A Medical Home for CYSHCN

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Disclosure*

I have no relevant financial relationships with commercial interests.

* If you see this……you can answer a question!

CYSHCN – Who Are They?

- As defined by the MCHB, *CYSHCN have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or an amount beyond that required by children generally. (1998)*

- Although composing 19% of children in the US, CYSHCN account for 80% of pediatric health care expenses.

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Examples of CYSHCN:

- Asthma
- ADHD
- Autism
- Cerebral Palsy
- Chronic Kidney Disease
- Congenital Heart Disease
- Cystic Fibrosis
- Mental Health Issues
- Down syndrome
- Epilepsy
- Muscular Dystrophy
- Sickle Cell Disease
- Spina Bifida
- Type I Diabetes
- Genetic Disorders

2016 National Survey of Children's Health

http://childhealthdata.org/

- ~14.2 million children ages 0-17 years in the US (19.4%) have special health care needs.
  - 5 million youth in the US ages 12-17 years old (transition age) have a special health care need.
  - *youth with a medical home are almost 2 times more likely to receive services to support their transition to adulthood*
  - *17% of CYSHCN of transition age met the overall transition measure for the survey*
    - *A greater proportion of YSHCN who received care coordination and a written plan met the criteria for the overall transition measure*

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Medical Home History

- 1967: Introduced by the American Academy of Pediatrics (AAP)
- 1992: AAP publishes a policy statement defining the medical home
- 2002: AAP Policy Statement on Medical Home Initiatives for Children with Special Needs
- 2007: Joint Principles of the Patient-Centered Medical Home are published by the AAFP, ACP, AOA, AAP.

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AAP working with Maternal & Child Health Bureau – 15 years of ensuring CYSHCN have access to a medical home.

- Medicalhomeinfo.aap.org:
  - *National resource center for Patient/Family-centered medical home*
  - For families and caregivers
  - For Practices
  - State Initiatives
  - Promising Practices

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Advancing Systems of Services for CYSHCN Network: AAP + Catalyst Center + Got Transition

- The goal of the network is to engage **90 percent or more** of state Maternal and Child Health Title V / CYSHCN programs in technical assistance, training, education, and partnership building activities designed to demonstrate improvement in one or more of the following areas:
    - coordinated, ongoing comprehensive care within a medical home for CYSHCN
    - youth with special health care needs receive the services necessary to make transitions to adult health care
    - adequate private and/or public insurance to pay for needed services for families of CYSHCN

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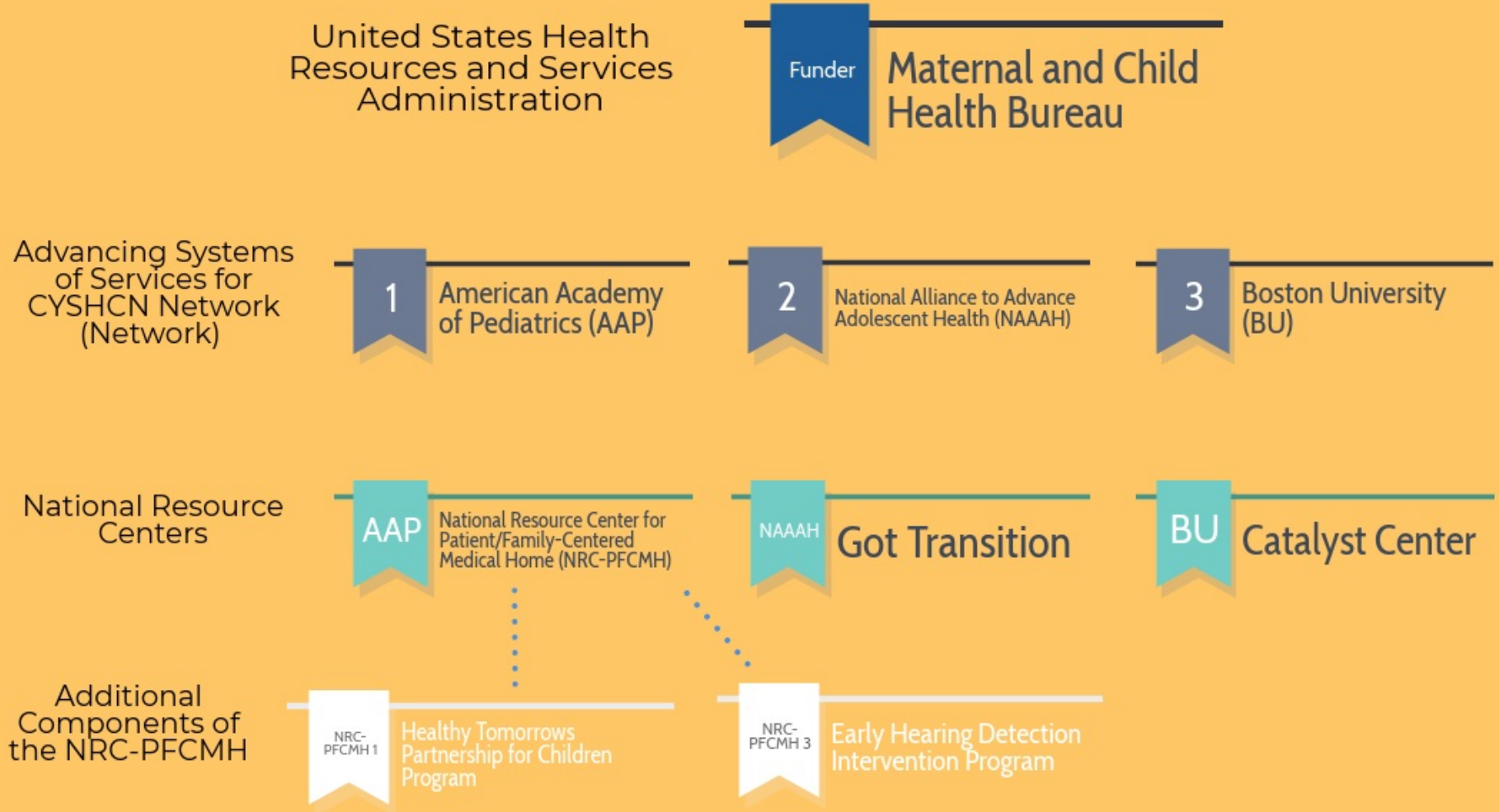
ADVANCING SYSTEMS OF SERVICES FOR CYSHCN NETWORK ORGANIZATIONAL CHART



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US-DHHS: Healthy People 2020

Healthy People 2020 goal:

Increasing the proportion of children, including those with special health-care needs, who have access to a medical home.

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Features of the Patient-Centered Medical Home (PCMH)*

- Patient-centered (family-centered)
- Comprehensive
- Coordinated
- Accessible
- Committed to Quality and Safety
- *Compassionate*
- *Culturally Effective*

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COLLABORATIVE

Why the Medical Home Works: A Framework

Feature	Definition	Sample Strategies
Patient-Centered	**Supports patients and families** to manage & organize their care and participate as **fully informed partners** in health system transformation at the **practice, community, & policy** levels	• **Dedicated staff help patients navigate system** and create care plans • **Focus on strong, trusting relationships** with physicians & care team, open communication about decisions and health status • Compassionate and culturally sensitive care
Comprehensive	**A team of care providers** is wholly accountable for patient's **physical and mental health** care needs – includes prevention and wellness, acute care, chronic care	• Care team focuses on '**whole person**' and **population health** • Primary care could **co-locate** with behavioral or oral health, vision, OB/GYN, and pharmacy • Special attention is paid to **chronic disease** and complex patients
Coordinated	Ensures care is **organized across all elements** of broader health care system, including specialty care, hospitals, home health care, community services, & public health	• Care is **documented and communicated** effectively across providers and institutions, including patients, primary care, specialists, hospitals, home health, etc. • Communication and connectedness is enhanced by **health information technology**
Accessible	Delivers **consumer-friendly services** with shorter wait-times, extended hours, 24/7 electronic or telephone access, and strong communication through health IT innovations	• More efficient appointment systems offer **same-day or 24/7 access** to care team • Use of **e-communications and telemedicine** provide alternatives for face-to-face visits and allow for after hours care
Committed to quality and safety	Demonstrates commitment to quality improvement through use of **health IT** and other tools to ensure patients and families make informed decisions	• **EHRs, clinical decision support, medication management** improve treatment & diagnosis. • Clinicians/staff monitor **quality improvement goals** and use data to track populations and their quality and cost outcomes

Potential Impacts

Patients are more likely to seek the right care, in the right place, and at the right time

Patients are less likely to seek care from the emergency room or hospital, and delay or leave conditions untreated

Providers are less likely to order duplicate tests, labs, or procedures

Better management of chronic diseases and other illness improves health outcomes

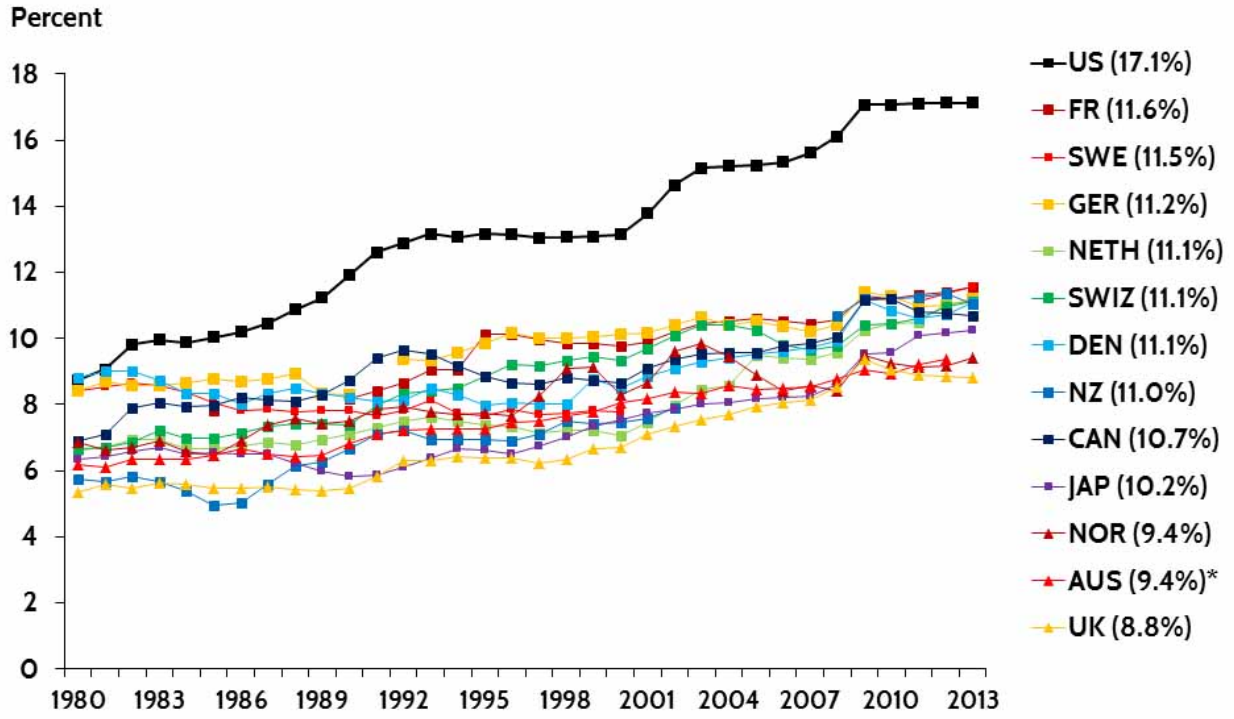
Focus on wellness and prevention reduces incidence / severity of chronic disease and illness

Cost savings result from:
- Appropriate use of medicine
- Fewer avoidable ER visits, hospitalizations, & readmissions

Why have a PCMH?

- US Health Care System has become more fragmented, inefficient, and expensive.
- Here are the categories of waste:
  - Failures of Care Delivery
  - Failures of Care Coordination
  - Overtreatment (overuse of technology is in this one)
  - Administrative Complexity
  - Pricing Failures (higher prices are in this one)
  - Fraud and Abuse

Exhibit 1. Health Care Spending as a Percentage of GDP, 1980–2013



* 2012.
Notes: GDP refers to gross domestic product. Dutch and Swiss data are for current spending only, and exclude spending on capital formation of health care providers.
Source: OECD Health Data 2015.

How does a practice become a PCMH?

- Start small – Assess the practice
- Team approach
- Build in stages – Using Quality Improvement
  - The model for Improvement
    - PLAN DO STUDY ACT (PDSA cycle)
- Acknowledge progress
- Involve patients and families

Building a comprehensive and effective Medical Home For CYSHCN – Assess the Practice:

Use a standardized questionnaire such as the **CSHCN screener.**

- Identify children at increased risk. (Ex: Autism)
- Create patient registries.
- Plan for patient visits.
- Identify and recall patients.

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Children with Special Health Care Needs (CSHCN) Screener©
(mail or telephone)

1. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?
   - ☐ Yes → Go to Question 1a
   - ☐ No → Go to Question 2

   1a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes → Go to Question 1b
   - ☐ No → Go to Question 2

   1b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

2. Does your child need or use more **medical care, mental health or educational services** than is usual for most children of the same age?
   - ☐ Yes → Go to Question 2a
   - ☐ No → Go to Question 3

   2a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes → Go to Question 2b
   - ☐ No → Go to Question 3

   2b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
   - ☐ Yes → Go to Question 3a
   - ☐ No → Go to Question 4

   3a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes → Go to Question 3b
   - ☐ No → Go to Question 4

   3b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

4. Does your child need or get **special therapy**, such as physical, occupational or speech therapy?
   - ☐ Yes → Go to Question 4a
   - ☐ No → Go to Question 5

   4a. Is this because of ANY medical, behavioral or other health condition?
   - ☐ Yes → Go to Question 4b
   - ☐ No → Go to Question 5

   4b. Is this a condition that has lasted or is expected to last for *at least* 12 months?
   - ☐ Yes
   - ☐ No

5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets **treatment or counseling**?
   - ☐ Yes → Go to Question 5a
   - ☐ No

   5a. Has this problem lasted or is it expected to last for *at least* 12 months?
   - ☐ Yes

Other tools to use*

- **Medical Home Index (MHI)** – rank your practice (1-4) in six domains: organizational capacity, chronic condition management, care coordination, community outreach, data management, and QI/change
- **Medical Home Family Index and Survey** – information gathered from families about the practice
- **TeamSTEPPS Training** – from Agency for Healthcare Research and Quality.
- **Quality Improvement Training** – from Institute for Healthcare Improvement

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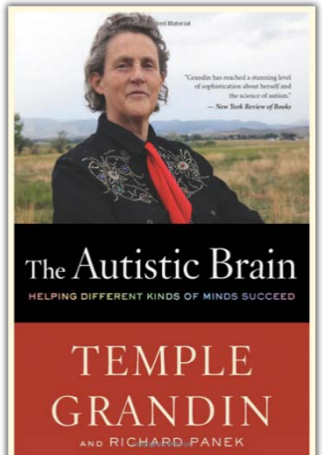
Office Environment: SPELL (Autism)

- **S**tructure – help predict what is going to happen with pictures and explanations
- **P**ositive – Supportive and caring environment, meet them where they are!
- **E**mpathy – anticipate overcoming difficulties (schedule first or last)
- **L**ow Arousal – calm environment (quiet room), no white coats!
- **L**inks - community



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Autism Pre-Check List

- **Autism Pre-Visit Assessment**
- Difficulty in waiting room
- Struggles waiting to see MD
- History of Aggression in a medical setting
- Needles cause anxiety
- Loud noises bother the patient
- Will be nervous/anxious
- Difficulty hearing someone crying or screaming
- Won't allow a blood pressure or other vital signs taken
- Lights bother the patient
- Doesn't like to be touched, or will not allow physical exam or genital exam
- May run from the room
- Will not get on elevators
- Lab draw (need sedation?)

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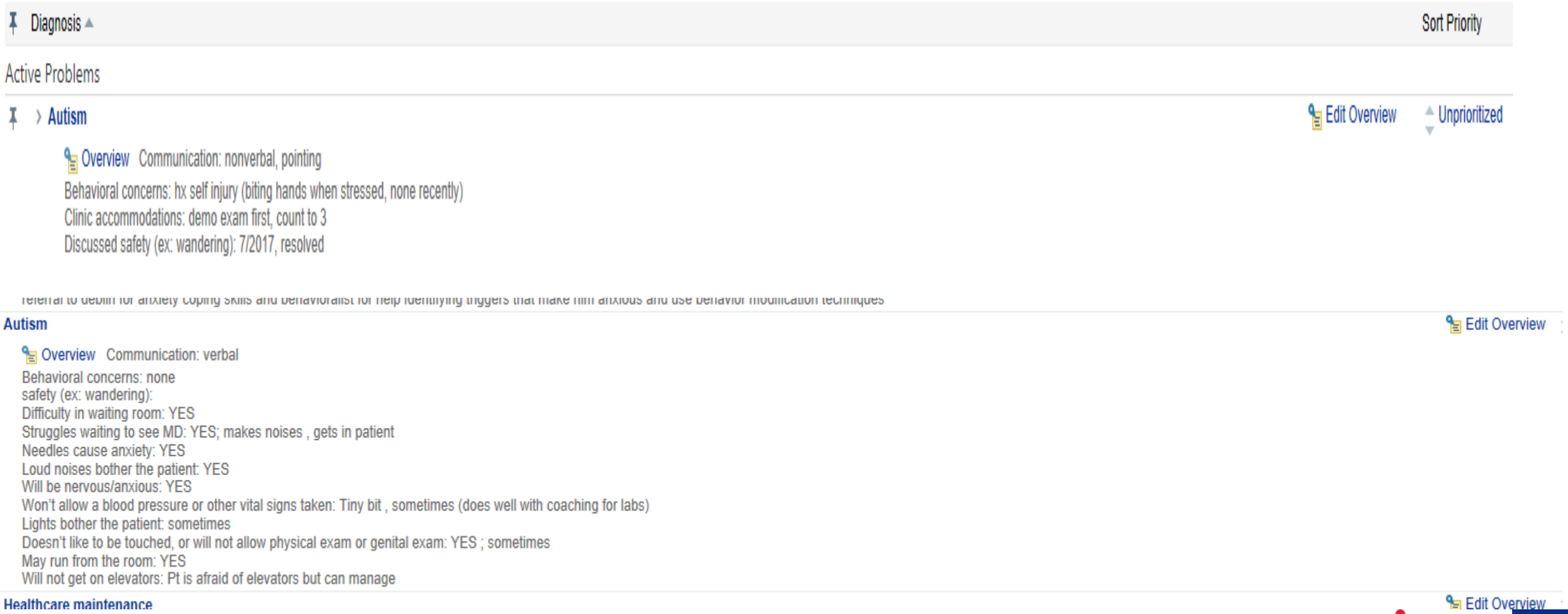
Problem List in EHR



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The PCMH Impact on Quality of Care and Health Outcomes*

www.pcpcc.org

- Increase anticipatory guidance provided
- Increase annual primary care visits and well-child visits
- Increase immunization rates
- Increase likelihood of having height, weight, and blood pressure checked
- Decrease rate of inappropriate use of antibiotics
- Increase family and patient satisfaction

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Studies show that the PCHM*

www.pcpcc.org

- Providers better support and communication
- Creates stronger relationships with providers
- Saves you time
- Decrease hospitalizations and decrease days spent in the hospital
- Decrease visits to the emergency department
- Decrease cost for families
- Lower PMPM cost

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Barriers to PCMH

- Inadequate reimbursement for services offered in the medical home remains a very significant barrier to full implementation
- Shortage of primary care providers
  - Knowledgeable providers!
- Healthcare Information Technology
- Practice Infrastructure and Coordination of Care

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The Three-Part Payment Model

- **Monthly care coordination payment** - work that falls outside of a face-to-face visit
- **Fee-for-service** - recognizes visit-based services
- **Performance-based component** - recognizes achievement of quality and efficiency goals
  - Apply **coding for Medical Home Visit Reimbursement**. The AAP's *Index of Current Procedural Terminology (CPT) Codes for Medical Home* highlights most of the commonly reported codes for the medical home.

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Medical Home Recognition and Accreditation Programs – does it help the practice with reimbursement?

- Accreditation Association for Ambulatory Health Care (AAAHC) Medical Home On-site Certification(www.aaahc.org)
- National Committee for Quality Assurance (NCQA) Patient-Centered Medical Home (PCMH 2014) Recognition(www.ncqa.org)
- The Joint Commission (TJC) Designation for Your Primary Care Home(www.jointcommission.org)
- URAC Patient-Centered Medical Home Accreditation(www.urac.org)

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So what about Transition Health Care?

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Transitioning Health Care – Why?

- More than 90% of children born today with a chronic or disabling health condition are expected to live more than 20 years.
- There are ***more*** adults with spina bifida, congenital heart disease and cystic fibrosis then children.

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Health Care Transition

- ***transition*** *is a process and not an event*. "age and developmentally appropriate process, addressing the medical, psychosocial and education/vocational aspects of care"
  - a ***purposeful, planned*** migration from child-oriented to adult-oriented health care
- ***Health Care Transfer*** - a point in time when a new provider assumes the medical care of a patient

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Consensus Statement 2002

- A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs

  AAP, ACFP, ACP-ASIM – 2002

"The goal of transition in health care for young adults with special health care needs is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood."

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Consensus Statement 2011

- The American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) published a joint statement describing a recommended clinical approach for transition to adulthood for all youth, not just for youth with special needs (5).
  - In the context of a medical home
  - Standard part of care for all youth/young adults
  - Involves six steps

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Transition Educational Effort for Adult Providers

- American College of Physicians' Council on Subspecialty Societies partnership with Got Transition. May 2016:
  - The specialty societies' subgroups customized a least three tools from the 6 Core Elements: 1) a transition readiness assessment (for use in pediatric care), 2) a self-care assessment (for use in adult care), and 3) a medical summary/transfer record containing the essential information needed for communication between pediatric and adult clinicians for practices

got transition

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About | News | Resources | Health Care Providers | Youth & Families | Researchers & Policymakers | Webinars

Got Transition aims to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

News & Announcements

Are you ready to transition to adult health care?

Take Our Quiz!

New Report Offers Value-Based Transition Payment Recommendations
A new report from The National Alliance, funded by the Lucile Packard Foundation for Children's Health, offers recommendations for value-based payment (VBP) for transitional care to address long-standing gaps in payment for transition from pediatric to adult care. more>

New Analysis of State Title V Transition Efforts and Recommendations
A Got Transition report examines innovative transition strategies and measures from 37 state Title V Programs selecting transition as a national performance measures and offers recommendations for future efforts. more>

New Study on US Health Care Transition Performance
A recent study of the newest 2016 National Survey of Children's Health data shows that few youth with and without special health care needs receive transition planning support. more>

The National Alliance Receives 5-Year Federal Grant to Continue Got Transition
The National Alliance to Advance

For Health Care Providers

Find out about how to implement health care transition quality improvement in your practice or plan using the new Six Core Elements of Health Care Transition (2.0). Download accompanying clinical resources and measurement tools for use in any setting.

Customize the Six Core Elements of Health Care Transition to meet your patients' and practice's needs!

Incorporating Health Care Transition Services into Preventive Care for Adolescents and Young Adults: A Toolkit for Clinicians

Condition-Specific Transition Toolkits (from the ACP Pediatric to Adult Care Transitions Initiative)

For Youth & Families

Hear what young adult and parent experts have to say about common transition questions and discover new resources to make this process work easier.

Turning 18: What it Means for Your Health

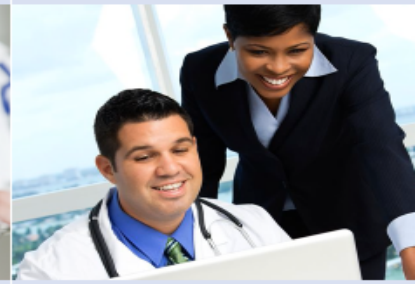
The "Medical ID" Feature on Apple's Health app

The "Medical ID" app for Android phones

Questions to Ask Your Doctor about Transitioning to Adult Health Care

For Researchers & Policymakers

Find new transition policy developments, research and measurement approaches, and federal and state transition initiatives.



Got Transition Webinar Series

2018 Report on Innovative State Tile V Transition Efforts

Recommendations for Value-Based Transition Payment for Pediatric and Adult Health Care Systems

The Process: Six Core Elements of Health Care Transition

got transition?
NATIONAL HEALTH CARE TRANSITION CENTER

1 Transition Policy
Posted
Staff /Family/CY Informed

2 Transitioning Youth Registry
Identify: 12-17, 18-21, 22-26

3 Transition Preparation
Teach & Track Skills

4 Transition Planning
Health Care Transition Plan
Portable Medical Summary

5 Transition & Transfer of Care
Transfer Checklist, EMR
Summary Med. Record

6 Transition Completion
3 months post/followup

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Transitioning Health Care*

- Barriers
  - Adult health care providers are not comfortable or knowledgeable about many pediatric diagnoses or working with a young population
  - Lack of insurance
  - Little to none transition health care planning during pediatric years.
  - Cultures are different: Pediatric vs. Medicine
    - Acute care – Adult hospitals

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What Works??

- Studies suggest that the transfer of care is more likely to be successful if a formal ***transition program*** is in place to prepare the patient and to facilitate the change in care providers.
- There is a growing evidence base that skills training for young people with chronic illnesses can be associated with positive outcomes.
- Independence visits have been shown to be one of the few determinants of attending appointments as an adult!
- Making it developmentally appropriate and not age based.

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Baylor College of Medicine Transition Medicine Section

- Part of the Strategic Planning between Texas Children's Hospital and Baylor College of Medicine
  - Incentive rewards for process built between specific pediatric and adult programs
  - Quality improvement grants for transition specific projects
  - Imbedded on the medicine side to address education, clinical and research opportunities
  - TCH side – adolescent medicine section
    - EPIC transition tool
    - *Transition from Pediatric to Adult-Based Care 19th annual chronic illness and disability conference, October 25th and 26th 2018 Houston, Texas*

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Texas Children's Hospital – Baylor College of Medicine Transition Medicine Clinic

- Medical Home for 19 years and older patients with neurodevelopmental disorders – same day appointments, chronic care management
- Medicaid 1115 Waiver Demonstration Project
- *AHRQ certification Level 2* – family advisory committee, TeamSTEPPs training, Advanced Quality Improvement training for faculty
- UnitedHealthCare Star Plus PMPM & Fee for Service – embedded service coordinator
- Medicare Care Coordination Fee
- HRSA grant working with Texas Children's Practices

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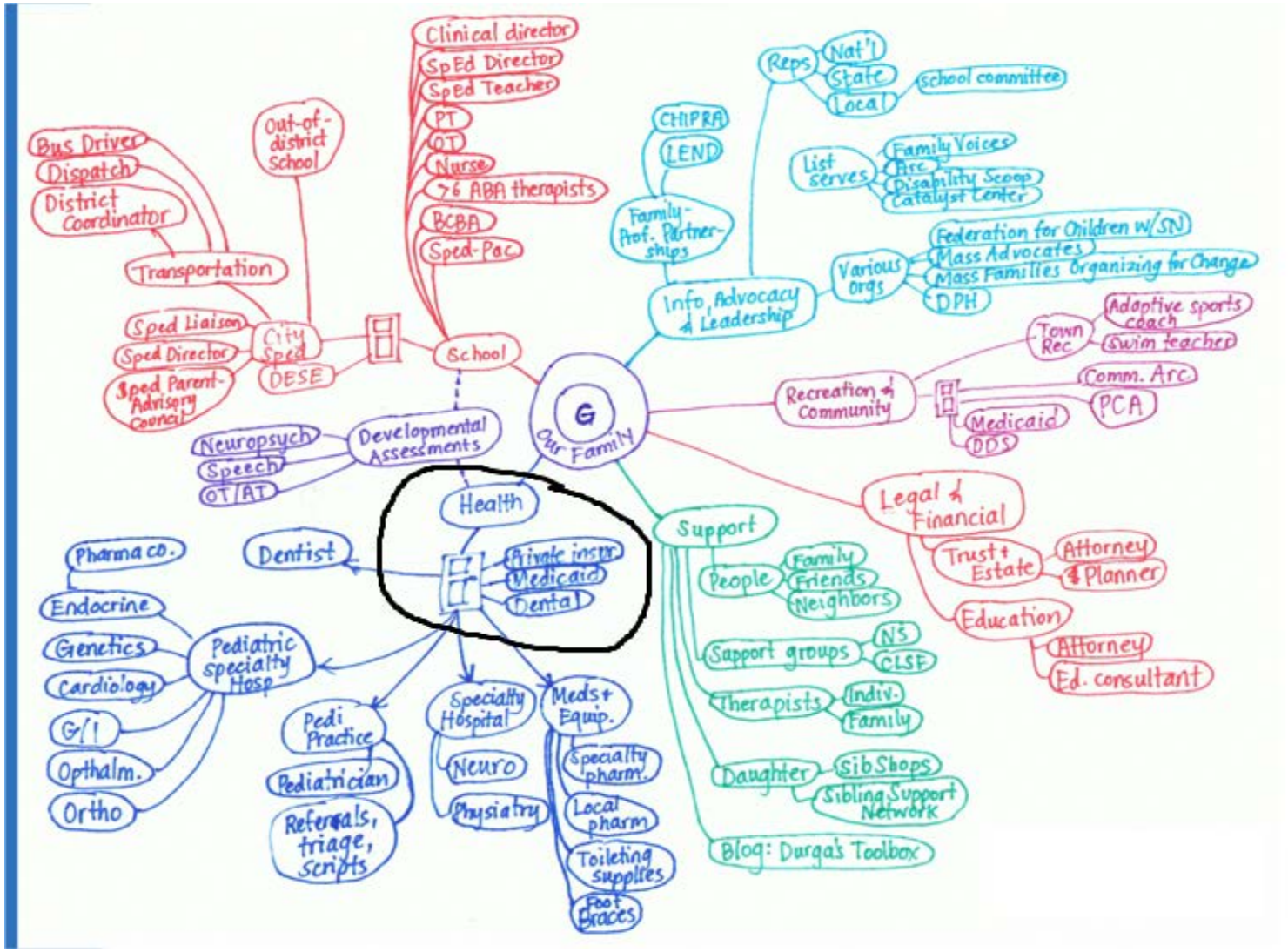
It just isn't about health care!



Courtesy of Amy Gibson, RN, Chief Operating Officer, PCPCC

When in doubt, ask Mr. Rogers

Resources

- www.pcpcc.org
- www.gottransition.org
- https://medicalhomeinfo.aap.org
- https://www.acponline.org/pediatric-adult-care-transitions
- https://www.ahrq.gov/teamstepps/index.html
- http://childhealthdata.org/learn/NSCH
- http://www.truthsabouthealthcare.com/category/costs/
- http://www.ihi.org/education/InPersonTraining/Pages/default.aspx
- http://www.nichq.org/resources/PFAC-toolkit-landingpage.html

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