



NATIONAL CENTER FOR EASE OF USE
OF COMMUNITY-BASED SERVICES

Case Studies

Exemplary Programs Making Services Easier to Use

Medical Home Portal

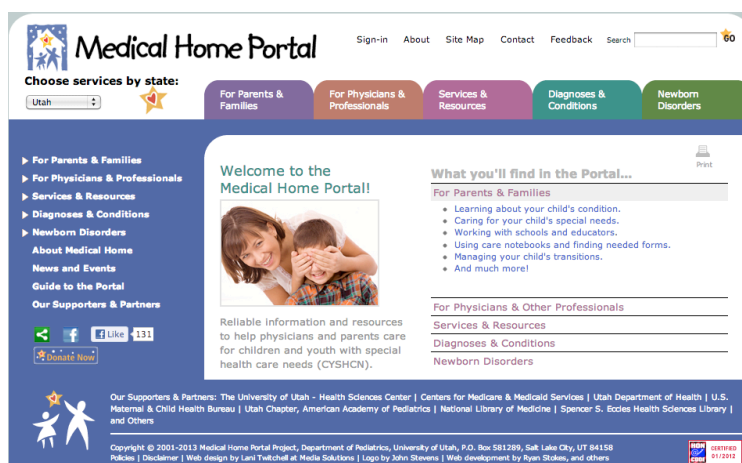
The Medical Home Portal is an online database that provides information for both clinicians and families who care for children and youth with special health care needs (CYSHCN). The Portal also serves as a way for families to learn more about the availability of local services and resources for CYSHCN in Utah, Idaho, and New Mexico (and more states in the future).

Description

The Medical Home Portal was developed in 2001 by a team led by Dr. Chuck Norlin, an expert on medical home and children and youth with special health care needs and a Professor of Pediatrics at the University of Utah. With a grant awarded by the National Library of Medicine to the University's Department of Pediatrics, Dr. Norlin and his colleagues researched and programmed the website to serve as a central source for information on best practices and local resources for families with CYSHCN. As the Medical Home Portal has increased in popularity, it has expanded beyond its home base in Utah to include information about services in Idaho and New Mexico. The Portal is currently funded by a grant from the Centers for Medicare and Medicaid Services and is frequently revised to reflect up-to-date information on both resources and best practices.

Highlights

- Contains over:
 - 500 pages of **content and resources**
 - 3800 links to other **reliable and valuable web sites** or downloadable information
 - 2400 **citations of scientific and other expert literature** to provide users with the evidence behind recommendations and links to explore topics in greater depth
 - 2800 Utah and 2400 Idaho services for CSHCN and their families¹
- **Continuously updates** information and resources based on collaborations with:
 - Local 2-1-1 agencies, which provide information about and referral to human services organizations
 - Parents of children and youth with special health care needs through groups like Utah Family Voices



¹ <http://www.medicalhomeportal.org/about-portal>

- An advisory committee of medical professionals and other stakeholders organized through the Utah Department of Health
- Offers **extensive information** for physicians and other medical professionals on:
 - Coordinating care
 - Screening and prevention
 - Medical technology
- Provides a **comprehensive** and **searchable database** of:
 - The most recent information about chronic conditions including definitions, prevalence, prognosis, impacts on daily life, and genetics, and a separate section on newborn disorders
 - Contact information for local non-profit and professional services that can assist families with children with special health care needs
 - Links to current research studies on chronic conditions being conducted across the country
 - Published articles by experts in the CYSHCN field
- Focuses on **patient-education** and **empowering families** to care for CYSHCN
 - Provides examples of forms, scales, and charts used by physicians when diagnosing and treating certain conditions
 - Answers to FAQs about designing a “medical home”
 - An increasing amount of content on the website will be available in Spanish
- Archived **newsletters** distributed by the Utah Collaborative Medical Home Project

“The purpose of the Medical Home Portal is to provide a one-stop shop for families and for clinicians who are caring for kids with special health care needs.”

-- Chuck Norlin, MD, Director, Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ); Medical Director, Children’s Healthcare Improvement Collaboration (CHIC); Professor, Department of Pediatrics, University of Utah School of Medicine

“We try to provide information to make learning about services easier.”

-- Dr. Chuck Norlin

How the Medical Home Portal is Making Services Easier to Use

One of the greatest assets of the Medical Home Portal is that it brings together both families and clinicians who are focused on caring for children and youth with special health care needs. By providing a centralized database of information about various chronic conditions, the Portal allows for increased understanding and better care coordination between physicians and families.

Dr. Norlin has received extensive positive feedback from families about how the Portal has helped them research local services and providers that are available for their children. Because this information can change so rapidly and is not always easily accessible—especially in rural areas—the Portal is an invaluable resource for families who might not otherwise know about their options. It also makes it easier for primary care physicians in more remote areas to educate themselves on CSYHCN, which is even more important in cases where sub-specialists are not available.

Based on its success in Utah and increasing popularity in Idaho, and New Mexico, the Medical Home Portal is positioned to continue to expand to other states with additional grant support. Families and physicians across the country benefit from access to such a vast array and depth of knowledge about uncommon and challenging conditions. Collaboration and information-sharing is the foundation upon which strong communities of professionals and families can grow and the Medical Home Portal offers just that!

For more on the Medical Home Portal, please visit www.medicalhomeportal.org