

Oregon

Project title: FamilyNet Data System

Organization responsible: Department of Human Services, Health Services, Office of Family Health

Service coverage area: State of Oregon

Annual birth cohort: Approximately 46,000

Project scope and goals

FamilyNet is a health data system under development by the Oregon Department of Human Services (DHS) to integrate public health programs and coordinate services for children and families on the local agency level.

FamilyNet will help public and private providers screen, assess, and coordinate services to children and families; monitor risks, conditions, services, and outcomes over time; and feed a state-level data warehouse for epidemiology, program evaluation, decision support, and research. This system will support coordination of services and evaluation of the service delivery system while ensuring individual and family confidentiality and data security. The Client Master module contains demographics and contact information (addresses, family links, telephone numbers, guardian's name) and links the other modules to each other. A module for the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) and the Immunization Record Information System (IRIS) for public-sector immunizations has been in use throughout Oregon since 2003.

FamilyNet goals include:

- avoiding redundant data entry by collecting data shared among programs only once.
- providing timely access to data for state and local health departments and their close partners.
- increasing accountability for state and federal program conditions, including program and fiscal assurances.
- reducing fragmentation of data and health care services available to the public by providing a method to coordinate services among health and social service programs.

Current development includes enhancing the WIC module, providing IRIS immunization status (forecasts) for WIC clients directly from IRIS, and completing a project to exchange data between the Oregon Immunization ALERT Registry and IRIS. Most immunizations in Oregon are given in the private sector. Linking ALERT data with other FamilyNet data would give public and private health-care providers a complete picture of the immunization status of their patients.

A Family & Child Module (FCM) is in development to support local services to pregnant women, infants, children, and their families. The first step in development, completed in 2004, was to link newborn dried blood spot (metabolic) and hearing screening data with birth certificate data and use the linked data for Early Hearing Detection and Intervention, one of the public health programs supported by the FCM. The next step will be to integrate the newborn identifying and demographic data into the FamilyNet Client Master and populate the FCM database with newborn screening program and birth certificate information about infants referred into an FCM program or needing follow-up on population-based screening.

When the FCM is completed for the seven participating programs, local public health and community-based programs will use the FCM for identification, assessment, and service coordination across programs; case management within programs; and referrals to and from programs and private sector providers. In addition to the goal of improving perinatal and child health, these programs seek to mitigate mental health, substance use, and other psycho-social risks.

The next FamilyNet goal is to develop a data warehouse that will give DHS and partners aggregate, de-identified data for state-level assessment, policy development, and assurance.

Funding

The USDA provided start-up funding, which represents about 75 percent of FamilyNet's \$15 million spent or budgeted to date. Other significant sources include CDC, HRSA (Medicaid and MCHB), and Oregon State General Funds.

History

FamilyNet has been in development since the mid-1990's. While development of the WIC and Immunization modules was well underway, development of a family and child service coordination module began in 2000. The rationale behind FamilyNet is to create a single, cumulative record for each client by tying together module-level records via the Client Master.

The Oregon's Children's Plan is a 2001 legislative mandate to provide voluntary screening for all pregnant women and newborns for health and psycho-social risks; to coordinate screening, assessment, referral, and services for children and families in each county; and to ensure that necessary services are available throughout the state to families who have agreed to participate.

The Oregon's Children's Plan legislation expanded data system integration beyond the FamilyNet health services model at a time when federal legislation and funding was pushing for similar expansion of service and system integration. As a result, FamilyNet is moving into an environment of integration within an Oregon Public Health Information Network.

Executive leadership and organizational endorsements

The executive sponsors for FamilyNet are Katherine Bradley, Oregon's Title V Director and Administrator of the Office of Family Health (OFH) in DHS, and Lorraine Duncan, Immunization Program Manager in OFH, DHS. Development partners participate in all phases of system design and implementation. Partners in development of the Family & Child Module of FamilyNet include the Oregon Department of Education, the Oregon Commission on Children and Families, the Child Development and Rehabilitation Center at the Oregon Health Sciences University, community programs, and the Conference of Local Health Officials.

Independent local health departments have a strong voice with each other and with the DHS Health Services through the Conference of Local Health Officials and its direct participation in FamilyNet development. FamilyNet is governed by a Steering Committee headed by the executive sponsors and FamilyNet's Information Technology (IT) project manager. A core team steers and develops each FamilyNet module. Each team includes program and IT project managers, program coordinators, research analysts, database analysts, and developers. The FamilyNet Steering Committee delegates a FamilyNet Users' Group to handle day-to-day interaction among modules and guide general system and Client Master module maintenance, modification, and support.

External endorsements

The Family & Child Module and ALERT registry are both supported by public-private partnerships. The EHDI Steering Committee and the Genetics Planning Steering Committee support and advise the FamilyNet Steering Committee and the FamilyNet Family & Child Module development.

Significant challenges

- 1) Identify all existing data sources and potential linkages to create an integrated public health data system that encompasses electronic medical record systems.
- 2) Work collaboratively with other state agencies to link social, health, and educational service data from separate and disparate sources into the FamilyNet interactive application system and data warehouse, and ensure patient confidentiality, which is often unique for each source/agency.
- 3) Focus on incremental progress, expanding from a solid foundation, and identify the many partners needed at each phase, to develop and maintain an integrated public health data system. Maintain a focus on the ultimate goals: reduce service fragmentation and gaps in health care and health-related services; provide a solid information base for policy development; and expand the knowledge base of public health informatics and public health program interventions.

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