

# RI MEDICAL HOME PORTAL BUILDING CAPACITY FOR COMPREHENSIVE PRIMARY CARE

---

November 1, 2018

Colleen Polselli

Kathleen Kuiper

Tammy Russo



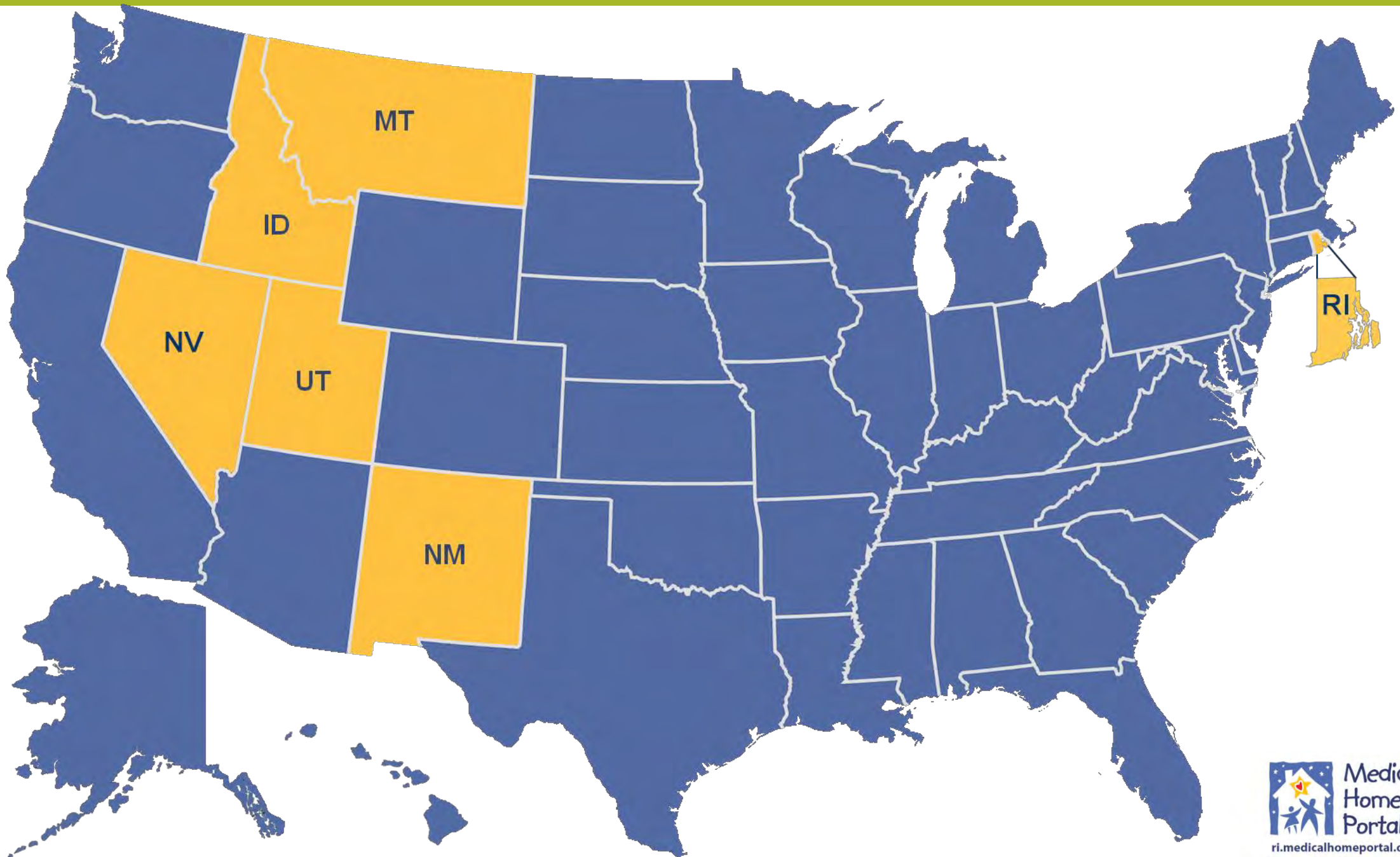
Medical  
Home  
Portal

[ri.medicalhomeportal.org](http://ri.medicalhomeportal.org)



# WHEN FAMILIES NEED HELP

---



# The Medical Home Portal

**The Portal's Vision:** All children and youth with special health care needs (CYSHCN) and their families achieve the best possible outcomes for their health, well-being, and success

**The Portal's Mission:** To assist and support professionals and families in working together (the Medical Home model) to care and advocate for CYSHCN by providing reliable and useful information about their conditions and caring for them and knowledge of valuable local and national services and resources

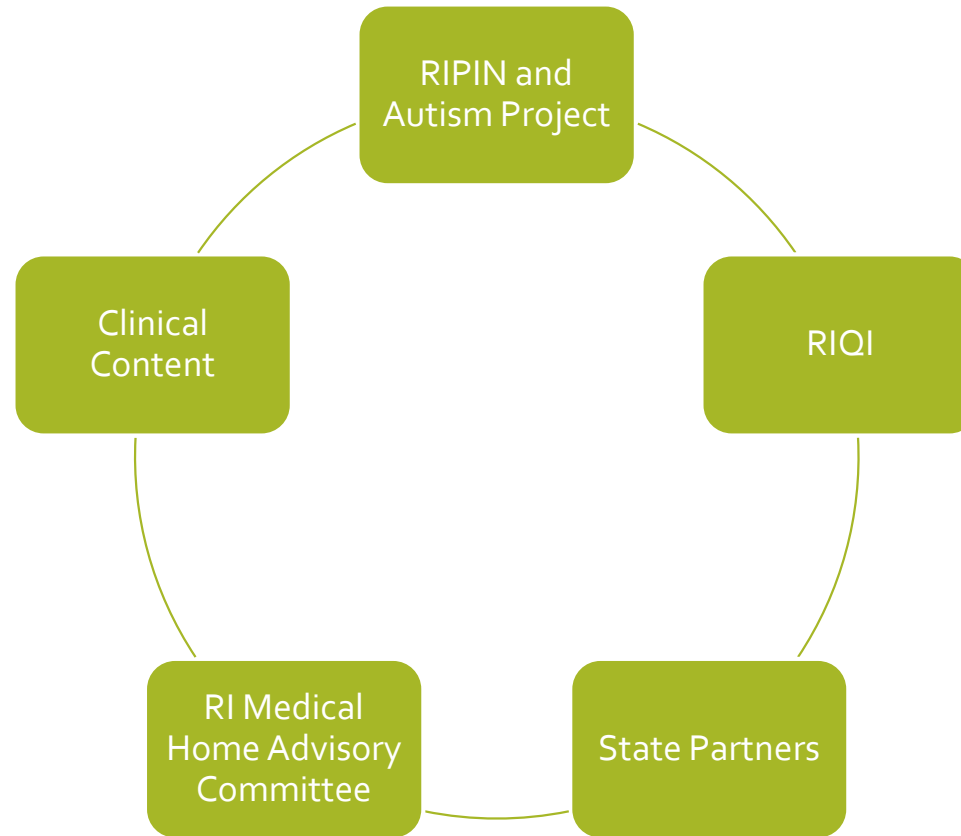
**The Portal's Long-Range Goal:** To improve outcomes for CYSHCN and their families by enhancing the availability and quality of healthcare, related services, and coordination of care



# Medical Home Portal Sections

- RI Medical Home Portal home page
- Diagnoses and Conditions
- Newborn Screenings
- Parent and Families
- Physicians
- Directory and customized lists
- Resources

# Content Connections



# RI Medical Home Portal Website and Video Links

- [https://www.youtube.com/playlist?list=PLGPZBtAtWIIVrJCq1sjvEBZj1w\\_qTgTNO](https://www.youtube.com/playlist?list=PLGPZBtAtWIIVrJCq1sjvEBZj1w_qTgTNO)



# Diagnoses and Conditions Modules

- Diagnoses Codes
- Pearls and Alerts
- Systems
- Detailed FAQs
- High Quality Information
- Informs practice
- Not just for Providers



- Description
- Resources
- Frequently Asked Questions
- Related Issues
- Treatment & Management
- Authors
- Clinical Assessment
- Services for Patients & Families
- Bibliography

The [Diagnosis Prevalence List \(Diagnosis Module\)](#) uses published prevalence rates to estimate the number of children you might expect in your practice with each of many diagnoses. Though written for primary care clinicians, these modules offer a wealth of information for other professionals and care givers, including parents of children with these special healthcare needs.

If you can't find the diagnosis or condition you're looking for below, see our [Modules in Revision/Development \(Diagnosis Module\)](#) page.

## A

Angelman Syndrome  
Anxiety Disorders  
Arginase Deficiency  
Asthma  
Attention Deficit Hyperactivity Disorder (ADHD)  
Autism Spectrum Disorder

## B

Biotinidase Deficiency

## C

Celiac Disease  
Cerebral Palsy  
Childhood Absence Epilepsy  
Childhood Obesity  
Cornelia de Lange Syndrome

## D

Depression  
Down Syndrome  
Duchenne and Becker Muscular Dystrophy

## F

Fabry Disease  
Foster Care

## H

Headache (Migraine & Chronic)  
Hearing Loss and Deafness  
Homocystinuria

## I

Infantile Spasms  
Inflammatory Bowel Disease  
Intellectual Disability

## L

LCHADD/TFP Deficiency  
Leukodystrophies

## M

MCADD  
Maple Syrup Urine Disease (MSUD)  
Mucopolysaccharidosis Type I  
Myotonic Muscular Dystrophy Type 1

## N

Neurofibromatosis Type 1

## P

PKU and Pterin Defects  
Prader-Willi Syndrome  
Premature Infant Follow-Up

## R

Rett Syndrome

## S

Seizures/Epilepsy  
Spina Bifida  
Spinal Cord Injury  
Spinal Muscular Atrophy  
Substance Abuse

## T

Tourette Syndrome  
Traumatic Brain Injury  
Tuberous Sclerosis Complex (TSC)  
Turner Syndrome  
Tyrosinemia Type 1

## V

VLCADD

## X

XXY (Klinefelter) Syndrome

## #

22q11.2 Deletion Syndrome

# Newborn Disorders

- RI Newborns are screened for 30 disorders including hearing loss.
- Quick orienting information for primary care providers
- What next....



# Parents and Families

- Largest section!
- Before/after Diagnoses
- Diagnoses FAQ's
- Care Notebook
- How to take care of yourself



# Physicians and Providers

The screenshot shows the Medical Home Portal website. At the top left is the logo with the text "Medical Home Portal". To its right is a search bar with "Google Custom Search" and a location dropdown set to "Utah". Further right is a "Select Language" dropdown. Below this is a dark blue navigation bar with the tagline "Caring and Advocating for Children and Youth" and buttons for "Diagnoses & Conditions", "Newborn Disorders", "For Parents & Families", "For Physicians & Professionals" (which is selected), "Services Directory", and "Other Resources".

The breadcrumb trail reads: Home > For Physicians & Professionals > Building a Medical Home. To the right of the breadcrumb is a "My Guest List" button with a star icon. Below the breadcrumb are icons for "Print", "Share", and "Get Help".

The main content area is titled "Building a Medical Home" under the "For Physicians & Professionals" section. On the left is a sidebar menu with the following items: Overview, Building a Medical Home (expanded), Overview (selected), About Children and Youth with Special Health Care Needs (CYSHCN), Care Coordination, Optimal Coding, Care Coordination in Portal Partner States, Common Issues for CYSHCN, Education & Schools, Feeding & Nutrition, Health Supervision Guidelines, Medical Technology, Screening and Prevention, and Transition Issues.

The main text under "Building a Medical Home" reads: "Building a Medical Home usually means adding on to the foundation of an existing primary care practice. Many of the components will already be part of your practice – becoming a Medical Home then involves reinforcing the infrastructure, enhancing skills, focusing on office systems and improving quality, and integrating partnerships with families and collaborations with other healthcare providers."

The second paragraph reads: "Though the term 'medical home' has been used in pediatrics for over 40 years, the concept evolved in the last 15-20 years to emphasize the comprehensive care, coordination of services, accessing resources, and partnering with families of children and youth with special health care needs (CYSHCN). More recently, adult-oriented specialists have embraced medical home as an ideal model of care, particularly for adults with chronic conditions (see the Joint Principles of the Patient-Centered Medical Home [JGIM] 37 KB). With this expanded view, employers, government agencies and legislators, some insurers, and many others have recognized the potential benefits of a broad implementation of the model. As of the end of 2008, over 40 states have some form of legislation to support or mandate 'medical home,' usually as part of a larger attempt at health care reform and often focused on care provided to Medicaid recipients. Numerous pilot or demonstration projects are underway to test the value of medical home and to learn how best to implement it. There is considerable optimism that these will lead to changes in compensation for primary care that will support the added infrastructure and services that are needed to build and sustain medical homes."

The third paragraph reads: "A precise definition of a medical home has yet to evolve, but a number of organizations and legislatures have provided definitions for their own use. A 'definition' that is being increasingly adopted is framed by an

On the right side of the page is a green box titled "Related Links" with two sections: "Within the Portal" containing links for "About Medical Home", "Newsletters & Conference Calls", and "External links" containing links for "National Center for Medical Home Implementation", "Center for Medical Home Improvement", "Digital Navigator", "Building your Medical Home: An Introduction to Pediatric Primary Care Transformation (AAP)", "Patient-Centered Primary Care Collaborative", "Patient-Centered Medical Home Intro (Video)", "Medical Home Training and Education (AAP)", and "Genetics in Primary Care Institute (AAP)".

# Rhode Island Service Directory

- 725 Service Providers-includes Pediatric Specialists
- Pediatric Specialists initially from Rhode Island Quality Institute
- Content by Family Voices and Autism Project
- Updated

# HOW TO USE MHP TO HELP HIGH RISK PATIENTS?

---

# Case Study #1



- *7 years old*
- *ADHD*
- *Multiple Accidents*
- *Trouble.... everywhere*

# ADHD

## Parent Section

- Treatment and Medicine Guide
- Tools and Treatments
- Children's Books: including the Percy Jackson Series
- Link to Educators' Guide to ADHD
- <https://ri.medicalhomeportal.org/living-with-child/diagnoses-and-conditions---faqs/attention-deficit-hyperactivity-disorder>

## Diagnoses and Conditions

- Issues related to ADHD
  - Coordination disorders
  - Specific Learning Disabilities link
  - Contains additional resources Understood.org
- <https://www.understood.org/en>
- Assessment scales and follow up in English and Spanish





## Case Study #2

- 3 years old
- Cerebral Palsy
- Moved from out of state
- Transitioning to School System from Early Intervention
- Missing vaccinations

# Case Study #3

- Age 10
- Asthma and Anxiety
- Often in Nurses Office at School
- Frequently Absent



# Letters of Medical Necessity

- Most popular page on entire site
- If treatment is denied , how to frame request
- Important details for requesting physician to include
- Samples

# Case Study #3

- 17 Years Old
- Downs Syndrome
- Very Social
- Would like to have a job
- Difficulty Coordinating Services



# Care Notebook

- See Examples



**KNOW A  
GREAT  
RESOURCE....  
PLEASE  
SHARE!**

---

# Suggest a Provider



Rhode Island  [Select Language](#)

[Diagnoses & Conditions](#) [Newborn Disorders](#) [Caring and Advocating for Children and Youth](#)  
[For Parents & Families](#) [For Physicians & Professionals](#) [RI Services Directory](#) [Other Resources](#)

Home > Services Directory

[Print](#) [Share](#) [Get Help in Rhode Island](#)

## Services Directory

Browse our services listings by category or search by keyword or name. Our database includes services offered by non-profit organizations and a growing number of private, professional services. To create or access your own lists of local service providers that can be shared with others, printed, copied, and modified, please first sign in or register.

### Services Search

Term:

Service Category:

City:

[Suggest a New Provider](#)

# Suggest an Edit



Rhode Island

Google Custom Search

Select Language

Diagnoses & Conditions

Newborn Disorders

Caring and Advocating for Children and Youth

For Parents & Families

For Physicians & Professionals

RI Services Directory

Other Resources

Home > Services Directory > Foster Forward

Print Share Get Help in Rhode Island

## Foster Forward

Foster Forward...

Suggest an Edit

Address: 55 South Brow Street Foster Care  
East Providence, RI 02914

Phone: 401-438-3900

URL: <https://www.fosterforward.net/>

### Services Provided:

Programs for Foster Parents :  
Foster Parent Mentor Program  
Foster Parent Support Groups  
Foster Parent Support Line 401-438-3900 ext 101 After hours call 800.655.7787

Programs for youth and young adults that were in DCYF care  
ASPIRE Initiative- 14-24 financial education and assistance setting goals and saving money  
YESS aftercare program ( Youth Establishing Self-Sufficiency) ages 18-21 who are closed to the states family court and DCYF.  
A time limited program that provides assistance in locating safe and affordable housing, enrolling in an educational program and identifying employment.





# Quality Improvement



# TOP ~~TEN~~ *Eleven*

- Access anywhere there is internet
- Responsive technology - can be viewed on smart phones or tablets
- Google translate
- YouTube Videos - how to use
- High Quality resources and links
- 52 Learning Modules
- Largest section is for Parents!
- Care notebook adaptable -in Spanish and fillable formats!
- Rhode Island Directory with Customizable Lists - can be shared
- Pediatric Specialists

# COMMENTS OR SCHEDULE A DEMONSTRATION

---

**KATHY KUIPER** **KUIPER@RIPIN.ORG**  
**TAMMY RUSSO** **RUSSO@RIPIN.ORG**