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Supporting a Medical Home for Young Adults with Chronic Conditions of Childhood

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Barriers to Transition for CYSHCN

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- Culture: Pedi vs. Medicine
- Health Insurance – they cost more and need coverage
- Adult Providers caring for Childhood Conditions
- Pediatric Providers – unaware of adult health care system or need for readiness curriculum
- Lack of Readiness – the need to improve chronic disease self-management

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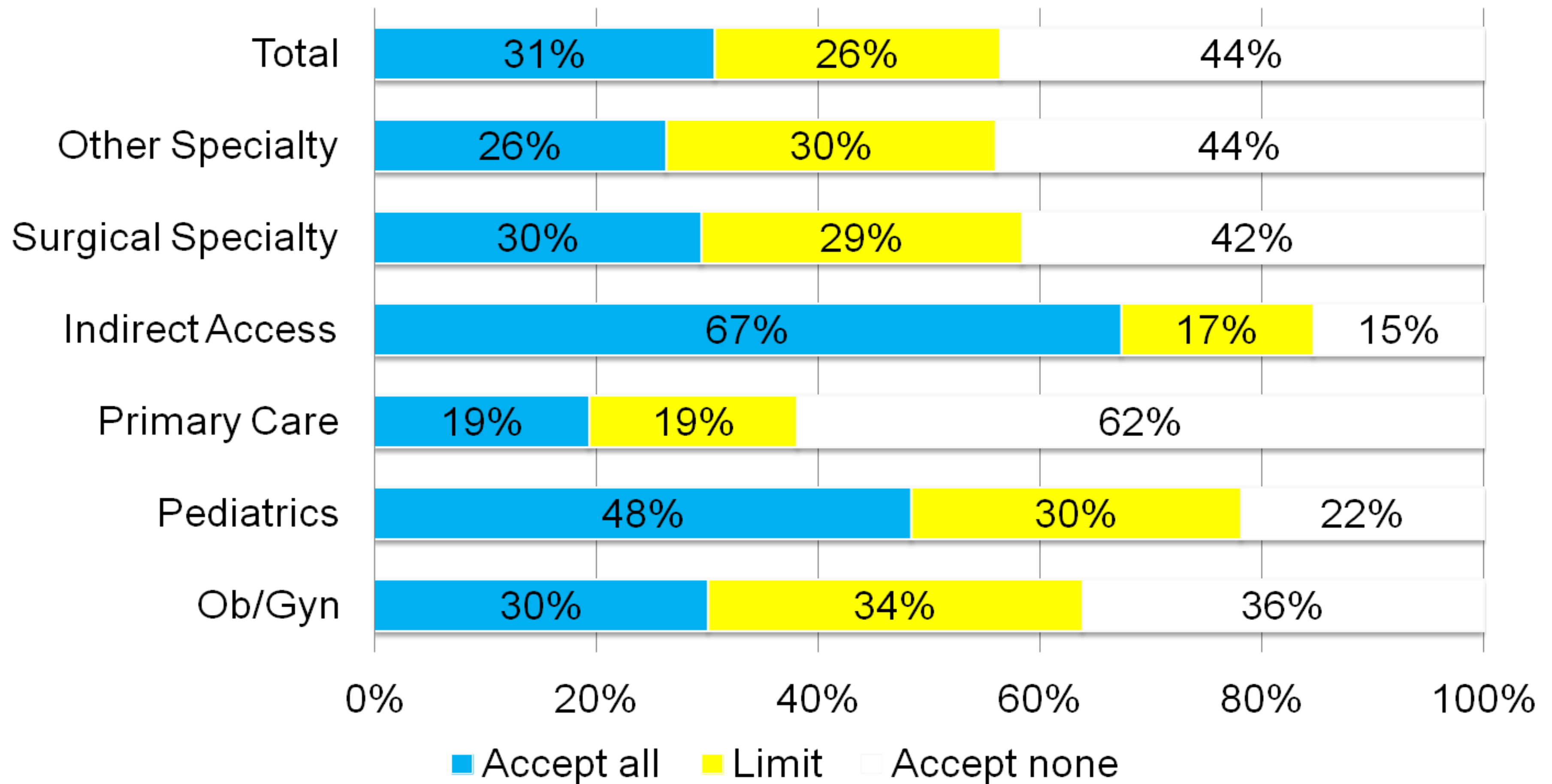
Acceptance of Medicaid Patients by Physician Specialty



Transition From Pediatric to Adult Care: Internists’ Perspectives

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- CONCLUSIONS. Internists clearly stated the *need for better training* in congenital and childhood-onset conditions, training of more adult subspecialists, and continued family involvement. They also identified concerns about patients’ psychosocial issues and maturity, as well as financial support to care for patients with complex conditions.
- *Pediatrics* 2009;123:417–423

- Only one out of six Pediatricians routinely discuss health care transitions with young adults with developmental disabilities
  - » Scal & Ireland, 2005

Down syndrome

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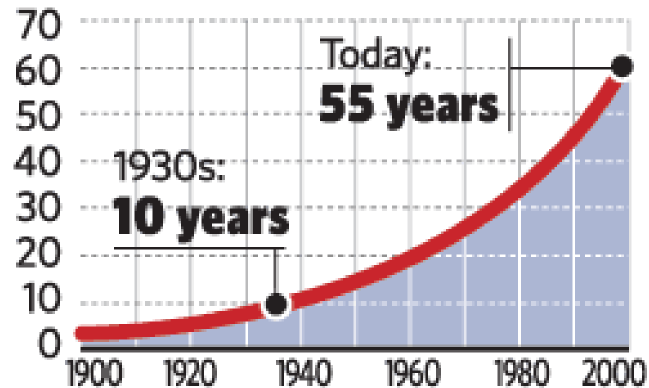

- Mortality use to be related to congenital heart disease and hematological malignancies.
- Chronic illnesses are common such as diabetes, dementia, OSA, endocrine disorders, obesity and osteoarthritis.

What Happens after Transition?

- **Adults** with Autism are higher risk for a slew of health problems ranging from diabetes and obesity to heart failure
  - "Nearly all medical conditions were significantly more common in adults with ASD than controls, including diabetes, gastrointestinal disorders, epilepsy, sleep disorders, dyslipidemia, hypertension and obesity,"
    - May 2014: For the study, researchers at Kaiser Permanente Northern California looked at medical records for 23,188 individuals ages 18 and older enrolled in the insurer's health plans between 2008 and 2012 to assess the prevalence of psychiatric, behavioral and medical conditions. Of the individuals whose records were studied, 2,108 were diagnosed with autism.

Pediatrics 2013: Current Status of Transition Preparation Among Youth With Special Needs in the United States.

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- 2009-2010 National Survey of CYSHCN
- 40% of CYSHCN meet the national transition core outcome
- Factors associated with transition: higher family income, white, female gender, condition other than an emotional, behavioral, or developmental condition, **having a medical home** and privately insured

McManus et al. Pediatrics 2013;131:1090-7.

Transition needs to be recognized as a process not an event:

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…"the purposeful, planned, movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems."

- Important for all teenagers
- Youth with severe chronic impairments experience additional challenges
- Ideal goal is to provide health care that is:
  - Uninterrupted , coordinated developmentally appropriate, psychosocially sound and comprehensive

Blum, R. W., Garrell, D., Hodgman, C.H., Jorissen, T.W., Okinow, N.A., Orr, D.P., Slap, G.B. Transition from Child Centered to Adult Health-Care Systems for Adolescents with Chronic Conditions. Journal of Adolescent Health. 1993;14:570-576.

Health Care Transition Milestones

- *Age 12-13*: Youth and family aware of practice's health care transition and transfer policy
- *Age 14-15*: Health Care Transition Plan initiated with family/youth input
- *Age 16-17*: Review and update Transition Plan
- *Age 18 or >:* Transition and Transfer to adult model of care

Six Core Elements of Health Care Transition

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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

CYSHCN

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- Asthma
- ADHD
- ***Autism***
- ***Cerebral Palsy***
- Chronic Kidney Disease
- Congenital Heart Disease
- Cystic Fibrosis
- Mental Health Issues
- ***Intellectual & Developmental Disabilities (IDD)***
- ***Down syndrome***
- Epilepsy
- Muscular Dystrophy
- Sickle Cell Disease
- ***Spina Bifida***

Transition Medicine Clinic Mission

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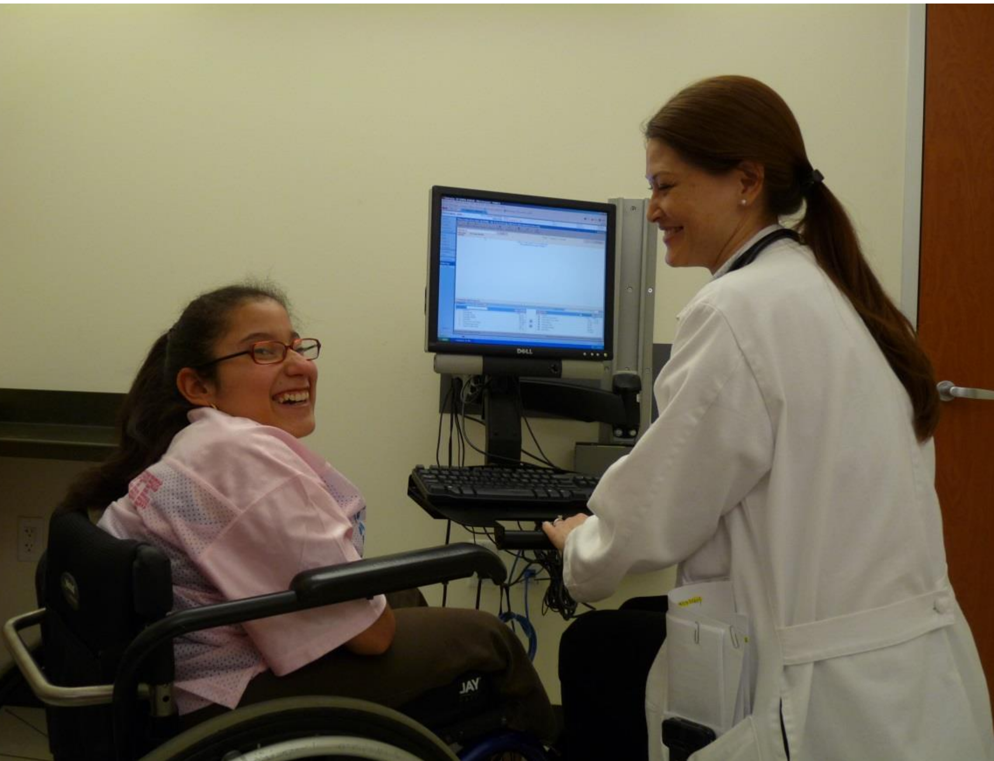

- Medical home for the most vulnerable adolescent/young adults with a chronic childhood condition (AYACCC)
- Teaching adult health care providers the health care needs of AYACCC
- Cohort a specific number to understand their health care needs in the adult health care system

Transition Medicine Clinic

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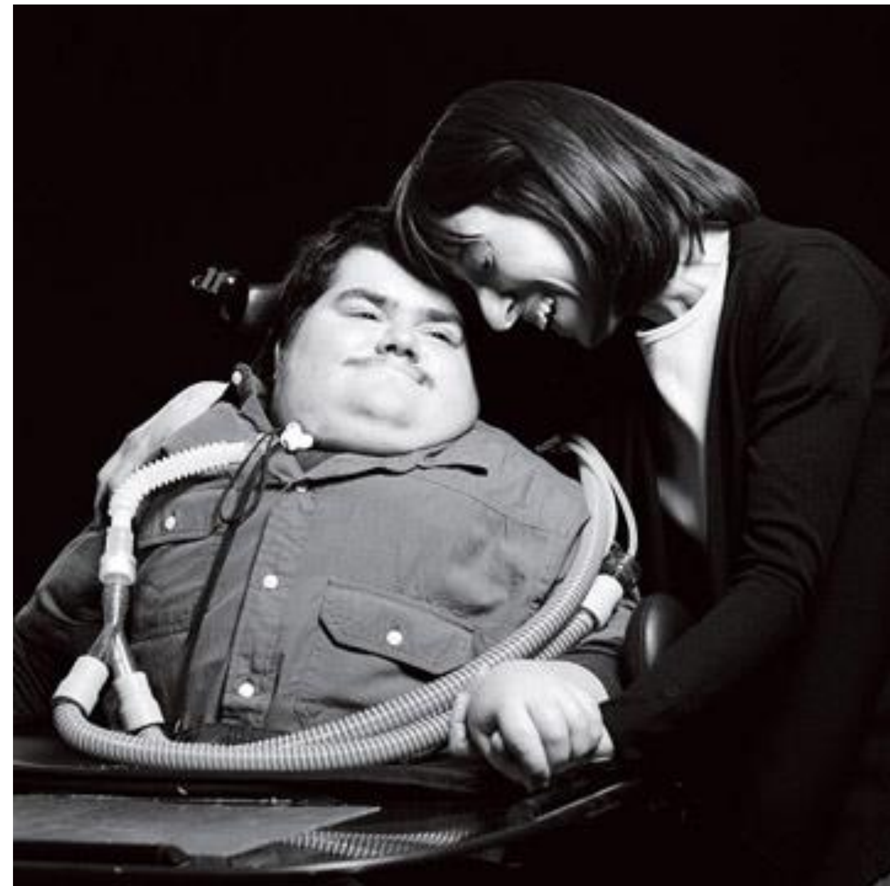
Clinic Characteristics:

- Wheelchair accessible rooms, wheelchair scale, hoyer lift
- Wide rooms that accommodate stretchers
- Same day appointments
- Social worker support
- Care coordinator
- Subspecialty access
- EHR – Portable Medical Summary
- Community Network/Resources
- Medicaid Access

Just added:

- Telephone appointments



What We Learned

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- Longer clinic time ~ 20 minutes per MD visit
- Paperwork (Faxing one hour a day for 500 patients)
- Labor intensive (Half Day Clinics)
- Majority are covered by Medicaid
- Complicated patients (technology dependent) are difficulty to have in the community
- CYSHCNs continue to require super-specialists in adulthood
- The families are not prepared for the transition – don't know about waivers!

What We Learned

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- Peds, Med-Peds and FCM trained physicians are seeing these patients.
- Health needs as an adult are under recognized.
- Employment, Respite, School
- Caretaker burn-out
- Standards for best practice?

CYSHCN Transition is Complicated!

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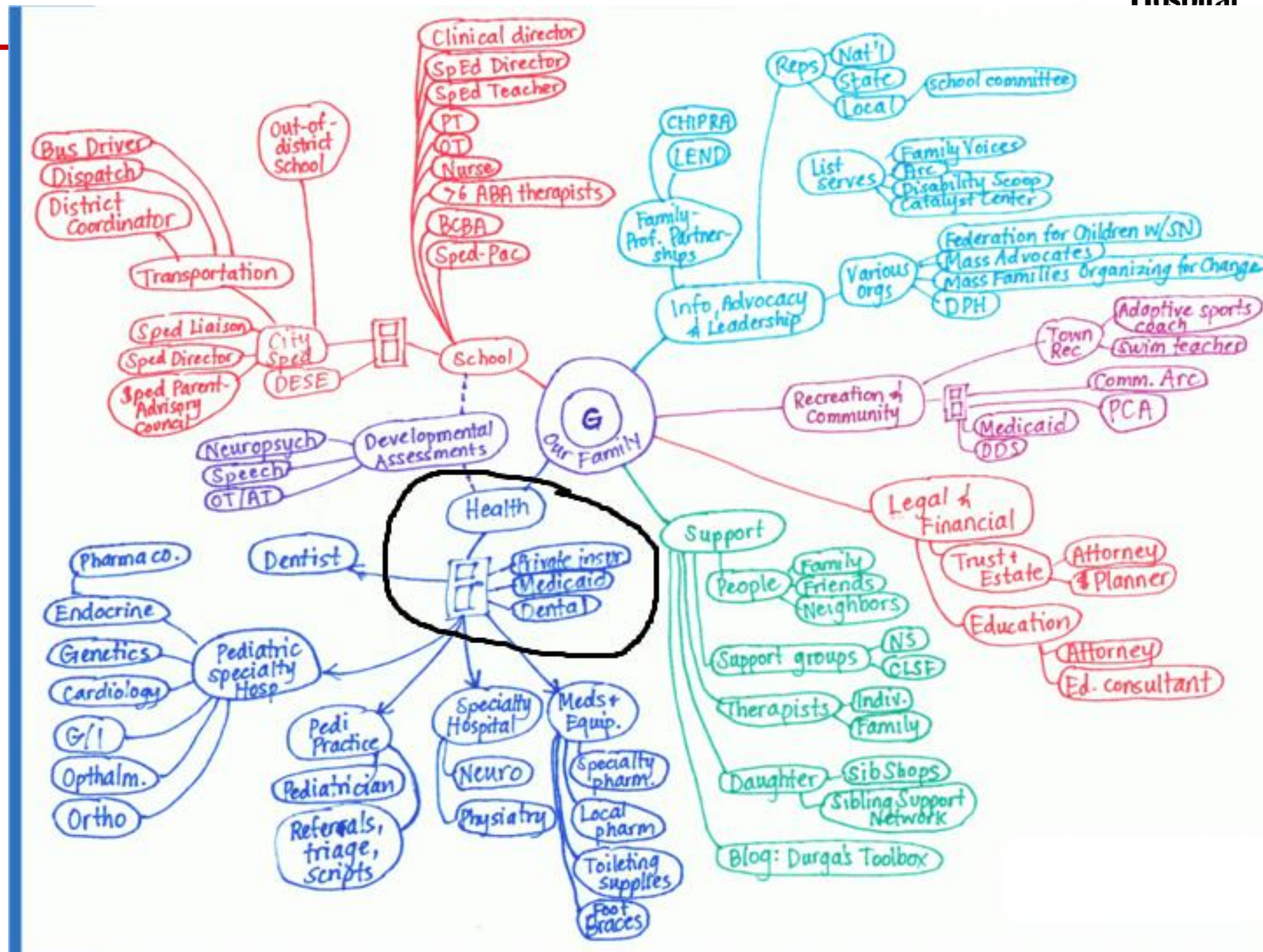

Courtesy of Amy Gibson, RN, Chief Operating Officer, PCPCC