

Document Type	Program Name
Data Sharing Agreement	CHARM

INTRA-AGENCY CHARM DATA SHARING AGREEMENT
BABY WATCH/EARLY INTERVENTION
Utah Department of Health
Child Health Advanced Records Management system (CHARM)

Data Provider:

Division/Office: Community and Family Health Services
Bureau/Program: Baby Watch/Early Intervention (BW/EI)
Manager/Director: Susan Ord
Address: 44 Medical Drive
Phone: 584-8441

Data Requestors:

Division/Office: Center for Health Data
Bureau/Program: Office of Vital Records and Statistics (OVRs)
Manager/Director: Jeffery Duncan
Address: Cannon Building
Phone: 538-6907

Division/Office: Community and Family Health Services
Bureau/Program: Utah Statewide Immunization Information System (USIIS)
Manager/Director: Nancy Pare
Address: Cannon Building
Phone: 538-6871

Division/Office: Community and Family Health Services
Bureau/Program: Hearing, Speech, and Vision Services (HSVS)
Manager/Director: Richard Harward
Address: 44 Medical Drive
Phone: 584-8215

Division/Office: Community and Family Health Services
Bureau/Program: Newborn Screening (NBS)
Manager/Director: Fay Keune
Address: 44 Medical Drive
Phone: 584-8255

Division/Office: Community and Family Health Services
Bureau/Program: Birth Defects Network (BDN)
Manager/Director: Marcia Feldkamp
Address: 44 Medical Drive
Phone: 257-0566 ext 203

Document Name	Author	Authorized by	Date/Time	Page
BW/EI_DSA	Perfili / Harward	George Delavan	1/16/2008 3:05:00 PM 1/16/2008 3:05 PM	1 of 6

Document Type	Program Name
Data Sharing Agreement	CHARM

I. PURPOSE

The Utah Department of Health (UDOH) has many programs that conduct traditional public health activities such as newborn hearing and metabolic, endocrine, and hematological screening, follow-up for at-risk children, early intervention for children with developmental delays, immunization documentation, birth defects monitoring, and many other population-based preventive and direct health services. Historically, UDOH's information systems have been very de-centralized, resulting in: (1) duplicate demographic information across Participating Programs, and (2) non-existent, or inefficient mechanisms for sharing pertinent data between Participating Programs. The CHARM program is a collaborative effort to share valuable data between UDOH Participating Programs. Each Participating Program maintains its own program data and controls what data is shared and with whom. This document covers general categories of shared data. Individual *Program Interface* documents describe how specific data elements will be shared.

Authorized Use: Requestors may use BW/EI data via CHARM to:

1. Access demographic information.
2. Contact service providers of Participating Programs.
3. Streamline registration and monitoring processes.
4. Reduce repetitive data entry.
5. Reduce duplicate records.
6. Identify adoption status and death.
7. Initiate public health surveys and research projects through administrative rule with written authorization(s).
8. Use health risk and medical information as specified in the Child Health Profile.
9. Use CHARM for official state purposes.

Note: Using BW/EI data for any other purpose must be approved by the BW/EI Program Manager.

II. JUSTIFICATION

Data are essential to the mission and purpose of the UDOH. Data collected by Participating Programs within the UDOH are collected under the authority of the UDOH. The stewardship and use of the data are ultimately the responsibility of the UDOH. In many instances, the missions and purposes of Participating Programs within the UDOH overlap. Sharing data will help the UDOH to accomplish its mission.

The Baby Watch/Early Intervention program provides early identification and developmental services for families of infants and toddler, birth to three, through the Utah Department of Health. BW/EI has public health exemption status under HIPAA (Health Insurance Portability and Accountability Act). However, requirements of the Federal Education Rights and Privacy Act (FERPA) apply to the BW/EI data. Therefore, FERPA guidelines will be followed for sharing BW/EI data with the

Document Name	Author	Authorized by	Date/Time	Page
BW/EI_DSA	Perfili / Harward	George Delavan	1/16/2008 3:05:00 PM 1/16/2008 3:05 PM	2 of 6

Document Type	Program Name
Data Sharing Agreement	CHARM

UDOH and its participating programs. Informed written consent from parents will be obtained. BW/EI data can be used for official purposes at the state and local government levels. The Program Manager/Data Steward of BW/EI has authority to review and approve data sharing requests.

Privacy and Confidentiality: Access to CHARM will only be given to users who have read, understood, and signed a *Confidentiality Agreement*. UDOH employees will use this information only under the conditions of the *Confidentiality Agreement*. If an outside researcher wants access to any of the data available through CHARM, the researcher must submit an application to the Data Rules Policy and Procedures Committee. The researcher must also comply with the rules of the Participating Program supplying the data and will typically only have access to aggregate data (or be approved through appropriate Institutional Review Board process).

Supportive Legislation for Data Sharing: It is imperative that the Participating Programs using BW/EI data have a direct, tangible, and legitimate purpose for access. The purpose must be directly related to public health activities.

Authority for Baby Watch/Early Intervention can be found in the Individuals with Disabilities Education Act of 2004, Part C.

III. DESCRIPTION OF POTENTIALLY SHARABLE DATA

Early Intervention/Baby Watch (EI/BW)

Major Roles and categories of data in BW/EI include:

1. Conduct a full assessment of a child's current health and development status. Data categories include--Child, Referral, and Evaluation.
2. Determine a child's eligibility for services. Data categories include-- EI Qualification.
3. Determine and implement strategies to build on family concerns, priorities, and resources. Data categories include--Family, Individual Family Service Plan, EI Providers.
4. Coordinate services for the child and family among providers, programs and agencies. Data categories include--Individual Family Service Plan, EI Providers, EI Site, EI Organization, and EI Tracking Plan.
5. Provide developmental services such as: occupational therapy, physical therapy, and speech language therapy. Data categories include--Individual Family Service Plan and EI Providers.
6. Support Health Plan data collection and improvement.
7. Provide information to meet federal data reporting requirements.

Document Name	Author	Authorized by	Date/Time	Page
BW/EI_DSA	Perfili / Harward	George Delavan	1/16/2008 3:05:00 PM 1/16/2008 3:05 PM	3 of 6

Document Type	Program Name
Data Sharing Agreement	CHARM

IV. DATA USE INTENTIONS

Office of Vital Records and Statistics. The OVRS intends to use core data BW/EI makes accessible through CHARM for matching purposes to ensure that they have complete and accurate data for legal purposes and for surveillance and monitoring of public health. The Program Director and assigned staff of the OVRS data system will access Participating Program alert(s).

Utah Statewide Immunization Information System. The USIIS intends to use core data BW/EI makes accessible through CHARM for matching purposes to locate infants for follow-up. Users conduct follow-up to ensure that a child's immunizations are current and the immunization history is complete. The Program Manager and assigned staff as well as the registered users will access Participating Program alert(s).

Hearing, Screening, and Vision Services. The HSVS intends to use core data BW/EI makes accessible through CHARM for matching purposes to locate infants for follow-up. HSVS follows up on infants born in Utah who were not screened in a birthing hospital, infants that have failed an initial hearing-screening test, or infants who need further diagnostic testing. The Program Manager and staff of the HSVS Program will access Participating Program alert(s).

Newborn Screening Program. The NSP intends to use core data OVRS makes accessible to CHARM for matching purposes to locate infants for follow up on infants with abnormal screening results, identify deceased infants prior to contacting family members, evaluate major program functions, and complete state and federal statistical reports. The Program Manager and staff of the NSP will access Participating Program alert(s).

Birth Defects Network. The BDN intends to use core data BW/EI makes accessible through CHARM for matching purposes to locate infants for follow-up. BDN conducts follow-up to assist families and their providers in preventing secondary disabilities. Additionally, BDN will use the core data in CHARM to verify residential information. The Program Director and staff of the BDN will access Participating Program alert(s).

*Note: This section can be amended as necessary. All amendments must be shared with and approved by the affected Participating Programs.

V. METHOD OF DATA ACCESS OR TRANSFER

CHARM is a secure, distributed middleware solution that integrates data from Participating Programs. CHARM does not store any program-specific data. Limited demographic data is stored for each child in order to cross reference records and identify duplicate records.

Document Name	Author	Authorized by	Date/Time	Page
BW/EI_DSA	Perfili / Harward	George Delavan	1/16/2008 3:05:00 PM 1/16/20083:05 PM	4 of 6

Document Type	Program Name
Data Sharing Agreement	CHARM

VI. LOCATION OF DATA AND CUSTODIAL RESPONSIBILITY

Each CHARM Participating Program is responsible for the security of its respective data and the prevention of unauthorized use. The CHARM application security specifications are assured by the Utah Information Technology Services (ITS) administrator.

VII. CONFIDENTIALITY

The Participating Programs [entities requesting data] agree to establish appropriate administrative, technical, and physical safeguards to protect the confidentiality of the data and to prevent unauthorized use or access to it. This agreement represents and warrants further that, except as specified in an attachment or except as authorized in writing that the data covered by this agreement shall not be disclosed, released, revealed, shown, sold, rented, leased, loaned, or otherwise made accessible to any other person. Access to the data covered by this agreement shall be limited to the minimum number of individuals necessary to achieve the purpose stated in this agreement and to those individuals on a need-to-know basis. The safeguards established by the Participating Programs [entities requesting data] shall provide a level and scope of security that is not less than the level and scope of security established by the Program Manager or required by federal or state statute/rule/regulation. Guidelines presented in the Model State Vital Statistics Act are applicable and are available from the U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, National Center for Health Statistics, Maryland (DHHS) Publication No. (PHS) 95-11 1 5.

VIII. SIGNATURES

Name: Susan Ord
Baby Watch/Early Intervention Program Manager

(Signature) (Date)

Name: Jeffery Duncan
Director, Office of Vital Records and Statistics

(Signature) (Date)

Name: Nancy Pare
Utah Statewide Immunization Information System Program Manager

(Signature) (Date)

Document Name	Author	Authorized by	Date/Time	Page
BW/EI_DSA	Perfli / Harward	George Delavan	1/16/2008 3:05:00 PM 1/16/20083:05 PM	5 of 6

Document Type	Program Name
Data Sharing Agreement	CHARM

Name: Richard Harward
Hearing, Speech, and Vision Services Program Manager

(Signature) (Date)

Name: Fay Keune
Newborn Screening Program Manager

(Signature) (Date)

Name: Marcia Feldkamp
Director, Birth Defects Network

(Signature) (Date)

Document Name	Author	Authorized by	Date/Time	Page
BW/EI_DSA	Perfili / Harward	George Delavan	1/16/2008 3:05:00 PM 1/16/2008 3:05 PM	6 of 6

**UTAH DEPARTMENT OF HEALTH
CONFIDENTIAL ACCESS AND CONFIDENTIALITY DIRECTIVE
SUPPLEMENT**

This supplement to the Utah Department of Health Confidential Access and Confidentiality Directive contains additional terms of records handling required of any person or entity accessing, using, or disclosing personally identifiable information classified and governed by FERPA and IDEA.

This supplement contains provisions required under the Family Educational Rights and Privacy Act of 1974 (FERPA) Pub. L. 93-380, ' 513, 88 Stat. 571 (20 U.S.C. ' 1232g) (Aug. 21, 1974); and the Individuals with Disabilities Education Act (IDEA) Pub. L. 91-230, as added Pub. L. 105-17, ' 101, 111 Stat. 37 (20 U.S.C. ' ' 1400 et seq.) (June 4, 1997).

INSTRUCTIONS:

Each employee, other public entity, or private contractor shall read and initial each of the provisions of this supplement to the directive acknowledging that each provision has been reviewed and discussed with his or her supervisor.

SUPPLEMENTAL DIRECTIVE:

1. _____ The information collected and used by the Baby Watch/Early Intervention Program (BW/EIP), Utah Department of Health, that is to be exchanged among CHARM participants, is subject to federal law requiring informed consent by the child=s parent.
2. _____ You may not disclose any confidential information obtained via CHARM from BW/EIP for any purpose other than what your program is designed to do unless authorized by law or a written consent is obtained from the parent.
3. _____ Informed consent obtained in writing must fully inform the parent of the records to be disclosed, the purpose of the disclosure, and to whom the disclosure is made. Consent has been obtained for use in the CHARM program and your use and further disclosure is limited by the terms of the agreements creating the sharing relationships among CHARM participants as well as the confidentiality directive.
4. _____ Your access, use, disclosure, and destruction of the information shared by BW/EIP is subject to the protections of FERPA and IDEA requiring confidentiality at all stages.