Health Care Transition
The Great Leap from Pediatric to Adult Medical Care

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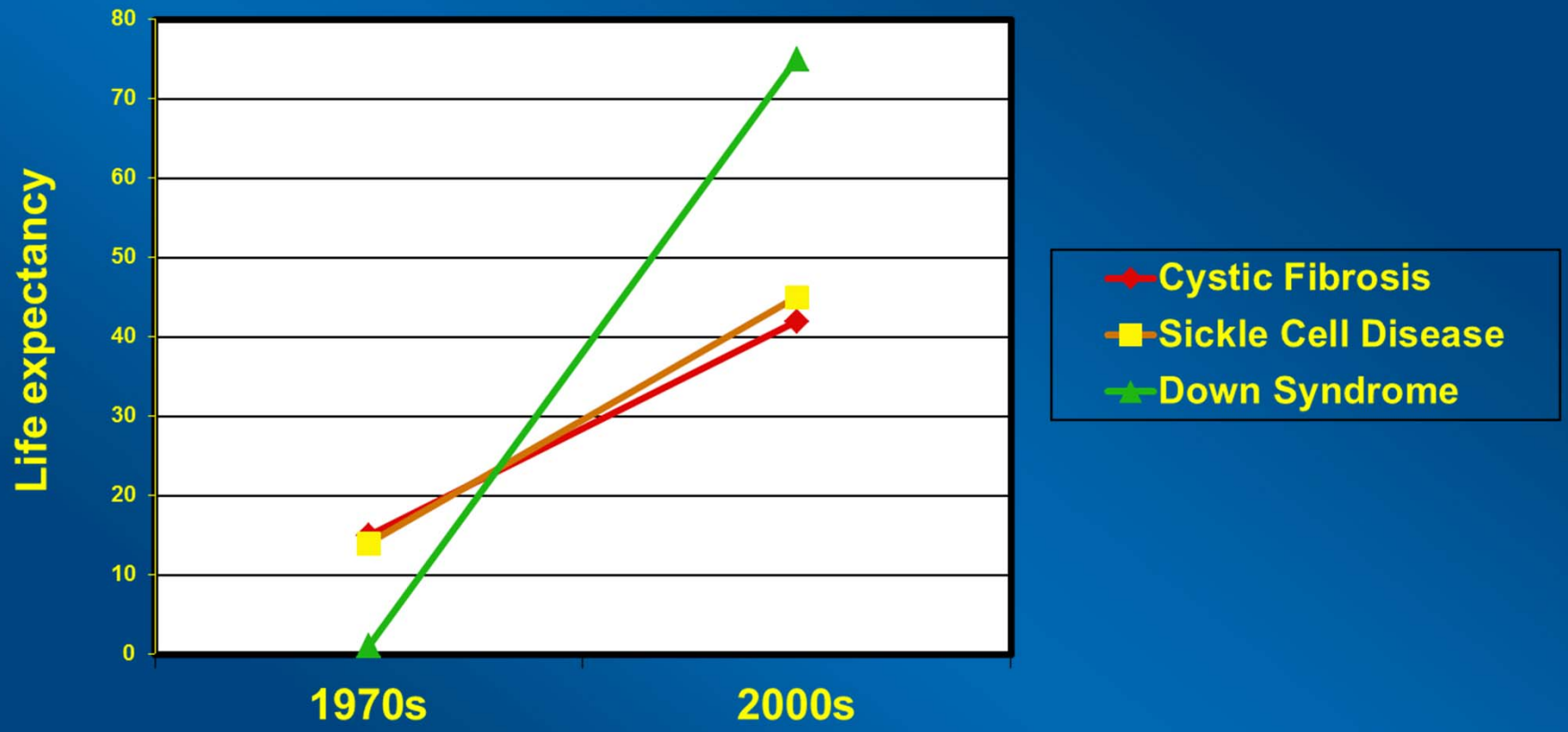
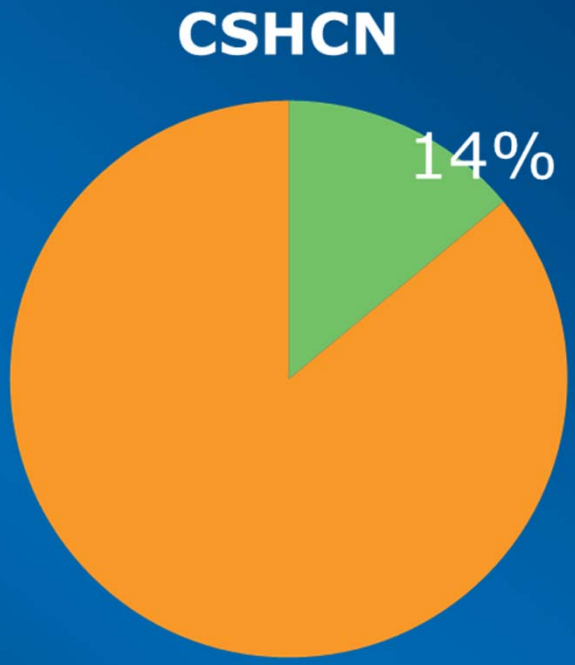
The problem of pediatric success... Children with chronic illness living longer



Youth with Special Health Care Needs (CSHCN)

500,000 turn 18 annually



Goals

Review the challenges of healthcare for patients with IDD

Understand the need for appropriate transition from pediatric oriented health care to adult-oriented health care

Identify the steps for optimal transition

Identify the differences in pediatric focused vs adult focused health care

Review the barriers to transition

Discuss new local resource

Challenges for Adults with IDD

2.5 million of NYS have 1 of 5 types of disabilities (limits activity)

Majority of those with developmental disabilities cared for and live with parents >80 yo and themselves are >60 yo

Lifelong impacts of underlying disease have more quality of life on this population

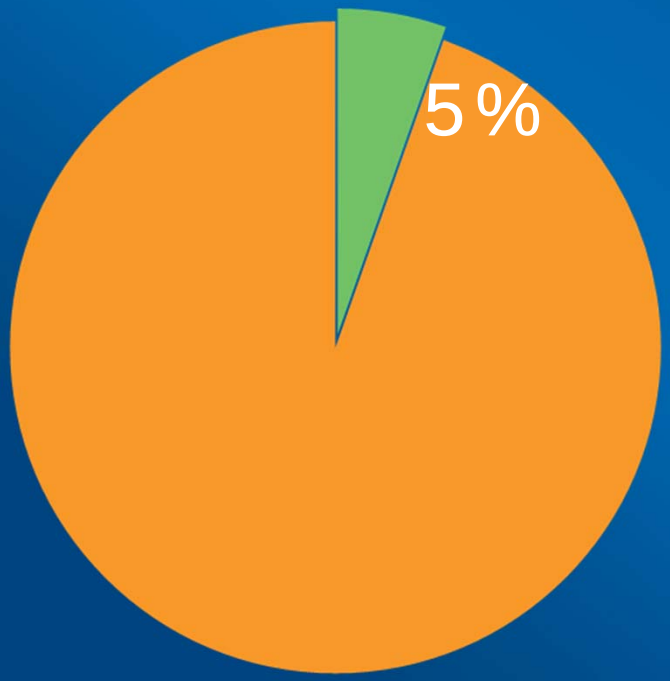
Challenges for Adults with IDD

People with IDD are more likely to:

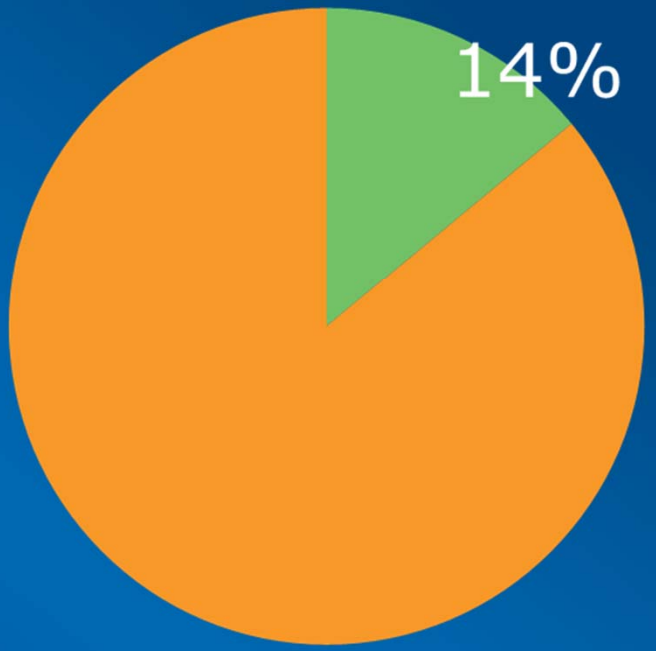
- Live with complex health conditions
- Have limited access to quality health care and programs
- Miss cancer screenings
- Poorly managed chronic conditions, ie epilepsy, HTN
- Be obese
- Undetected poor vision and hearing
- Mental health problems and be on medications (maybe too many)

Health Care System Impact: Adults with IDD

Medicaid Population



Medicaid Spending



Health Care System Impact

When admitted patients with IDD stay longer and come back to the hospital more often

SMH	Age 0-17		Age 18+	
	Length of admission to hospital	%30 day readmit	Length of admission to hospital	% 30 day readmit
With IDD dx	10 days	14%	13 days	16%
Without IDD dx	6 days	7%	6 days	13%

Defining Health Care Transition

- Purposeful, Planned, Well timed
- From child-centered to adult-oriented health care systems
- Optimize ability to assume adult roles and functioning
  - Developmentally appropriate
  - Maximize lifelong functioning

What happens if we do nothing…

Transplant rejections

Worsening control of diabetes and inflammatory arthritis

Increased need for urgent cardiac care in congenital heart disease

Increased mortality

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The helpful diagram from the AAP….

Got Transition
6 core elements

Develop a transition policy

Transition Tracking and Monitoring

Transition Readiness

Transition Planning

Transfer of Care

Transfer Completion

http://www.gottransition.org

Transition Policy…

beginning at ages 12-14…creating educational tools available for patients, families, and providers… Systems of transfer will be in place to facilitate tracking and monitoring of patients through this process. Beginning at age 18 …the transfer of care plan including identification and engagement of adult primary care providers, specialists, and goals of care. By age 19 the process of transfer to the “adult” health care system will begin … goal of graduation to the “adult” health care system by age 22.

Transition Tracking

Create Registries

- Know who is moving into adolescents
- Identify those with special health care needs
- Ensure engagement of caregivers and patients

Approaches:

- “I know my patients”
- Electronic medical Record
- Reports from billing and insurers

Transition Planning

Identify

Create

Receive

Prepare

Identify

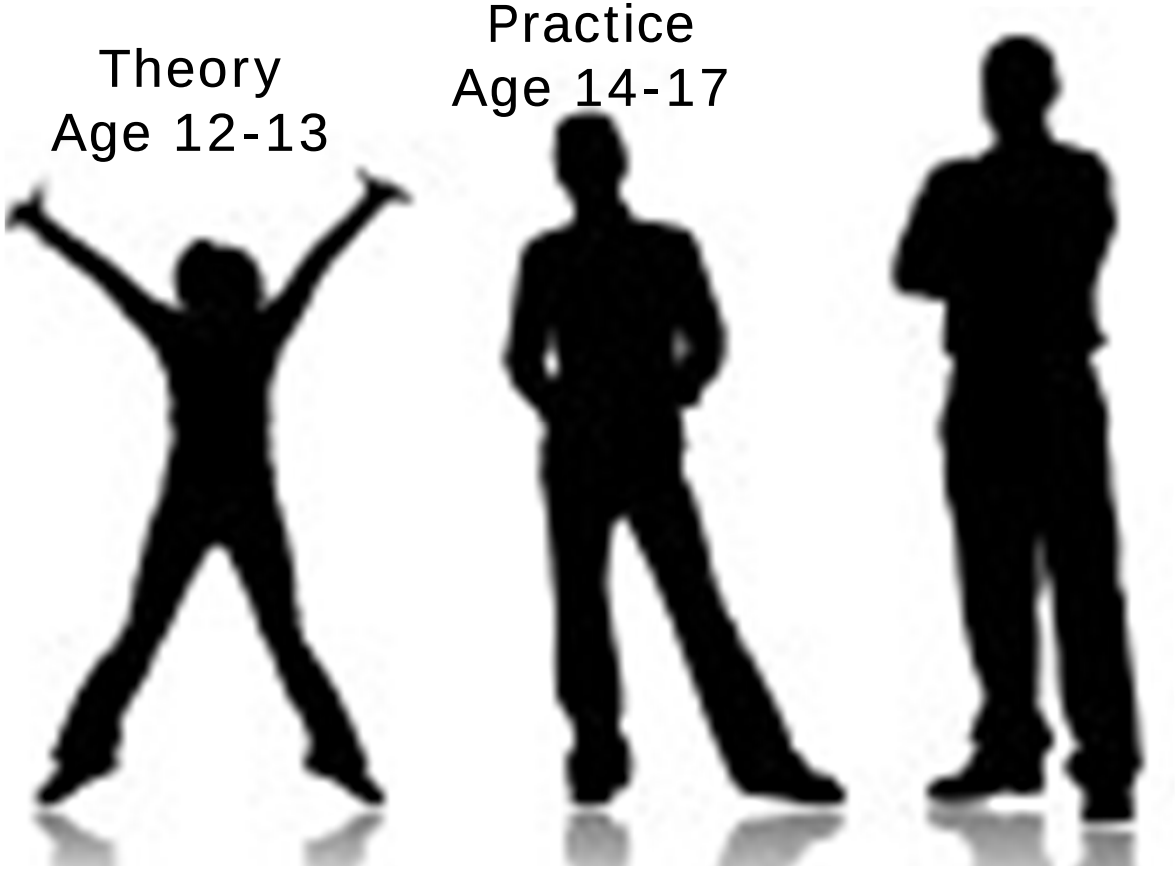
Other s

Transition Readiness

Theory
Age 12-13

Practice
Age 14-17

Implementation
Age 18+



Readiness Assessment

My Health:

- I know my medical needs

Using Health Care:

- I can navigate the system

http://gottransition.org/resourceGet.cfm?id=224

Decision Making

A Skill that Requires Practice and a Variety of Experiences

The Right Support at the Right Time

Guardianship is legal, binding and pervasive

- Educate your providers
- Provide documentation

My GOALS

My SKILLS

My Circle of Support









www.healthytransitionsny.org

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Transition Plan

- Which providers will change and when
- Where will we receive inpatient care
- What health goals will change in adulthood
- Anticipated health impacts
- Skill limits and supports
- Plans for the unanticipated
- Advanced care directives

Timing of Transition

Transition Summary

Ongoing/Re

Surgeries/P

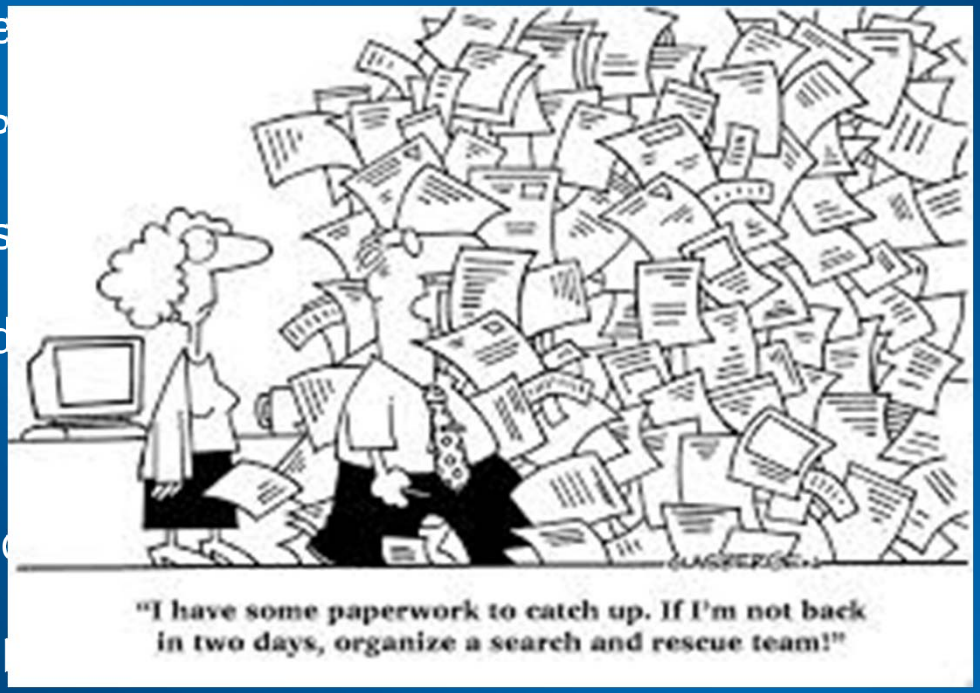
Medications

Medical and

Emergency

Goals medi

Circle of su



"I have some paperwork to catch up. If I'm not back in two days, organize a search and rescue team!"

Identifying an Adult PCP

Availab

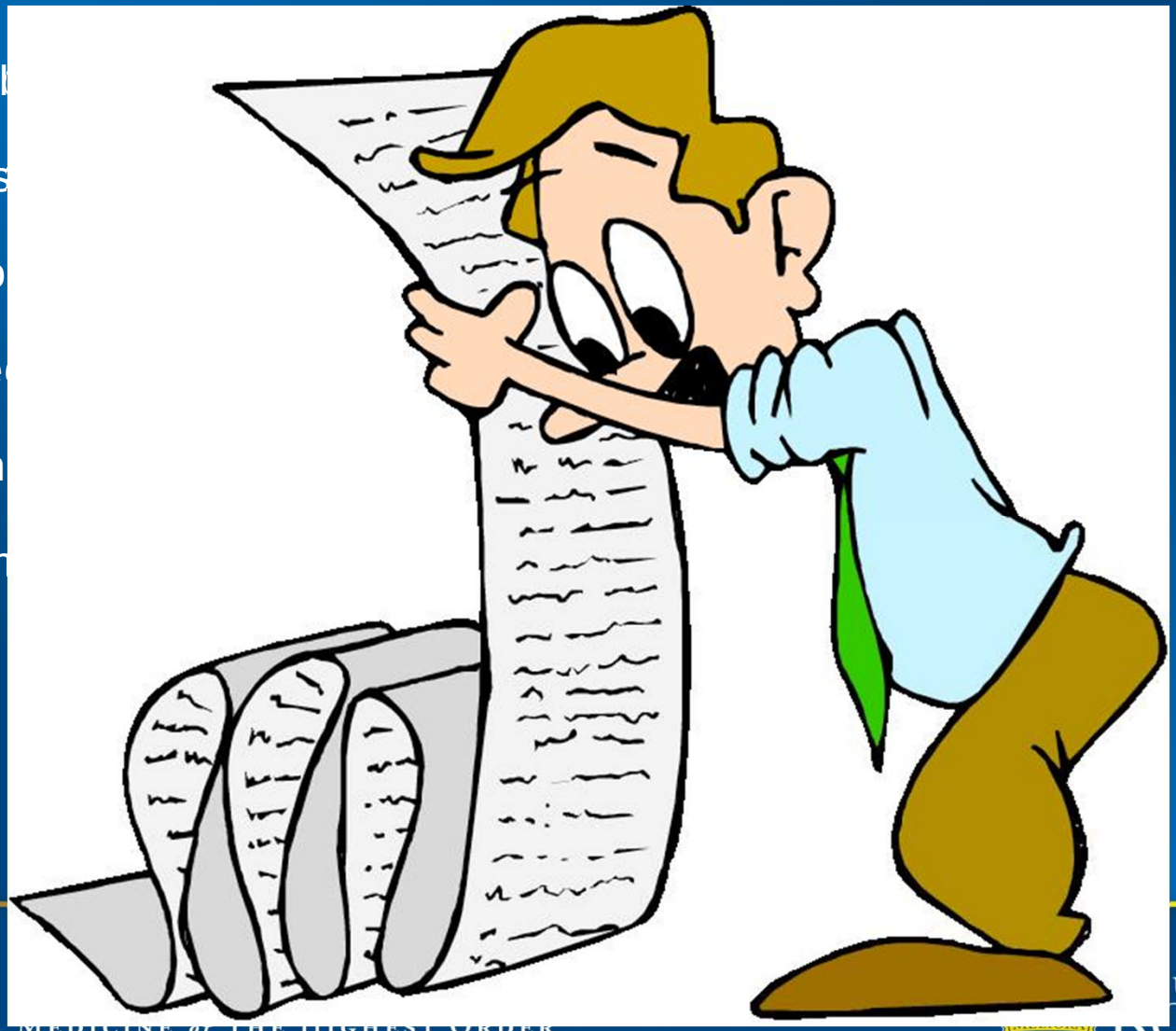
Access

Comfo

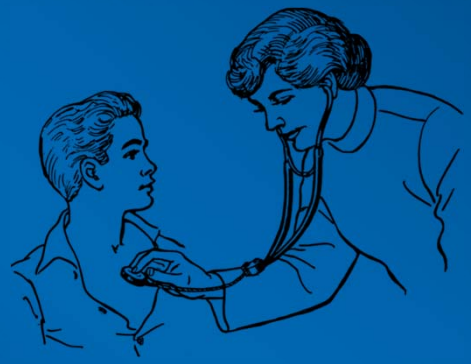
Connec

Contin

After h



Primary Care Medical Home



Specialists

PCMH Care Coordinator

Inpatient Care

PCMH Triage Nurse

Urgent Care

PCMH Secretary

Family

The Exam Room

Primary Care Access Barriers with IDD

More time required for visits

Premature aging

Challenging health conditions (things we can't fix)

Lack of training in their condition/complexities

Poor coordination

Challenges of consent & communication

Less focus on prevention/exam

Primary Care Interaction

Learned from the patient

More likely to provide direct phone support

More likely to do home visits

Inpatient Transition

High acuity & Complexity

High patient turnover

Quick changes in patients health

Constant stream of data

Multiple locations of care

Relies on Patterns

Develop a Care Plan

Know your advocates

Transfer of Care / Completion

Warm hand off

Well summarized and prepared patient

Barriers to Transition

Culture Gap

Barriers of Perception

Pediatricians – it's safe here out there is unknown

Internist – they are complicated and deserve more time then I have

Youth/Caregiver – the time is never right and uncertainty of change

A round peg in a square hole…

"I am invincible" – concrete operational developmental stage

Broad/Shifting circles of support

Changing community supports/resources

Thinking about medicine from a new perspective

Taking risks

Health Insurance

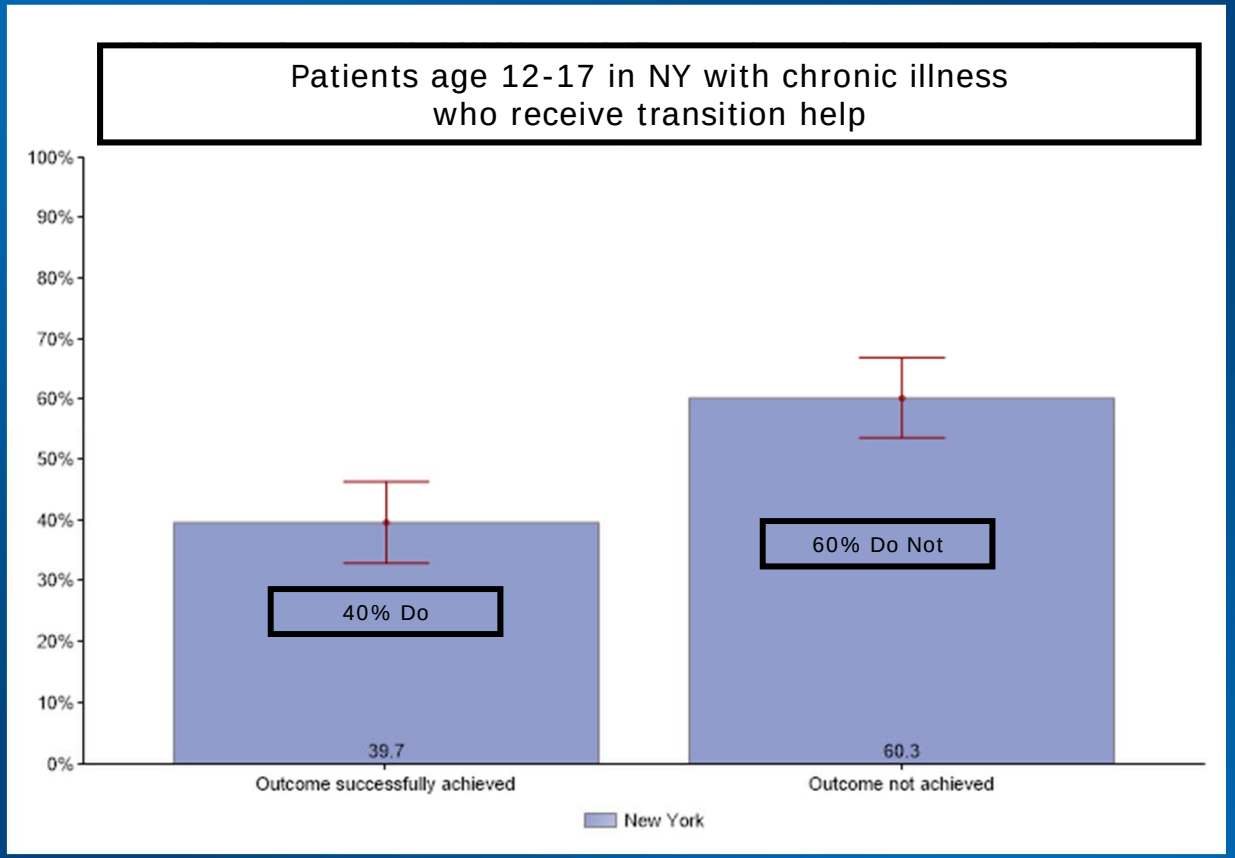
30% of 19-21yo reported no insurance

62% reported a gap in insurance during 3 year period

Complex health care coverage system

Affordable Care Act has helped

Transition: Barriers



What is the best way…

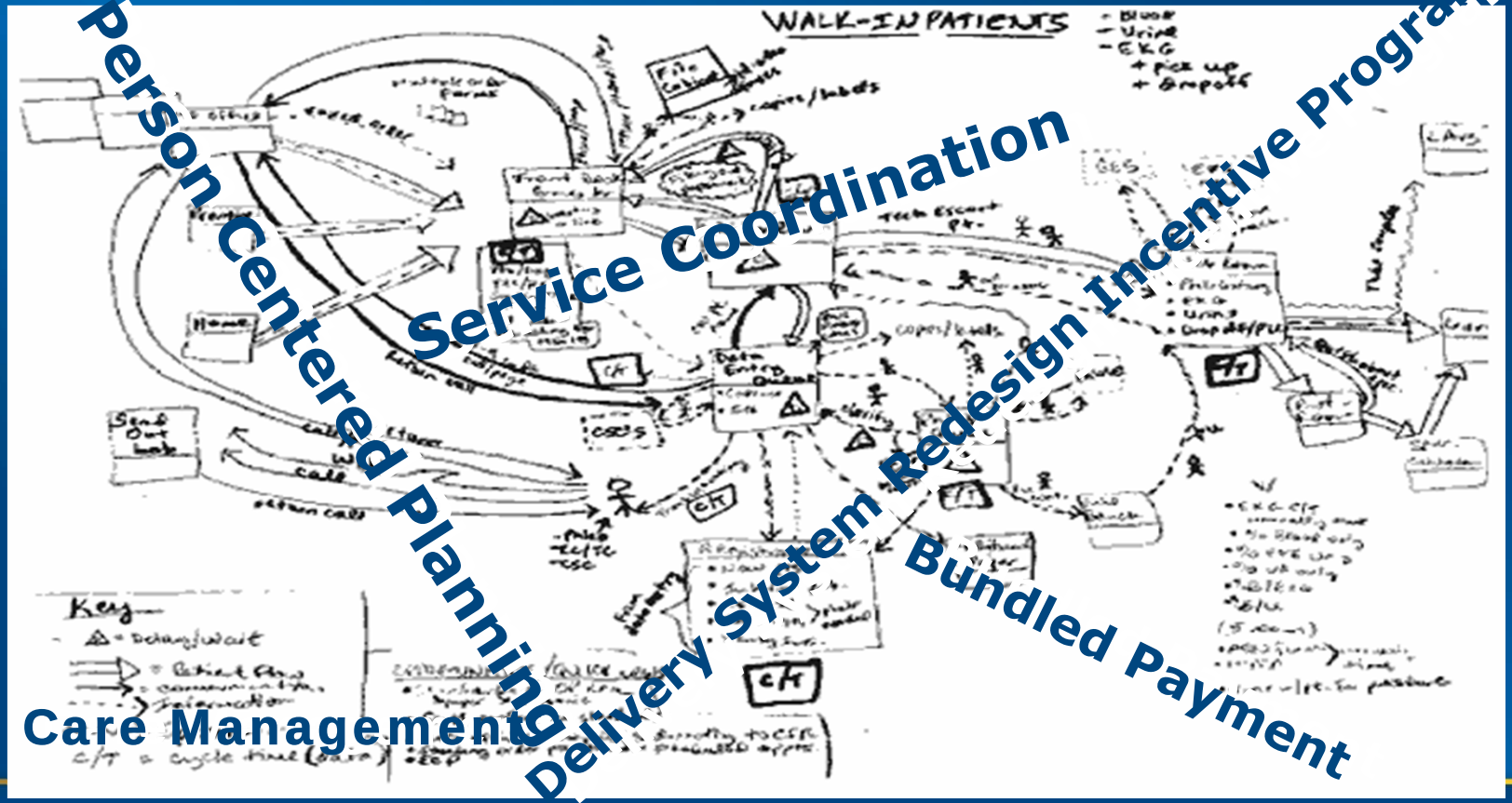
Specialty clinics

- Few knew their treatment
- Med summary, attending long term f/u clinic, worry not associated with increased knowledge

Intensive care management

- Cost savings
- Decreased morbidity/mortality

Current Model of Care with Redesign Demands

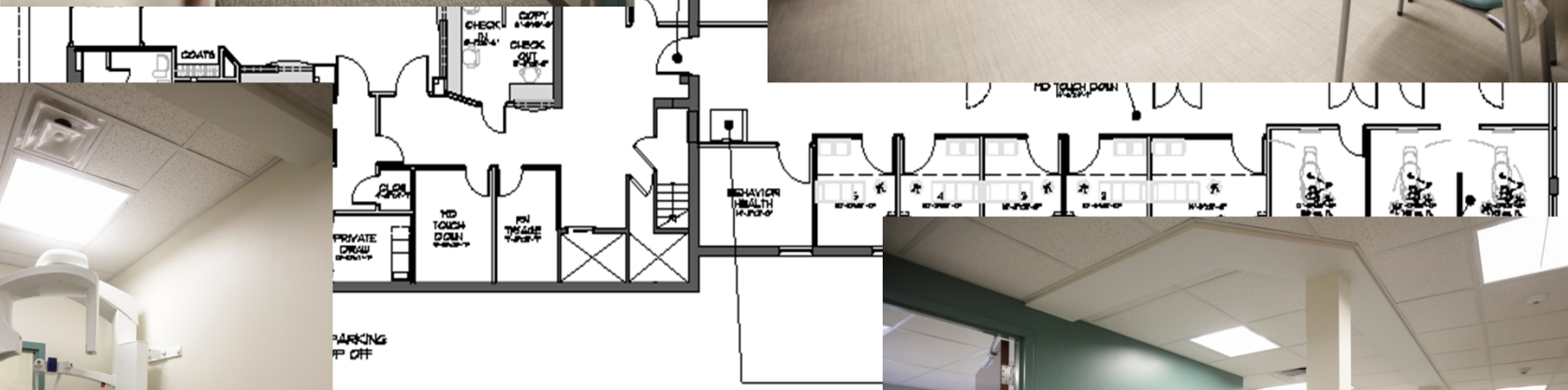


Complex Care Center

- Full Primary Care opened March 21, 2016
  - Med-Peds Providers
  - Age 19, chronic illness of pediatric onset
- On – Site services available May 15, 2016
  - Care Management
  - Clinical: Dental, Nutrition, RT, PT, OT
  - Behavioral Health
- Consultation available July 1, 2016
  - By Phone, eRecord
  - Inpatient

Complex Care Center

Centralized resource center for providers/patients in the region



905 Culver Road

Lower Level Floor Plan

April 21, 2015

Specialized Medical Home / Clinical Services

Interdisciplinary Primary Care Home

A team that meet weekly to ensure “capture” of all patient needs are part of the plan

Primary Care Providers

- Med Peds trained with additional expertise in IDD
- Limited patient panels/longer visits/increased access
- Increased engagement in care plans/circle of support

Community Outreach

Group orientation/education sessions for patients and families

Consolidation of contact within community based resources

- Needs assessments of continued gaps in resources
- Mobilization to address those gaps
  - Availability of neuropsychiatric testing for diagnostic/functional assessments
  - Vocational resources
- Simplifying the path to access

Workforce Development

Address clinical questions at the point of care – “phone a friend”

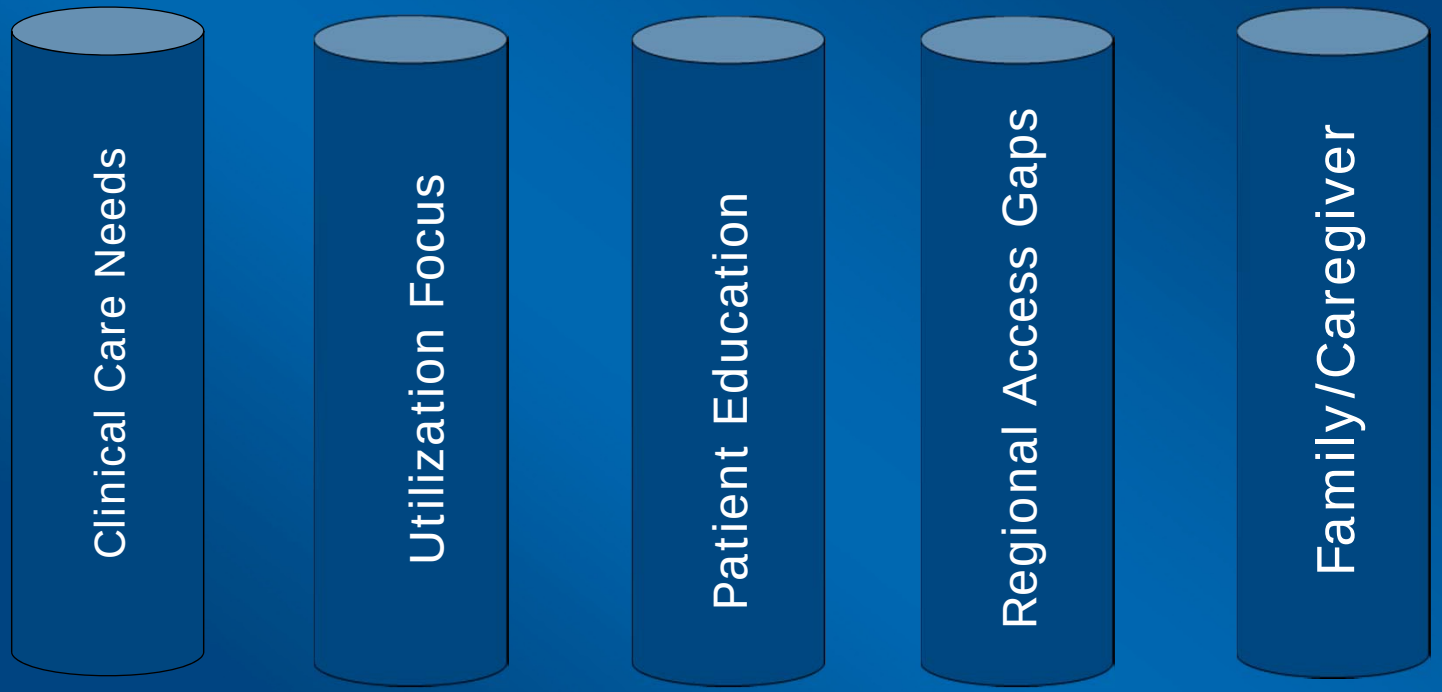
Creation educational & continuing interprofessional education materials

Creation of training programs for formal & informal caregivers

Training of regional providers to increase patient access to services

Create coordination of specialty services to improve access

Workforce Development



Benefits to Community

One touch resource

Data management and education tool development

Decrease Emergency Room and hospitalization rates

- System impact will expand beyond this population of patients as clinical service coordination will have spill over

Improved patient satisfaction and health outcomes

National model in this emerging area of medicine

Conclusions….

Caring for patients with pediatric onset illness is complex in many ways

Families and patients are seeking a navigator and a map

Transition is a process, not an event

One of the most rewarding and challenging aspects of medicine

Complex Care Center

New patient packets: www.ccc.urmc.edu

Call 276-7900

Find us at 905 Culver Rd, entrance in the rear of the blue building

Stop by and staff will be happy to give you a tour

Hours M-F 8:30-5

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