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The Medical Home Portal (medicalhomeportal.org) aims to be a shared resource, providing the information needed by primary care clinicians, care coordinators, families, and others to improve care and outcomes and advocate for children and youth with chronic health conditions and/or disabilities.

Over 30% of children have at least one chronic condition, 13-24% meet criteria as children and youth with special health care needs^{1,2} (CYSHCN), and 23% of U.S. households include at least one CYSHCN.³ Because many of CYSHCN's diagnoses are uncommon or rare,⁴ primary care clinicians may know little about those conditions and are likely to have few patients affected by them. Parents often struggle to find and understand reliable information about those conditions and about managing the myriad associated challenges. Often, communities have numerous valuable services and resources to help these children and their families but clinicians and parents may be unaware of them or have difficulty accessing them.

Sharing information about these conditions and their management and about local services and resources can enhance collaboration among clinicians, their teams, and families to improve health-related, educational, and social outcomes for CYSHCN. To these ends, the Medical Home Portal offers:

- Detailed information and guidelines for primary care clinicians on the care and management of 60 chronic conditions and on how to respond to a positive test for any of 44 disorders commonly included in newborn screening programs
- Information to guide parents in raising a child with a chronic condition or special needs, managing their care, caring also for themselves and balancing priorities within the family, working with health professionals, understanding key laws and school-based services, planning for transitions, accessing resources, and advocating for their child
- Information for clinicians and care coordinators on implementing the medical home model, partnering with parents, coordinating care, screening and prevention, using medical technologies, working with schools, writing letters of medical necessity, supporting transitions, etc.
- Information about local professional and community services/resources for CYSHCN and their families that is searchable, browseable by category, and linked to from within the Portal's content

The Portal hosts information about local service providers in Utah, Nevada, New Mexico, Ohio, and Rhode Island, each with a state-specific URL (e.g., <http://ut.medicalhomeportal.org/>). In each state, we partner with programs that maintain such information to help share it with Portal users. Those organizations include state health departments and Title V agencies, Family-to-Family Health Information Centers, academic centers, child/family advocacy organizations, professional organizations, and information and referral services such as 2-1-1 and Help Me Grow.

The Medical Home Portal is a project of the University of Utah, in collaboration with the Utah Department of Health and Human Services (UDHHS). It was launched in 2001 and has been expanding its content, resources, features, and state partners ever since – providing a one-stop-shop for information and resources related to CYSHCN and their families. The Portal offers a feature to create lists of service providers that can be saved, edited, and shared. The Portal's content can be accessed directly from electronic health records via “infobuttons”. We are eager to partner with other states and organizations that share the desire to improve care and outcomes for children with chronic conditions and the well-being of their families.

¹ McPherson M, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102:137-40.

² childhealthdata.org, *Explore the Data > NSCH Interactive Data Query (2016-2018) > All States > Indicator 1.11*

³ N-CSHCN Chartbook 2009-2010 (mchb.hrsa.gov/cshcn0910/population/pages/pc/pcih.html)

⁴ see medicalhomeportal.org/diagnoses-and-conditions/diagnosis-prevalence-list