pediatrics, CA Chapter 4
- CalOptima
- Child Abuse Prevention Center
- CHOC Children’s
- Comfort Connection Family Resource Center
- Family Support Network
- Help Me Grow Orange County
Orange County, CA (continued)

• Collaborators (continued):
  • MOMS Orange County
  • Orange County Department of Education
  • Orange County Head Start, Inc.
  • Orange County Health Care Agency – Maternal
  • Child Health
  • Orange County Social Services Agency
  • Children's Museums
  • Regional Center of Orange County
  • Children and Families Commission of Orange County
  • School Readiness Nurses
  • The Center for Autism & Neurodevelopmental Disorders

• See training for registry: https://www.youtube.com/watch?v=oSyKJcy1ebw
Vermont

• The system uses a single ASQ Online Enterprise account for the Title V grant. It is a systems focused Enterprise account to help the Title V program meet its grant obligations. It does not involve a broad range of stakeholders.

• To date, 2,250 ASQ-3/ASQ:SE screens have been completed by all programs via the HMG ASQ online system. The ASQ Enterprise screens are integrated into VT Health Dept Developmental Screening Registry.
  • VT IT has almost completed this automatic electronic data file transfer process.
  • It is the Registry platform that allows providers to check to view a child’s screening history and avoid duplicate screening by checking ahead of time if a screen has already been completed by a provider.

• Health care providers get reimbursed for screening by Medicaid/PI if they use the screening results done by another (home visitor, childcare provider, etc.) rather than rescreening. This is how VT is trying to reduce screening in silos.

• HMGVT/UW has been key to scaling up and spreading MCH efforts to increase and coordinate developmental screening across providers:
  • HMGVT/UW is managing VT’s ASQ Online Enterprise system,
  • HMGVT/UW is helping to implement widespread use of the ASQ platform across sectors got the Title V grant.

• The Vermont registry is reducing duplicate and unnecessary multiple screens, increasing communication around screening/referral across sectors, and align efforts for system efficiencies/cost effectiveness/ROI.

• VT is working to educate health care providers that screenings done by home visitors/childcare/PreK programs are often more accurate (due to ability to observe the child completing ASQ tasks in play-based environment and strong partnerships with parents) than can usually be done during a 15-minute well-child visit.

• VT has embedded developmental screening into their QRIS system as indication of high-quality child-care program and the Agency of Education partners want all PreK programs to be required to screen using the ASQ online screening tools.
  • Physicians get to bill for screenings. For details also at: https://dvha.vermont.gov/providers/clinical-practice-guidelines/developmental-screening-young)
• Historically, VT has braided federal grants (ELC-RTT, PDG) with philanthropic and some Medicaid-MCH funding and Title V. They rely on Title V for back up.
  • Applying for HRSA ECCS new grant to support HMG sustainability.
  • The approach is to get braided state funding from partners who are mandated to screen to meet Title V national performance measure.
  • VT uses HMG as strategy for obtaining that measure.
  • It is also a key VT priority as part of their State Health Improvement Plan and VT EC Action Plan: https://buildingbrightfutures.org/what-we-do/early-childhood-action-plan-ecap/.
  • VT also views developmental screening holistically to address social determinants of health as early as possible since children’s developmental progress is impacted by toxic stress, poverty, systemic inequities, etc.

• To view a demonstration of VERMONT:
  • https://mail.google.com/mail/u/0/#search/Janet.Kilburn%40vermont.gov?projector=1
Data Gateways

• We considered the possibility of using various data gateways that would allow organizations to upload ASQ screening data to a statewide repository.

• The team concluded that this approach offers no benefit for the following reasons:
  • Utah will have to implement and operate a central repository of ASQ data;
  • Brookes Publishing owns the rights to the ASQ screening tools;
  • Organizations must purchase screening kits;
  • The workflows will require some amount of double data entry or extra steps; and
  • Brookes Publishing offers an online system for parents to complete ASQ screenings, making it unnecessary to build our own data gateway for it.
DOHMPI data file upload

• DOHMPI is in the process of implementing a file upload feature.
• This feature could allow DOHMPI to act like a Data Gateway for ASQ data.
• However, this approach would have all the same draws mentioned for Data Gateways. Therefore, the subcommittee concluded that it offer no benefit to add this, over using the ASQ Online Enterprise system.
Pediatric Patient Summary Portal

• The Pediatric Patient Summary Portal is still in the planning and design phase and will be not available in time for this project.

• Details about the scope and function of the Pediatric Patient Summary are not currently available.
Alternate Plan Analyzed
Alternative Plan Analyzed

- Designed and discussed at length from Aug. 2020 to Apr. 2021 with technical data experts from Brookes, the DOHMPD technical team, the CHARM technical team, USU, and other outside experts.
- CHARM still needs to be involved because of its connection with USIIS, its web portal (CHARM WebIf), and other child-health medical information systems.
- The data-flows between the data sources and medical providers are longer and more complex:
  - Multiple experts strongly recommend that the data flows needs to be as simple as possible, i.e., the data users need to be as close as possible to the original data sources (System and Services Enterprise accounts);
  - This minimizes risk of system failures and security breaches; and
  - It also improves the efficiency of real-time queries.
Conclusions

• The alternate plan involves more organizations as part of the mainstream work.

• The main data flows must go through additional components, which adds:
  • Additional points of failure;
  • More security complexities and introduces more risk of security breaches; and
  • Additional agreements.

• The alternate plan has a longer critical path.
  • Therefore, it will take more time to implement the first use cases.

• Development costs will be higher because more components need to be built and more people need to be hired.

• Long-term maintenance costs will be higher.

• The missions and purposes of CHARM, DOHMP, ECIDS, UDRC, USIIS, and the other child medical-information systems analyzed, should be utilized for their intended purposes to most effectively and efficiently integrate and coordinate identifiable child-level data into medical information systems for this project.
Architectural Design Decisions
Rationale for Separate ASQ Enterprise Accounts

• Data stewardship
  • Systems should retaining stewardship over their own data to increase program accountability and to be able to better align with screening funding requirements.

• Better pathways for long-term sustainability and management
  • Each organization will manage its own programs and each program would manage its own users.
  • A centralized approach would complicate the onboarding and user management issues.
    • With Brooke’s system, an account can contain multiple programs and programs have users, but programs can not be organized into a hierarchy or formed into groups.
  • Cleaner, more manageable boundaries between agencies.

• Better accountability
  • Each organization is directly responsible for the quality and confidentiality of its data in its own ASQ Enterprise account.

• Simplification of certain legal issues
  • Although there may be more signed licenses and agreements, the different kinds of documents is no greater and each license or agreement involves just two parties.
  • With one just one ASQ Enterprise Account, the relationships and therefore the licenses and documents would be more complicated.
Rationale for Separate ASQ Enterprise Accounts (continued)

- ASQ screening data will be made available to the current data-using agencies
  - The proposal includes funding to extend DOHMPI so it can retrieve ASQ screening data from the additional ASQ Enterprise Accounts.

- Existing data in the DOH for non-DOH programs can be easily moved to another ASQ Enterprise Account.
  - For example, the existing HS programs using the DOH account can be easily moved to HS’s own ASQ Enterprise Account.
  - With the DOHMPI enhancement included in the proposal, ECIDS will continue to receive that data.
Rationale for Complimentary use of CHARM and DOHMPI

- Both systems are data brokers, but have distinct domains and purposes:
  - CHARM exchanges identified child-health data in real-time.
  - DOHMPi focuses on making de-identified data available to longitudinal-study systems, like ECIDS.

- Because of their different domains and purposes, each system:
  - Offers a unique value to the project;
  - Ties into different federal sponsoring agencies and funding sources; and
  - Satisfies different requirements and adheres to different constraints.

- For Utah’s integrated and coordinated developmental screening project:
  - CHARM domain, mission and purposes fit to the primary goals of this project, which is to make identified screening data available to those who interact directly with children and their parents in real-time; and
  - With its ability to provide de-identified data to longitudinal-study systems, DOHMPi adds value with respect to the second objective of understanding trends and how programs are impacting the population.
Other Important Considerations

• The data-sharing component of Utah’s integrated and coordinated developmental screening project is broad by design to reach its full potential.

• However, this doesn’t mean the plan is overly ambitious:
  • Most of the software components, like CHARM, already exist;
  • The necessary expertise for all facets of the project are available; and
  • The decentralized or systems centralized approach allows for considerable flexibility in supporting stakeholders during the implementation phases.

• The responsibilities of each organization are consistent with that organization’s mission.

• This plan maintains organizational funding and programmatic boundaries, while increasing coordination, collaboration and alignment within and between organizations to improve child wellbeing and school readiness for Utah’s children.